Developing coping skills in pre-transplant patients

A facilitator's guide to group intervention

Tasneem Remtulla MSW RSW, Dee Miner MSW RSW & Julie Craig MSW RSW

ALTRA -Southern Alberta Transplant
Program, Foothills Medical Centre
Calgary, Alberta, Canada

Alberta Health Services

This manual has been written by the Alberta Health Services (AHS) Staff: Tasneem Remtulla MSW RSW, Dee Miner MSW RSW & Julie Craig MSW RSW

Cover photo credit: Public domain image Piqsels.com (https://www.piqsels.com/en/public-domain-photo-fonwx)

LEGAL DISCLAIMER

ABOUT THIS MANUAL

The following manual is based on the 'Transactional Theory of Stress' developed by Richard Lazarus and Susan Folkman (1986) and the model of 'Behavioral Self-Regulation' by Charles Carver (1989). This model identifies three constructs of coping; problem-focused, emotion-focused and dysfunctional coping strategies. An onslaught of investigations on various medical populations have demonstrated consistent findings indicating that specific coping strategies; emotion- focused and problem-focused, produce favorable outcomes when used with a particular stressor in the right context. Conversely, dysfunctional strategies are consistently associated with negative mental-health outcomes.

This intervention assists pre-organ transplant candidates by adding to their repertoire of healthy coping skills and reducing their reliance on dysfunctional coping. This manual incorporates aspects of Cognitive Behavioral Therapy, Mindfulness Based Stress Reduction and Narrative Therapy delivered within a framework of positive coping skills.

As authors of this manual, we have utilized this intervention in a group format with patients awaiting solid organ transplant. We have done so in a closed group format, enrolling a maximum of ten patients per group to participate in the eight week program. We assert that emotional distress related to chronic illness, and the wait for transplantation does not discriminate based on disease etiology. Our clinical experience would support the same. In facilitating this group over the last seven years, we have consistently observed that patients find more similarities in their illness narrative and treatment goals than they find differences. We have witnessed this foster a cohesive environment of trust, belonging and safety amongst members despite the particulars of their physiological symptoms.

Your scope of practice, service requirements and population needs will determine how you implement this manual and deliver the content, therefore it is the authors' recommendation that facilitators create their own teaching tools, ie; power point slides, visual aids and/or handouts that capture the curriculum.

This manual was simultaneously developed while completing an embedded research design. This was an intentional and purposeful measure to ensure efficacy of the content and its utilization in clinical practice. Please refer to the following for details:

Craig, JA., Miner, D., Remtulla, T., Miller, J., Zanussi, L.W. (2017). Piloting a Coping Skills Group Intervention to Reduce Depression and Anxiety Symptoms in Patients Awaiting Kidney or Liver Transplant. *Health & Social Work*, Volume 42, Issue 1, 1 February 2017, Pages e44–e52, https://doi.org/10.1093/hsw/hlw064.

TABLE OF CONTENTS

WEEK ONE: 2 HOURS

Overview:

- **Introduction:** Introduce participants and cover the purpose of the group: To learn about the stressors of transplant and to incorporate new coping strategies into their lives.
    - ❖ Introductory Exercise: writing down hopes and fears and passing them to the person on their right. OR having individuals interview the person next to them sharing 2 strengths they have discovered while being ill. (**20min)**
- **Create Rules & Norms:** It is important that this is a collaborative process, however, attendance, participation/ homework completion, confidentiality and mutual respect should be covered. **(15min)**
- **Create Hopes & Fears List:** Create a discussion about the hopes and concerns of members in the group and how they will know whether or not they have made progress in the group **(15min)**.
- **Stress & Transplant:** Gauge what individuals know about stress and its effects on health and incorporate below curriculum to support discussion **(60 min)**.
- **Relaxation Technique:** One of the following - Guided Imagery/Progressive Muscle Relaxation/ Breathing Exercise/Mindfulness Exercise **(5min)**.
- **Homework and Check out:** Experimenting with 'focusing technique' and becoming more aware of one's physiological reaction to stress **(5min)**.

Stress and Transplant

Definition: "Stress is described in terms of a relationship that exists between a person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being." (Lazarus & Folkman, 1986, p. 572)

Objective - Normalizing stress for the pre-transplant population:

- Explain that stress is a part of the transplant process
- On a list of life's major stressors- illness came sixth on the list, after the death of a spouse, divorce or separation, imprisonment and death of a close relative(Parr & Mize, 2001).
- Distress has been shown to peak in the pre-transplant period (Myaskovsky et al., 2006; DiMartini, Dew, Chaiffetz, Fitzgerald, Devera, & Fontes, 2011). (DiMartini et al., 2011).
- "Learning that you must prepare yourself mentally and emotionally for a radical surgical procedure, while you are still trying to cope with the chronic effects of an end-stage organ disease is a lot to contend with- your ability to cope will be tried in this process. In fact, ones' ability to cope emotionally with transplant has shown to have positive effects not only on the patient's mental health but also their physical health and graft survival rate. Research has demonstrated that these skills can be learned by patients and that pre-transplant is the ideal

time to acquire these skills for optimal benefit. ”
(Parr & Mize,2001, p. 42)

Categories of Stressors

MEDICAL STRESSORS: In the process of preparing for transplant there are an array of medical stressors that one must contend with, including: navigating the health-care system, reading and processing a wealth of medical information, and making treatment decisions. Transplant candidates often face concerns in regards to leaving family or work unattended in order to enter the hospital, attend clinic visits, or deal with acute illness caused by symptoms of end-stage organ disease. Additionally, one must deal with the stress of being fit to receive an organ when an organ is available.

INSTRUMENTAL STRESSORS: On top of managing medical demands, transplant patients also contend with basic tasks of daily living such as household work, child-care, elder care, and outside employment. Given the patient's physical limitations, the division of labor in one's household needs to be spread out differently to accommodate these limitations.

SOCIAL STRESSORS: This type of stress may be experienced by a patient in terms of the expectations that others may have of them.

EMOTIONAL STRESSORS: High levels of depression, sadness and anxiety. Typically emotional distress has shown to peak at the pre-transplant period.

EXISTENTIAL STRESSORS: This stress involves issues around the meaning and purpose of life, the unfairness of disease. The fundamental fear of death is often associated with end-stage organ disease.

(Par & Mize, 2001)

The experience of transplantation is marked by a feeling of powerlessness and lack of control. Ironically, research shows that patients hold a large degree of control in the outcomes of transplant that rest on their ability to manage their distress- taking control internally (Telles-Correia, Barbosa, Mega & Monteiro, 2009; McMillan et al., 2006; Blumenthal et al., 2006). This is an empowering discovery that requires the individual take recovery into their own hands and develop skills of self-advocacy.

Brainstorming Exercise: Identify Possible Shared Stressors

Before Transplant:

- Prolonged hospital stays
- Diminished energy
- Cognitive impairments
- Role transition
- Financing the transplant
- Time off of work
- False alarms or “dry runs”
- Being passed over on the list
- Loss of control
- Anxiety
- Fear
- Guilt
- Depression
- Sexual dysfunction

Directly after Transplant:

- Recovering from a radical surgery
- Possible rejection of the organ
- Infection
- Hospital stay on the ward

Post-Transplant:

- Side effects from being immunosuppressed
- Other drug side effects
- Travel and your medication
- Lifestyle changes
- Fear of organ rejection
- Fear of cancer diagnosis due to immunosuppression
- Guilt; survivors and/or self blame
- Feelings of victimization
- Feeling the need to reciprocate
- Body image
- Returning to work
- Psychological/emotional lability
- Adjusting to a “new normal”

Transplant & Psychological Disorders

Prevalence of Depression & Anxiety

- Pre-transplant patients have clinical levels of anxiety among **35 – 45%** and clinical levels of depression ranging from **25- 60%**(Frazier, Davis, & Dahl, 1995; Gross et al., 2010; Corbett, Armstrong, Parker, Webb, & Neuberger, 2013)
- Research has found that these mental disorders do not resolve immediately after transplant and can affect recovery (Noohi et al., 2007; Neipp et al., 2006) .
- Anxiety is associated with avoidance, risky health behaviors & denial (Cooper, Katona, Orrell, & Livingston, 2008)
- Depression is associated with low adherence with medication advice (Cukor, Rosenthal, Jindal, Drown, & Kimmell, 2009)
- Some studies have demonstrated that anxiety & depression pre-transplant is the greatest predictor of anxiety & depression post-transplant and also predict physical health after transplantation (Baranyi, Krauseneck, & Rothenhausler, 2013; Kimmel et al., 2000; Lopes et al., 2002;) Owen, Bonds, & Wellisch, 2006
- Taken in aggregate the research suggests that pre-transplant is the most appropriate time to address anxiety & depression thus reducing the probability of it affecting a patients' mental and physical health post-transplant.

Symptoms of Depression

If patients are experiencing 5 or more of the following symptoms of depression for at least a two week period over the last 6 months he/she may be experiencing depression:

- can't sleep or sleep too much
- feel sad for most of the day, nearly every day as noticed by self or others.
- can't concentrate or find that previously easy tasks are now difficult
- feel hopeless and helpless
- can't control their negative thoughts, no matter how much they try
- have lost appetite or can't stop eating
- are much more irritable and short-tempered than usual
- feel fatigued or 'slowed down'
- have lost interest in activities he/she used to find pleasurable including sex.
- have excessive feelings of guilt/ worthlessness or brooding
- have thoughts that life is not worth living

(Notify mental health providers *immediately* if they are experiencing these symptoms.)

(American Psychiatric Association, 2013)

Symptoms of Anxiety

- worrying significantly disrupts his/her job, activities, or social life.
- worrying is uncontrollable.
- worries are extremely upsetting and stressful.
- he/she worries about all sorts of things, and tends to expect the worst.
- he/she has been worrying almost every day for at least six months

(American Psychiatric Association, 2013)

Coping Skills and The Impact on Depression & Anxiety

- Patients that use active coping skills have been shown to have substantially longer graft survival, better quality of life and less risk of anxiety and depression pre and post transplant.

- Individuals that use passive or dysfunctional coping strategies are more likely to experience higher levels of depression and anxiety and have increased health complications. This may be due to the relationship between anxiety and depression with lifestyle choices (diet, hygiene) and their relationship with medical adherence

- The good news is these active-coping strategies can be acquired through training and practice, rendering more favorable physical and psychological health outcomes after transplantation

(Blumenthal et al., 2006, Wolf & Mori, 2009).

Benefits of Coping Intervention Groups

- Improve quality of life of transplant patients
- Reduce anxiety and depression
- Improve interpersonal relationships
- These improvements have been demonstrated sustainability at 6 months and 1 year post-group

(Tsay et al., 2005; Blumenthal et al., 2006).

Have a group discussion around stress. How does one know that they are stressed? What are the common signs: physiological, emotional, behavioral? Highlight the importance of being aware of the body's signals around stress and the functionality of stress (ie.not something to be avoided or feared but rather a message from the body about one's environment).

The Stress Response and the Body

Stress is an important motivator in people's lives. There is a functional amount of stress that is necessary in motivating individuals to address problems, meet deadlines and achieve daily tasks. The stress-response (sympathetic nervous system) is a person's body telling them something about the environment that they need to be aware of. In this way, the body releases hormones that increase energy for the body to react immediately to the threat by taking physical action. Cortisol is one of three important hormones activated as part of the "fight or flight response". Commonly known as a "stress hormone", when an adequate amount of Cortisol is produced, the physiological processes needed to help one adapt and calm the body are activated. Subsequently, the body is able to mitigate and cope with the stress. The stress- response however, becomes problematic when it is chronically triggered or is overreacting to neutral environmental triggers. It is important to understand how this mechanism works in order to manage the bodily reaction.
(Sternberg, 2016)

The 'fight or flight' response is a hardwired system in the brain that is involuntarily initiated by a perceived environmental threat. The human brain processes information in a bottom-up manner meaning that sensory information from the environment is processed in the most primitive structure first, the brainstem, and from there it moves to successively higher, more complex regions. In other words, when people are calm, they think using higher brain processes, allowing for verbalization and reasoning. When under threat, the lower brain system responds, leading to a reaction before reasoning. This is significant for survival, as in the face of a threat one needs to respond in a timely fashion. The additional time it would take for information to travel to high-order systems in the brain may mean the difference between life or death. Therefore, the more fear we feel, the less thoughtful, and the more emotional and reactive we become.

For pre-transplant patients who are often in a chronic state of fear the stress-response system becomes problematic in that it drains much needed energy, internal resources and creates interpersonal problems as individuals become more emotionally reactive leading to an increased risk for depression and/or anxiety. Coping strategies act as a buffer between environmental stresses and the stress-response(fight or flight) reaction.

(Girdano,1993; Schniederman, Ironson, & Siegel, 2005).

Effects of Cortisol on the Body

Symptoms of increased Cortisol levels:

- Increased heart rate and blood pressure
- Increased breathing rate
- Increased muscle tension
- Increased cholesterol/fatty acid levels in blood

Effects of long-term Cortisol exposure:

- Hypervigilance
- Lowering of the body's immune system
- Decreased ability to concentrate
- Increase of gastric acid in the stomach
- Gradual increase in blood pressure
- Increased likelihood of heart disease

Sometimes it is difficult for individuals to identify the emotion of stress, especially if they have become adept at ignoring, normalizing and/or denying these emotions. However, symptoms of stress can become physiological when unrelieved.

Physiological Symptoms

- Headaches
- Chronic fatigue
- Muscle aches/ back pain
- Loss of sexual drive
- Feeling dizzy
- Loss/ increase in weight
- Diarrhea or constipation
- Frequent illness

Note: *These symptoms of stress may overlap with/or exacerbate symptoms of a person's disease.*

Emotional Symptoms

- Irritability
- Impatience and frustration
- Feeling anxious, restless
- Feeling angry and hostile
- Feeling blue, little or no interest in anything

Behavioral Symptoms

- Difficulty sleeping
- Eating too much or too little
- Increased use of alcohol, other substances, gambling
- Avoiding work or other responsibilities
- Being late for commitments frequently
- Overreacting to things
- No interest in social activities
- Letting personal appearance and hygiene decline
- Frequent crying spells

- Increased conflict with family/ friends or co-workers

Cognitive Symptoms:

- Increased forgetfulness
- Difficulty concentrating
- Poor self esteem
- Being preoccupied with unreasonable or negative thoughts
- Rambling thoughts and speech
- Not being able to adapt to new or changing situation

(Girdano, 1993; Schniederman et al., 2005)

Focusing Exercise: A Tool to Identify Stressors Focusing Exercise

Sometimes, when overwhelmed with a multitude of stressors, it is difficult to identify exactly the source of one's distress. The focusing technique is a tool created by Eugene Gendlin (1978) that patients can use to quiet the 'chatter' in their mind and identify where the bodily emotions are coming from. It requires an attitude of warmth, gentleness, allowing, valuing and listening. It is a way to tune into the stressors in their life and to evaluate them in a non-judgmental way. It is paying attention to something not yet clear but definitely felt or experienced by the body and distinctly connected to something in their life, by paying attention and staying with this vague felt-sense.

These steps will help them connect their emotional distress to a particular issue and will change the way they perceive it. It is a body to mind approach so encourage them to stay away from over reasoning with the issue, and focus intently on how they carry the issue in their body- this is not always easy to do.

It is helpful to explain to participants that the "inner process" has a slow pace, makes itself known in images, metaphors and feelings and is bodily felt. Whereas the obstacles to the "inner process" can show up as a critical voice, imposing concepts or 'shoulds', impatience and the fear of what is there.

Steps to Focusing:

1. Clear a Space
   - How are you ? What is between you and feeling fine?
   - Don't answer, let what comes in your body do the answering.
   - Don't go into anything.
   - Greet each concern that comes. Put each aside for a while, next to you.
   - Except for that are you fine?

2. Felt-Sense
   - Pick one issue to focus on.
   - Step back a moment and ask gently: What is the sense in my body when I recall the whole of that issue?
   - Sense all of that, the whole thing, the murky discomfort, or the unclear body-sense of it.

3. Get a Handle.
   - Ask…
   - What is the quality of the felt-sense?- Where do you hold this issue in your body? (chest, stomach etc)
   - What is one word, phrase, or image that comes out of this felt-sense?

- What quality word would fit it best?

4. Resonate:
   - Go back and forth between words or images, and the felt-sense.
   - Check to see if they match. If they do, you'll sense an inner yes.
   - If the felt-sense changes, follow it gently with your attention.

5. Ask
   - What is it about this whole issue that makes me feel so…?
   - What is it really about?-*get to the heart of the issue.*
   - What is the worst of it?
   - What does this need?

6. Receiving:
   - Welcome what came- stay with it. Be glad that it spoke and protect it from the critical voices that interrupt.

(Gendlin, 1978, p.201)

This exercise will aid individuals in identifying what type of coping strategy their issues need. If they have other concerns that need attention they may continue this process as homework, ideally addressing each one until they feel each concern has been addressed.

Labeling these Feelings

It is important and liberating for patients to be able to label their experienced emotions as it helps them to acknowledge how the situation is affecting them. Encouraging participants to develop a language around their emotions and feelings may foster or enhance communication, empathy and self-care. It helps the care provider(s) or support person(s) identify and acknowledge what is happening to those they are in a relationship with.

Recommendation: Provide participants with a list of words to describe feelings. There are several sample "feelings" charts available online; these can be used to encourage participants to develop a wider range of descriptives to articulate emotions.

The next 3 weeks will be devoted to discussing different types of coping strategies and practicing skills around these strategies.

Home Work

1. This week- become aware of your bodily reactions to stress. This stress may be caused by getting caught in traffic or running late for an appointment. Make a list of the sensations as they progress.

    - How do you know that you are becoming distressed- what are the initial signs?
    - How do you know that your stress is becoming intensified?
    - What was the source of your distress?
    - How did you cope with this situation?

2. Practice this focusing technique at least 2 times this week. Find a quiet space and run through the steps. Sometimes it is helpful to have a supportive partner read the questions to you while you close your eyes and focus inward.

    - What was this experience like for you?

WEEK TWO: 2 HOURS

Overview:

- **Check-In:** Discuss the past week with group participants and debrief any challenges that they may have experienced. Reflect on the homework and what it was like to identify and focus on the stress that they felt. Question to ask: Did you learn anything new? It is important to steer discussion away from just focusing on symptoms but rather guide members to focus on their strengths and resilience in coping with symptoms. Summarize the themes that emerge from check-in. Time permitting review effects of cortisol **(40 mins).**
- **Hand-out** group guidelines from week one. **(5 mins)**
- **Introduction to Coping Strategies:** Have participants become familiar with the concept of the stages of change and coping. Prompt a discussion about coping strategies: what are they and what has worked in the past. Highlight that the best coping strategy depends on the context and the individual's skill set. **(30 mins)**
- **Break (10 mins)**
- **Continue discussion on different change processes**. Generally outline the three categories of coping (problem focused, emotion focused, and dysfunctional coping). Now continue with a more detailed discussion of problem focused coping.
- **Handout**: "Steps for Problem Focused Coping" and review it together **(25 mins).**
- **Relaxation Technique:** We recommend one of the following - Guided Imagery/Progressive Muscle Relaxation/ Breathing Exercise **(5min)**.
- **Homework and Check out:** Experimenting with problem-solving steps and identifying situations where it is appropriate. **(5min)**.

This section will be devoted to introducing the change process and three types of coping strategies. We will be inviting participants to experiment with new styles of coping that may be uncomfortable initially, but will eventually add to their repertoire of coping skills to use when dealing with the stressors of transplant.

Change

Any form of change in one's life does not come easy. This is especially true of coping strategies as they are survival techniques that people depend on in turbulent times in their lives. These coping strategies become habitual and comfortable and sometimes people will use them to alleviate the acute discomfort of stress *even* when the consequences of using these strategies may be dire in the long-term (ie. substance use or avoidance). Therefore, we ask individuals to be patient in trying to attain these skills and be prepared for the challenges that may arise when acquiring new strategies. As facilitators we aim to discuss these challenges weekly as participants experiment with their new skills.

The 5 Stages of Change:

Facilitators are encouraged to familiarize themselves with the Transtheoretical Model, also called Stages of Change Model:

1) Pre-contemplation 2) Contemplation 3) Planning 4) Action 5) Maintenance/ Relapse

(Prochaska & DiClemente, 1986)

Advise participants to be prepared for regressing into old patterns of coping but to not let this discourage them; this is part of the change process.

It is not unusual for change to seem scary. People often become habituated and comfortable in their existing patterns. We acknowledge that this process may require trust, both internally and externally, which can leave participants feeling vulnerable. It is important for facilitators to help prepare them for this.

To improve the chances of participants using these skills, when they are appropriate, they need to **practice** in lower arousing situations thus increasing their comfort with them. It takes 30-60 times to practice a new skill before it is second nature (Edgar, 2007)

How Change in Coping Occurs

1. **Retrospective**: Looking back on a situation where another coping strategy would have been more appropriate.

2. **In the Moment**: Recognizing in the moment when a certain coping strategy would be helpful.

3. **Planning**: Looking forward and identifying possible stressors, in order to plan how one is going to deal with them. This requires the ability to think through various events that could occur and how they will cope in the case of each one. If the stressful event is a confrontation, writing out a script might be a good idea OR role playing can also be helpful. Preparation, in and of itself, will lower a person's anxiety about the event.

Definition: “Coping is defined as constantly changing cognitive and behavioral efforts to manage specific external and or internal demands that are appraised as taxing or exceeding the resources of the person.”

(Lazarus & Folkman, 1984, p.141)

Types of Coping

Problem-Focused Coping: Concerned with changing the situation by defining the problem and looking at alternative solutions; evaluating the implications of the alternatives and choosing the best one to act on. It is primarily rational.

Emotion- Focused Coping: Refers to controlling emotional responses to an event. This could consist of using cognitive processes to decrease emotional distress or using techniques to minimize the emotional intensity and the physiological response to the stressor.

Dysfunctional Coping: Efforts made to deal with emotional stress that does not result in positively changing the situation or the cognitive appraisal.

(Carver,1997)

The remainder of this module elaborates on Problem-Focused Coping. The following modules will address the two remaining types.

Problem-Focused Coping

When a person is experiencing stress it is difficult to be an effective problem-solver. When experiencing heightened levels of stress, it is common for an individual to struggle with solution finding. The process can be demanding, requiring focused attention on the task and less on their emotions.

There are steps to effective problem-solving that they can follow in the context of stress. The following steps are a suggested tool.

Exercise: Steps in Problem- Solving

Step 1:

Identify the problem

This is the most important action you'll take. You can't manage your stress unless you know what's causing it. Make a list of the things you know cause you stress. Then select one to work on.

Step 2:

Break the problem down into specific parts

Make certain you describe all of the elements. Ask yourself these questions:

Who and what are involved?

Where and when does it happen?

How do I react?

Step 3:

Make a list of all possible solutions

Decide what you want out of the situation. Then brainstorm ways to solve your problem. Ask yourself these questions:

Can I change the stressful situation?

Can I avoid it?

Can I change how I respond to it?

Step 4:

Explore the consequences of each solution

Once you've made your list, look at the pros and cons for each option. How will it make you feel? What effect will it have on the other people involved? What are the short-term and long-term consequences? Do the benefits outweigh the costs? Now rank the alternatives and choose the solution that promises the best outcome.

Step 5:

Set your course

Write down your plan if you think it will help. Discussing it with a trusted friend, family member or co-worker may be useful; if your stress is due to conflict with another person, consider rehearsing what you'll say or do when the conflict occurs. Revise and rework your plan until you feel comfortable with it.

Step 6:

Go for it

You may find that having a plan in place will boost your confidence.

Step 7:

Take some time to reflect on what helped and what didn't

Make changes to your strategy if you need to. Otherwise, celebrate your success.

(Roeder, 2004, p.1)

Home Work

1. Create a list of stressors in your life that can be addressed using a problem-solving technique. Prioritize these stressors.

2. Ask yourself: are there aspects of this situation that I can change? Write out the changes you would like to see.

3. Use the problem focused coping handout to work through the rest of the problem: we recommend that you do this in writing.

4. How does your perception of the problem change through this process?

5. Do your feelings about the problem change?

WEEK THREE: 2 HOURS

Overview**:**

- **Check-In:** This time will be put aside to allow members to discuss the challenges that they experienced over the week, to reflect on the last session and to give general feedback about how the homework went. Ask members about the process of using the problem-focused technique **(20 mins)**
- **Emotion Focused Coping: Cognitive Restructuring & Relaxation:** Introduction to the principles of Cognitive Behavioral Therapy (CBT)- its effectiveness and how these techniques can be integrated into one's life- through consistent and constant practice these techniques will become habitual- ie will not need to write out thought records. Mindfulness will also be introduced in this session. **(15 mins).**
- **Paired discussion** - Thinking Errors (handout): Examples of distressing thoughts; How do participants cope with these? Can they identify any of their own thinking errors **(20 mins).**
- **Challenging Negative Thinking:** Have participants look for the proof or evidence to support or disprove their negative thoughts; explore alternatives, positive reframing **(10 mins)**
- **Break (10 mins).**
- **Mindfulness:** What is it? Why is it important? Explore the concept that we can change how we feel **(10 mins).**
- **Mindfulness Technique:** We recommend using an exercise specifically related to mindfulness meditation for this module e.g., peeling an orange mindfully and having them acknowledge the various sensations or the Raisin Exercise outlined in the curriculum **(15min)**.
- **Introduce concept of Wise Mind**: Reasonable Mind vs. Emotional Mind **(15 mins)**
- **Homework and Check out:** Awareness of automatic negative thoughts and practicing mindfulness techniques **(5min)**.

Emotion-Focused Coping

The transplant experience is inherently unpredictable. Patients are faced with the daunting task of navigating their emotional response to both the uncertainty of their illness trajectory, as well as, if and when they will receive a transplant. Such circumstances can have patients struggling to find an obvious or attainable solution; leaving them feeling powerless, vulnerable and helpless. The subsequent emotions must be coped with given that the source of the distress is out of the patients' control. Coping by employing emotion-focused techniques has shown to affect, most prominently, feelings of anxiety (Cooper et al., 2008). Studies on transplant patients have highlighted the importance of using emotion-focused coping. Not only are such strategies effective in situations where elements cannot be changed, they can also be used in combination with problem focused coping where a solution is viable. In other words the utility of emotion focused coping is far reaching, and complementary to many other strategies.

There are two basic approaches to emotion-focused coping:

1. Changing how we **think** about the issue or situation in order to change how we **feel** about it.

2. Using techniques that allow us to have **higher distress tolerance** by de-escalating the physiological response to the stressor, like meditation and mindfulness. Meditation and mindfulness focus on improving our ability to ride out the waves of anxiety by confronting it head on rather than fearing and avoiding the emotion. This type of coping also encourages the use of emotional support from others as well as humour (when appropriate) to lighten the situation.

Changing How we Think

The following techniques are based on Aaron and Judith Beck's Cognitive Behavioral Therapy Model and are used with permission.

Introduction to Cognitive Behavioral Therapy (CBT)

Basic Principle: How individuals think about a situation affects their emotional reaction which then determines behavior. These thoughts can be monitored and altered thus changing the emotions and behaviors. The locus of control is the individual, and this is where a patient's energies may be directed for best results.

How individuals think about a situation can cause distress. For example, a patient says hello to their doctor in the hallway before their clinic visit but the doctor walks by and does not respond. Imagine different ways one could interpret this, and how their interpretation impacts their emotional reaction.

Another important aspect of CBT are automatic thoughts. These thoughts are based on the individuals' beliefs about themselves and the world. Lawsin (2008) identifies the following key aspects:

- There are 3 types: positive, negative & neutral.
- These thoughts impact how we feel.
- We treat these automatic thoughts as facts: thus, they increase distress.

Automatic Negative Thoughts

Automatic negative thoughts, or ANTs as we often refer to them, are those thoughts that automatically occur while engaged in a situation and often go unacknowledged. ANTs can impact a person's emotions and behaviours; when they are prevailing they can lead to increased levels of distress. The process of developing awareness around one's automatic thoughts and subsequent emotional responses can be extremely beneficial, and impact an individual's physiological, psychological, and behavioural outcomes.

Example: A transplant patient finding out that a friend has received a transplant before them may start thinking “I am never going to get a transplant, there is no point in trying to stay healthy”. In response to this thought the persons’ anxiety or distress level will likely increase, further impacting their behaviour. For instance this could lead to the decision to stop taking their medication or following medical advice. This outcome could be altered by:

1) Awareness

2) Practicing alternative thoughts (positive and neutral)

(Beck, Rush, Shaw, & Emery,1987)

Common Thinking Errors with Transplant Patients

Automatic negative thoughts can often lead to thinking errors. To illustrate this, many transplant patients pay very close attention to changes in their physiology and often link these symptoms to their disease. Even when symptoms like fatigue can be accounted for by other causes such as a busy day or playing with their kids, patients often attribute this to their failing organ. This is an example of a thinking error referred to as “magnification” or ‘catastrophizing”. Due to the uncertainty associated with transplantation and the distress that accompanies this, patients may be predisposed to experience more negative automatic thoughts and thinking errors.

Facilitated Paired Discussion:

- How do you cope with distressing thoughts?
- What works well, and not so well?
- Provide the Thinking Errors as a handout

Use this discussion and handout on the following page to highlight common maladaptive coping strategies i.e. cognitive distortions such as magnification or overgeneralization etc.

Thinking Errors

1. ALL-OR-NOTHING THINKING: You see things in black-and-white categories. If your performance falls short of perfect, you see yourself as a total failure.

2. OVERGENERALIZATION: You see a single negative event as a never-ending pattern of defeat.

3. MENTAL FILTER: You pick out a single negative detail and dwell on it exclusively so that your vision of all reality becomes darkened, like the drop of ink that discolors the entire beaker of water.

4. DISQUALIFYING THE POSITIVE: You reject positive experiences by insisting they "don't count" for some reason or other. In this way you can maintain a negative belief that is contradicted by your everyday experiences.

5. JUMPING TO CONCLUSIONS: You make a negative interpretation even though there are no definite facts that convincingly support your conclusion.
    - Mind Reading: You arbitrarily conclude that someone is reacting negatively to you, and you don't bother to check this out.
    - The Fortune Teller Error: You anticipate that things will turn out badly, and you feel convinced that your prediction is an already established fact.

6. MAGNIFICATION (CATASTROPHIZING) OR MINIMIZATION: You exaggerate the importance of things (such as your goof-up or someone else's achievement), or you inappropriately shrink things until they appear tiny (your own desirable qualities or the other fellow's imperfections). This is also called the "binocular trick."

7. EMOTIONAL REASONING: You assume that your negative emotions reflect the way things really are: "I feel it, therefore it must be true."

8. SHOULD STATEMENTS: You try to motivate yourself with shoulds and shouldnt's, as if you have to be whipped or punished before you could be expected to do anything. "Musts" and "oughts" are also offenders. The emotional consequence is guilt. When you direct "should" statements toward others, you feel anger, frustration, and resentment.

9. LABELING AND MISLABELING: This is an extreme form of overgeneralization. Instead of describing your error, you attach a negative label to yourself: "I'm a loser." When someone else's behavior rubs you the wrong way, you attach a negative label to him: "He's a louse." Mislabeling involves describing an event with language that is highly colored and emotionally loaded.

10. PERSONALIZATION: You see yourself as the cause of some negative external event which in fact you were not primarily responsible for.

11. GLOOMING AND DOOMING: Depressive/pessimistic attributional style. You see your stressors, bad outcomes, failures and/or hassles as attributable to or caused by unchangeable character flaws that are personal/internal, global, and stable as in "I was rejected or failed because I'm unlovable to everyone or stupid in everything."

12. UNHEALTHY THINKING of a situation: Somehow you are looking at this situation in a way that keeps you stuck and miserable, even though it seems accurate, unbiased, or logical to you.

(Burns, 1989, p. 8-11)

Exercise: Challenging My Negative Thinking

Instructions: Apply these questions to negative thoughts and beliefs you're having. Imagine that your distressing thoughts are on trial in court to see if they are really true, fair, and helpful in solving the problems that you face. Go through each question until you come up with a positive answer to your negative thoughts that is helpful and that you truly believe in. These questions are powerful tools for building awareness and challenging the thoughts that cause distress, especially the negative emotions of depression, anger, and anxiety.

1. Where is the proof?

   A) What is the evidence—pro or con—for my *perception* of the situation?

   - What is *really* happening in this upsetting situation? Am I *misperceiving* the situation?
   - Do I have all the facts I need to know about what is really happening in this situation?
   - How can I test the truth of this belief in the real world?
   - What will it take to convince me that it is true or false?
   - Have I defined my terms exactly so I know what I am trying to prove or disprove?
   - How much of this is my fault, the fault of others, or nobody's fault (just bad luck or chance)?

   B) What is the evidence—for or against—my *interpretation* or *evaluation* of the situation?

   - What does this situation *really* say about me, my worth, my ability to succeed, my future happiness, my world, and my future?
   - Am I *misinterpreting* what this situation means for me and my future?

2. What are the real odds of “disaster”?

   (a) What are the *real* odds (0% to 100%) of something bad happening?

   - Compare this to your *fearful* or *imagined* odds when feeling really upset about the situation.

   (b) Do I need more facts or information to know the real odds of “disaster”?

   (c) Am I underestimating the skills, talents, and resources I have to prevent the worst from happening?

3. Is there a better way to look at this?

   (a) Is there a different way to look at this that will help me feel better and do the right thing?

   (b) What would a compassionate friend (or role model) say (or *think*) about this situation?

(c) What would I say to a friend with my problem?

(d) What are the advantages and disadvantages of this belief or schema? Is there a more healthy belief I could adopt with more pros than cons?

4. Can I eventually—*survive and thrive* the worst?

(a) Can I—eventually—survive and thrive if the worst happens?

- Will “the worst” really be so bad, awful, terrible, and unmanageable for me?
- Have I overcome problems like this before?
- What skills, talents, and resources do I have for dealing with this problem?
- What options do I have for dealing with this problem?
- How can I change this situation or learn to live with it?
- How confident am I (0% to 100%) that I can do what it takes to get my needs met in this part of life? How much self-confidence or *self-efficacy* do I have?

(b) How important is this to my overall happiness?

- How important will this seem in 6 months, 1 year, or 5 years?
- Do I still have other things going for me?

(c) Can I survive and thrive if something bad about me is true?

- Can I survive, thrive, accept myself, and enjoy life even if I've done some bad things and made mistakes?

(Sharp, 2002)

THE FOLLOWING IS PROVIDED AS A HANDOUT THAT PATIENTS MAY FIND HELPFUL WHEN CHALLENGING THEIR NEGATIVE THINKING:

Realistic Self Talk

REALISTIC SELF-TALK
1) This too shall pass and my life will be better.
2) I am a worthy and good person.
3) I am doing the best I can
4) Like everybody else, I am a fallible person and at times will make
mistakes and learn from them.
5) What is, is.
6) Look at how much I have overcome so far.
7) Be honest and true to myself.
8) It is okay to let myself be distressed for a while.
9) I am not helpless. I can and will take the steps needed to get
through this crisis.
10) I will remain engaged and involved instead of isolating myself
and withdrawing during this situation.
11) I will use this challenging situation to learn something new,
and change my direction.
12) One step at a time.
13) I can stay calm when talking to difficult people.
14) Is this really important enough to become upset over?
15) I don't really need to prove myself in this situation.
16) Other people’s opinions of me are just their opinions.
17) I cannot control the behaviors of others, I can only control my own.
18) I will respond appropriately, but not reactively.
19) I will enjoy myself, even when life is hard.
20) I choose to be a happy person.
21) I am willing to do whatever is necessary to make tomorrow better

(Johnson, 2009)

2. CHANGING HOW WE FEEL USING MINDFULNESS & RELAXATION

What is Mindfulness?

- The state of being attentive to, and aware of what is taking place in the present moment.
  "Awareness in itself is healing" Fritz Perls (Perls, 1992, p.7)

- Putting your mind to what you are doing, but not reacting to it.
- A kind of meditation in daily life.
- A way of celebrating in small ways the passage through the day.

Why is it Important to us?

- Mindfulness is linked to positive well-being outcomes and can be useful in managing automatic negative thoughts and unhealthy behaviors. It can also positively impact a persons' energy and a sense of joyful well-being.
- It is the conscious awareness of being. In mindfulness the mind is likened to a river with flowing positive, negative and neutral thoughts. The positive thoughts are full of truth and wisdom that help us move toward a more contented life whereas the negative thoughts can defeat us, and distract us from enjoying life. The objective of mindfulness is not to focus on any of these thoughts but to notice them flowing through your mind, detached from any emotional investment. It is the observation of these feelings and/or thoughts, without judgment, that is paramount in the practice of mindfulness. (Siegel, 2009).

I have thoughts, I am not these thoughts

I have feelings, I am not these feelings

I have a body, I am not this body

I am an awareness of all of these things.

(Tolle, 2003 p.47)

The Mindfulness Theory on Suffering

The theory behind mindfulness asserts that mental suffering often takes place due to the mind focusing on occurrences that have happened in the past or anticipating events in the future. In this way, we suffer for things that cannot be changed or predicted. Therefore, it encourages one to stay in the present and focus on what is occurring in the moment. In training ones' mind to focus on the present and observing those senses, we can alleviate much of this needless suffering and train the mind to focus on the here and now, where change can take place (Kabat-Zinn, 2013).

Mindfulness is especially relevant in the transplant experience as it allows patients to alleviate the distress associated with past and future anxieties, by focusing on the present moment, even when that moment is challenging.

Mindfulness, although the concept seems simple, is extremely hard to do at first. The mind is a muscle that must be trained. At present, most of our minds have the freedom to venture to the past and future at will, in a disorganized and chaotic fashion. With practice, however, the mind can be trained to stay in the present moment as we are experiencing it. This process requires gentle patience and perseverance with the mind.

Exercise: Facilitated Mindfulness

The Raisin Exercise:

- Hold one raisin in the palm of your hand. Look carefully at it, feel it and smell it.
- Then put it in your mouth and pay attention to the taste and texture of it.
- Keep your mind on how it feels in your mouth as you chew it.
- Then swallow it, still paying close attention on how that feels.
- You may notice that by paying attention, you become more awake and aware. When we are mindful of the present, we discover relaxation, calmness, energy and insight into ourselves

(Kabat-Zinn, 1990)

In an attempt to support patients' in developing their mindfulness in their daily lives, we encourage them to pay close attention to some of the usual things that they tend to do automatically, for example drinking a glass of water, watching the sun filter through a window etc.(Kabat-Zinn, 1990).

WISE-MIND

Wise mind is a therapeutic concept that was developed by Dr. Marsha Linehan and used predominantly in Dialectical Behavioral Therapy. We have found that some aspects of this model have been useful with the transplant population in helping establish balance between emotions and thoughts. It is the balance between an individual's reasonable mind and their emotional mind in order to facilitate good decision making while in distressing circumstances.

Mindfulness is crucial to wise mind as it allows one to acknowledge all aspects of being and step back from a problem and find a solution from a calm and centered state.

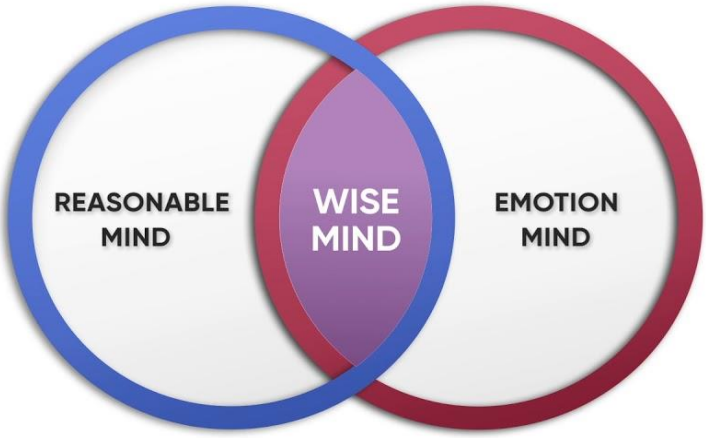

Image source: Retrieved Oct 14, 2019 from ***https://www.youtube.com/watch?v=-UnCu5xgChE*** *Psychwire: Dr Marsha Linehan - Emotion, Reasonable and Wise Mind.*

Reasonable Mind: Uses facts and logic. It frames reality in terms of facts, numbers, equations, or cause and effect. It is an important aspect of the mind that can regulate emotion in order to reason out the situation. Reasonable mind is much easier to access when you are healthy, strong, sober and rested. Emotional mind takes over when one is under stress.

Draw backs: Reasonable mind is critical to dealing with reality, however, many of life's problems have an emotional aspect. Also, others often perceive individuals who are highly reasonable to be cold and abrasive.

Emotional Mind: Emotional mind is passionate, extreme and intense, making reasonable-thinking difficult. Acting the way you feel is how the emotional mind behaves. An emotional mind that is in check, can be beneficial. For instance devotion can motivate one to stay with difficult tasks, and love can motivate one to seek intimate relationships.

Draw backs: Acting solely on emotion is impulsive and can lead to irresponsible decisions. Strong emotions can oftentimes lead one to disregard the consequences of one's actions.

Wise Mind: Is the integration of both the reasonable and emotional mind. It acknowledges that both aspects of thinking are functional. Wise mind is achieved when a person considers both reasonable and emotional mind simultaneously, in a balanced fashion. This practice links the emotions that are causing distress with your logical abilities, while being flexible, aware and open minded. “It is grasping the whole picture instead of only parts” (Linehan, 1993).

Wise Mind does not come naturally to most. When practiced regularly, it can help patient's ability to regulate their emotions.

Home Work

1) Notice at least one time where automatic negative thoughts occurred and identify the thinking error(s).

2) Find times this week to be ‘mindful’ – i.e. feeling the sun on your face while driving, drinking your coffee in the morning etc.

3) Identify one example from the week where you made a decision using ‘wise-mind’ or wish you would have made a decision using ‘wise-mind’.

EMOTION-FOCUSED COPING: RELAXATION

WEEK FOUR: 2 HOURS

Overview:

- **Check-In:** Discuss how members were able to identify automatic negative thoughts and implement mindfulness into their week. Explore what they found helpful and challenging in attempting to use these strategies. (20 mins)
- **Emotion Focused Coping: Relaxation -** Discuss benefits of using relaxation techniques (abdominal breathing handout) (10 mins)
- Group Exercise: Brainstorm perceived benefits of relaxation. (10 mins)
- **Break (10 mins)**
- **Dysfunctional Coping:** Introduce dysfunctional coping strategies and explore their purpose. (20 mins)
- Brainstorm how individuals may use common dysfunctional coping styles in everyday life. (15 mins)
- Group discussion: How emotion focused strategies can be used to combat dysfunctional coping styles. (20 mins)
- **Relaxation Technique:** One of the following - Guided Imagery/Progressive Muscle Relaxation/ Breathing Exercise/Mindfulness Exercise **(10 min)**.
- **Homework and Check out:** Practice a relaxation exercise at least two times over the next week. Have members identify when they are using dysfunctional coping and have them replace it with a suggested antidote. Introduce “illness story” exercise for next week **(5min)**.

Relaxation refers to a distinct physiological state that is the direct opposite of the stress response. The system in a persons’ body that controls for the stress response (sympathetic nervous system) is turned ‘off’ by the activation of the relaxation system (parasympathetic nervous system). In this way, learning to induce the relaxation response allows one to control stress. Relaxation is characterized by a **decrease in; heart rate, respiration rate, blood pressure, skeletal muscle tension, oxygen consumption, and metabolic rate.** There are many healthy ways to accomplish relaxation including abdominal breathing, progressive muscle relaxation, meditation, yoga, guided imagery etc. For example, practicing **20-30min of abdominal breathing** each day for at least a month, can produce a generalized feeling of relaxation to broader areas in an individual’s life, enhancing their sense of well-being and allowing them to gain control of their stress. (Lawsin, 2008 p. 11)

The Benefits of Relaxation

1) **Gain Control of the Mind.** This clears the mind of negative thoughts and feelings, promotes creativity and enhances problem solving as alpha brain waves are increased. Alpha waves are associated with peace of mind and feelings of well-being.
2) **Never out of Control:** Patients allow themselves to relax to the degree that they choose, and are able to terminate the experience at will.
3) **Inoculation Against Future Stress:** With experience, patients learn to recognize stress and tension when it starts to build up and can correct it before it becomes a headache, backache, pain in the neck etc.
4) **Useful for People with Chronic Illness/ Pain:** Relaxation helps to release endorphins, the body's own natural painkillers. Relaxation combined with certain visualization techniques helps to lessen pain.
5) **A General Calming Response:** Can be used at any time regardless of surroundings. Once familiar and practiced, the relaxation response can be elicited within a few minutes, in any place, at any time; this for example, may help in countering insomnia, as well as calm the mind in high stress situations so that one may think rationally.

(Lawson, 2008 p.12)

The exercise on the following page is intended for participants to practice at home. Take some time in group to review and remind them to only do this as their body and abilities permit.

Exercise: Abdominal Breathing

Abdominal breathing is a form of focused breathing that relies on the diaphragm muscle for regulation of breathing.

Step 1: Breathing Awareness

1. Lie down on a rug or blanket on the floor, with your legs straight, slightly apart, your toes pointed comfortably outwards, your arms at your sides, not touching your body, your palms up, and your eyes closed (some patients may have to sit for this). It is best to breathe through your nose. If possible, clear your nasal passages before doing breathing exercises.

2. Bring your attention to your breathing, and place your hand on the spot that seems to rise and fall the most as you inhale and exhale. Note that if this spot is in your chest, you are probably able to make better use of the lower part of your lungs. Anxiety and nervousness typically involve breathing in short, shallow breaths in the upper chest, while deep relaxation involves diaphragmatic breathing at the bottom of the lungs. The diaphragm is the muscle that separates the lung cavity from the abdominal cavity. Your chest should move only slightly while your abdomen expands, because as the diaphragm moves downward, it causes the muscles surrounding the abdominal cavity to push outward.

3. Rest both your hands gently on your abdomen--right below your rib cage--and follow your breathing. Notice how your abdomen rises with each inhalation and falls with each exhalation.

4. Is your chest moving in harmony with your abdomen, or is it rigid? Spend a minute or two letting your chest follow the movement of your abdomen.

5. Scan your body for tension, especially your throat, chest and abdomen.

Step 2: Deep Abdominal Breathing

1. In the beginning, you may want to practice deep abdominal breathing as above--on the floor, but you can also practice sitting up in a chair or sitting up on the floor in a meditation pose.

2. Note the level of tension you're feeling. Place one hand on your abdomen just below your rib cage.

3. Inhale slowly and deeply through your nose into the bottom of your lungs, so that your abdomen pushes up your hand as much as feels comfortable. Your chest should move only a little and only with your abdomen. When you've taken in a full breath, pause for a moment and then exhale slowly through your nose or mouth, depending on your preference. Be sure to exhale fully. As you exhale, allow your whole body to just let go--like a rag doll.

4. Do ten slow, full abdominal breaths. Try to keep your breathing smooth and regular, without gulping in a big breath or letting your breath out all at once. Remember to pause briefly at the

end of each inhalation:

Slow inhale.....pause.....slow exhale (count one)
Slow inhale.....pause.....slow exhale (count two)
Slow inhale.....pause.....slow exhale (count three)

…and so on up to ten for each set. If you start to feel light-headed while practicing abdominal breathing, stop for thirty seconds, and then start up again.

5. You can extend the exercise if you wish by doing two or three sets of abdominal breaths, remembering to count up to ten for each set. Notice how your body feels at the end of this exercise.

(Lawsin,2008 p. 12-13)

Dysfunctional Coping

Dysfunctional Coping are maladaptive strategies used to alleviate stress. They are non-productive and in some cases are destructive over the long-term. We all use these strategies occasionally, however, effective copers have shown to use problem-focused and emotion-focused techniques more frequently. They also show more self-awareness while using dysfunctional coping strategies. (Carver, 1997; Wolf, & Mori, 2009). Some examples of dysfunctional coping strategies are:

The Dirty Half-Dozen

1) **Self-Blame:** Criticizing oneself for things that happen.
2) **Venting:** Expressing negative feelings without the intention of finding a solution.
3) **Self-Distraction:** Turning to work or other activities that take one's mind off the situation.
4) **Substance Misuse:** Using alcohol or drugs to mask negative emotions. This category can also include gambling, food misuse, gaming etc.
5) **Behavioral Disengagement:** Giving up efforts in trying to deal with the problem
6) **Denial:** Refusing to believe the reality

Given the strategies practiced in the emotion-focused and problem-focused sessions, discuss alternatives to each of the 'dirty half-dozen'. For example, **behavioral disengagement** often occurs when a person is feeling overwhelmed; alternatively breaking down a problem into more digestible components would be considered a functional approach to disengagement.

Techniques to Combat Dysfunctional Coping

The following section aims to provide some indicators of various dysfunctional coping strategies and their antidotes.

DYSFUNCTIONAL STRATEGY	ANTIDOTE	TECHNIQUE
Self- Blame	Self- Compassion	Counter-Thoughts
Venting	Use as Means to an End	Problem-Solving
Self-Distracting	Addressing	Mindfulness, Problem-Solving
Substance-Use	Self-soothing	Relaxation & Mindfulness
Denial/Behavioral Disengagement	Acceptance	Reality Checking & Worst Case/Best Case

1) Self-Blame:

Indicators of self blame:

- Shame about illness

- Expressing responsibility for getting sick
- Guilt about impact on others
- Regret
- Self Judgement/Criticism

Antidote: Self-Compassion

Indicators of self-compassion:

- Using kinder language when referring to oneself
- Expressing understanding about the universality of illness and disease process
- Acknowledging the impact on others but not taking ownership
- Having empathy for oneself

****Facilitator Tip: Get the participant to notice the emotional surge of guilt and shame. Building awareness is key to reframing and implementing counter thoughts. Participants often have a difficult time recognizing what self compassion looks like, when it is needed and how it can be applied; this is a role for facilitators.

2) Venting:

Indicators of venting:

- Jumping to conclusions
- Feelings of persecution
- Expressions of self pity
- Irrational thought processes
- Repetitive storytelling with little motivation for resolution

Antidote: Problem-Solving

Indicators of problem solving:

- Identifying problem
- Break problem down to specific parts
- Make a list of all possible solutions (concrete and tangible)
- Explore the consequences of each solution
- Make a plan
- Take action

****Facilitator tip: Suggest to participants to allot a certain amount of time for venting (5-10 min) and then to shift the focus to constructive problem-solving using the above steps.

3) Self-Distracting:

Indicators of self-distraction:

- Over scheduling
- Always socializing or doing things for others
- Self created chaos - disorganization
- Rarely talk about their health and/or management of same
- Over engaging in activities unrelated to illness management or other purposeful life activities

Antidote: Addressing

Indicators of addressing:

- Acknowledgement with self and others about illness
- Asking for help
- Setting internal and external boundaries
- Having reasonable expectations of self and others
- Using a daytimer and/or electronic reminders

****Facilitator tip: Explore potential risks and negative outcomes related to self distraction in the context of serious illness. Stress the importance of treating both physical and mental wellness as a priority that cannot be neglected.

4) Substance Use:

Indicators of substance use or misuse:

- Drinking or using mood altering substances in order to cope with emotions or difficult life events
- Rationalizing use of substance(s)
- Drinking or using more than intended
- Guilt and shame related to using
- Consequences related to using -impact on relationship, employment, health, legal etc.
- Lack of insight and/or denial related to use
- Collateral information supporting history of current substance use

Antidote: Self-Soothing

Indicators of Self-Soothing:

- Positive internal self-talk -daily affirmations and/or mantras
- Meditation, yoga or other mindful practice that may enable the relaxation response
- Deep breathing and/or guided imagery exercises

- Religious and/or spiritual practices
- Activate self-care plan

****Facilitator tip*: Make addiction resources available to participants when facilitators feel that misuse has been identified. Provide education around the consequences of substance misuse and encourage them to access the resources. With respect to self-soothing provide exercises and opportunities in class for participants to practice.

5) **Denial/ Behavioral Disengagement:**

Indicators of Denial/Behavioral Disengagement:

- Difficulty following through with medical recommendations
- Refusal to take medication as prescribed or not showing up for appointments/lab work
- Not actively engaged with care team, or their support network
- Actively avoids conversation about their illness

Antidote: Acceptance

Indicators of Acceptance:

- Active participation in healthcare management
- Open communication with care teams regarding disease process and adjustment
- Willingness to include support network in care process
- Engages in conversations with others about illness, coping, quality of life etc…
- Able to tolerate time in personal reflection with respect to illness adjustment

****Facilitator tip*: Introduce the concept of externalization as this can be a powerful tool in helping the participant separate between what their disease process is and who they are as an individual. This may help the participant gain some awareness and insight around the reality of their situation, in hopes of developing acceptance.

The following exercise is intended to support this weeks' homework:

Exercise: Patterns of Dysfunctional Coping

Identifying the use of the dirty dozen. Which did you use:

1)

Situations that triggered its use

1)

2)

3)

Emotions that triggered its use

1)

2)

3)

Relationships with other people that trigger its use

1)

2)

3)

Home Work

1) Use a relaxation technique at least twice this week.

2) Look for times when you use, or are tempted to use dysfunctional coping strategies- what circumstances lead you to use these strategies? Attempt to replace it with a suggested antidote.

3) **Write out a 5 minute "illness story" and consider the following:**
   - Tell us about your life before your illness.
   - What was it like for you when you learned about your diagnosis?
   - Share what it is like to live with your illness.
   - Describe what it is like waiting for a transplant?

**** Facilitator tip: The preparation of the illness story is paramount to supporting week five's curriculum. It is imperative that all members attending the following week participate as this leads to group cohesion and safety, and can highlight aspects of a "shared illness experience" among members.

Inform participants that they will have 5 minutes of uninterrupted time next week to share what they have prepared with the rest of the group.

SELF-IDENTITY

WEEK FIVE: 2 HOURS

Overview:

- **Check-In:** Review how previous week was for members; review last week's homework. Explore how the group is practicing coping skills; can they identify any triggers for dysfunctional coping? Are they tempted to use dysfunctional coping and if so, how do they overcome? **(15 mins)**
- **Introduction to Illness and Identity.** Briefly discuss how identity may be affected by illness and/or by transplant. Intro to sharing of illness story; each member will be allotted 5 uninterrupted minutes to share their illness story; members will be invited to provide feedback after presentation. This session will be highly unstructured in allowing members to disclose their illness narrative. Facilitators may want to take notes and identify common themes **(60 mins)**
- **Feedback:** Debrief illness story process with group and identify shared themes. **(5mins)**
- **Break (10 mins)**
- **Reframing your story**: provide a brief introduction re: loss of old self and creation of new self; use a group exercise format to discuss ways in which members can edit /externalize their illness story. **(15 mins)**
- **Power point:** presentation on the implications of Guilt, Shame and Society on Identity. **(10 mins)**
- **Relaxation Technique (time permitting):** One of the following - Guided Imagery/Progressive Muscle Relaxation/ Breathing Exercise/Mindfulness Exercise **(5min)**.
- **Homework and check out:** Reflection exercise **(5min)**.

Life-altering experiences, like illness, can have a profound impact on a persons' beliefs about themselves. This can lead to expectations or assumptions about what they can expect from themselves and others. During this session, we will be giving participants the opportunity to consider the impact their own experiences, and illness has had on their self-identity. We will also look at the costs and benefits of holding these beliefs, and will consider alternative ways of perceiving these or reframing them.

How people construct their 'illness story' in their head affects how they think and feel about themselves. Being attentive to the language they use is very important, for example, using the word "survivor" in an illness story rather than "victim" can impact their self perception. In listening to the illness stories, suggest that participants focus on the consistent elements that are threaded throughout each. This will better equip individuals to provide encouragement (Tschuschke,

Hertenstien, Arnold & Bunjes, 2001).

Illness Stories -Group exercise:

- Sharing of ‘illness stories’; five minutes of uninterrupted time per person.
- Revisit the concept of cross talking and side talking in an attempt to minimize disruptions, and to create a safe space.
- Inform the group that a facilitator will be keeping track of time at their discretion.
- Allow group members to provide encouragement, support, empathy and/or validation after each person has shared, this is not a time to offer solutions and/or constructive criticism.

****Facilitator tip**: You can expect that this exercise will be emotional for both participants and facilitator. Acknowledging and normalizing the intensity of emotions helps promote the notion that feelings are not something to be feared or avoided. The ability to sit in that space in a supported way, can lead to greater tolerance for emotional distress and foster compassion for others. It is encouraged that facilitators model authenticity in their reaction, while remaining mindful of the therapeutic process. This authenticity enhances group cohesion, allowing facilitators to be more relatable.

Reframing and Externalizing

Often times, individuals who endure a serious illness find themselves grieving their past ‘self’ and romanticizing about their old abilities and roles. This type of ‘black and white’ thinking can cause a great deal of distress for participants as they have difficulty accepting their new role. It is important to keep a balanced view of the past and present; noting that one is unlikely to be entirely bad and the other entirely good.

Exercise: Reframing

Have participants consider the following in the context of their illness:

What have you gained?

What have you learned?

In what positive ways have your relationships changed?

In what positive ways has your relationship with yourself changed?

It is common for individuals to over identify with their illness. Externalizing the illness is an effective strategy in acknowledging that while the illness has an impact on their life, it does not define who they are in the world. Individuals often find this reframing to be very useful.

Exercise: Reframing Analogy

Have participants think of their illness as a renter in their home and consider:

- How does this renter affect them?
- Is the renter noisy or bothersome or other times quiet?
- Does the renter take up space?
- Does the renter feel like a visitor or an intruder?
- How do they share their space with the renter and maintain who they are in the process?

****Facilitator Tip**: Suggest that participants explore their beliefs, values, likes and dislikes in an attempt to remember who they are, not only what is happening to their bodies. It is important to recognize that "the problem is the problem. The person is not the problem"
(White & Epston, 1990)

Society & Self-identity

Western Culture often discounts and devalues unable bodies and creates societal attitudes that contribute to higher levels of stress, distorted realities and feelings of inadequacy. Deconstructing societal norms or expectations can support participants in restructuring their roles and abilities in society and relationships in the context of their illness.

Western Society Promotes:

- Productivity
- Independence
- Masculine Stereotypes/ Feminine Stereotypes
- Health/ Youth
- Intelligence

Transplant Experience can lead to:

- Limited work ability
- Dependency on caregivers and health care system
- Changes in sex drive and impacts intimate relationships
- Bodily Changes: jaundice, weight gain, etc
- a disease process that may cause cognitive impairments

Exercise: Group Discussion

How do societal standards and gender expectations play a role in informing one's self-worth and self-identity?

- Is it true that an individual's worth is defined by their work-capacity?
- Are there worthwhile individuals that people know who are retired, differently-abled or unable to work?
- Are there other ways in which worth can be constructed?
- How can one negotiate with these societal standards?

****Facilitator Tip: Deconstruction involves breaking down societal beliefs, and gender norms in order to evaluate their truth. Critically analyzing these societal values is an empowering exercise. Expect some resistance as many of these beliefs are pervasive and often held life long.

Shame & Guilt

Shame and guilt are common emotional constructs. Shame is an interpersonal emotion experienced when individuals fear embarrassment, rejection or disapproval. Guilt is a person's own evaluation of themselves against standards they have learned through socialization.

Transplant candidates often feel shame and guilt for a variety of reasons. Individuals can feel responsible for their illness or feel guilty because someone must die or go through pain (ie. living donation) in order for them to receive an organ. It is also common for them to express feelings of guilt related to the burden of care associated with their illness, or feel shame related to needing care in the first place.

In some cases guilt can be a helpful tool to modify behaviour; shame however seldom offers any beneficial outcome as it can be damaging to one's mental wellbeing. With respect to the transplant patient it remains important to develop awareness of these emotions and any purpose they may serve. It is imperative that such self-exploration be transparent and without judgement.

****Facilitator Tip: Encourage patients to engage in self-reflection as this may increase their tolerance of uncomfortable emotions and assist in identifying and addressing potential thinking errors that may be contributing. By developing a familiarity with these feelings and how they present themselves, individuals may be better able to manage them in a sustainable way.

Home Work

Reflection exercise:

- Consider ways in which you are not defined by your illness.

- Explore how both guilt and shame have shown up in your life and ask what purpose they serve.

- Challenge some of your beliefs around the roles that you play and consider how they may be reconstructed.

INTERPERSONAL RELATIONSHIPS & TRANSPLANT:
STRESS AND COMMUNICATION

WEEK SIX: 2 HOURS

Overview:

- **Check-In:** How has the week been? How did the homework exercise go? **(20 mins)**
- **Interpersonal Relationships & Transplant:** Present power point material and roll into brainstorm exercise re: transplant related stress and inter- personal relationships. **(20 mins)**
- **Communication:** Present power point material on stress and communication, assertive communication and good communication.. (Give "Good Communication" hand out) **(20 mins)**
- **Break (10 mins)**
- **Communication (cont'd):** Present power point on Steps to Open Communication (Give hand out) Pitfalls and Tips **(20 mins)**
- **Role Play exercise -** present scenario **(15 mins)**
- **Debrief** role play and review **(10 mins)**
- **Homework and check out (5min)**.

Stress & Communication: Leading to Relationship Problems

Interpersonal problems are often exacerbated during times of increased stress. It is very common for pre-transplant patients to experience marital problems or other interpersonal issues as a result of stress. Research shows that a person's ability to communicate effectively is especially impacted by stress. The spillover effect of chronic illness stressors on interpersonal communication has been demonstrated in research and is particularly evident in literature on organ transplant candidates (Daneker, 2001). Stressed individuals were more withdrawn and displayed more angry and hostile behavior. An experiment on seventy couples videotaped for 10 minutes in two identical settings, once before and once after an experimental stress induction, revealed that dyadic communication decreased by 40% under the stressful condition. Under stress, positive interactions such as **active listening, interest** and **empathy** were reduced, AND negative behaviors such as **criticism, contempt, belligerence** and **withdrawal**, increased significantly. Improving communication skills, especially for use in times of high stress, has shown to improve relationship quality and reduce emotional distress that is associated with poor interpersonal relationships (Gottman & Levenson, 1992; Kiecolt-Glaser et al., 1996).

Good Communication: (3 factors)

1) **Active Listening:** is listening respectfully in order to genuinely understand what the other person is trying to say. A person can demonstrate that they have heard and understand the other person by making reflective statements.
   a) **Repeating**– simply repeating what the person said.
   b) **Rephrasing**- rephrase with a few word substitutions
   c) **Paraphrasing**- Infer the meaning of what was said. It can be thought of as stating the next sentence the speaker is going to say- not the same as finishing someone's sentence.
   d) **Reflecting**- Reflecting the emotion underneath the content of what someone is saying.

2) **Empathizing**: Is the capacity to, through imagination, share the emotional experience of another. It is feeling compassion or concern for another in trying to see a situation from their perspective.

3) **Collaborative Solution**: Taking into account both perspectives and needs in order to arrive at a solution that is amenable to both parties.

Steps to open communication

Open & Assertive Communication often looks like an individual having their needs met while respecting the needs of the other. It is standing up for oneself without being forceful or aggressive.

STEP 1: THEIR SIDE OF THE STORY

Understand where they are coming from. Give them time to explain.

- "I understand why you did this."
- Use open-ended questions such as "What does that feel like?" or "Can you tell me more about __?"
- The purpose is to lower their defenses and acknowledge that their point is relevant.
- Paraphrase. For example, "So what you're saying is____, do I have that right?"
- "So____ is your problem- ____ is at the heart of the issue."
- "You seem really angry when we talk about _____ - Why is that?... What does that mean?" (Get to the heart of the problem and try not to waste time on superficial problems.)
- Prompt them to elaborate.
- The use of ** Empathy** is key in lowering defenses.

Empathetic Response Statements	
So what you're saying is **….**	Do I have that right?
From your perspective **….**	Is that how you see it?
When you __ you feel __ **….**	Is that what you are saying?
Can you help me understand **….**	At times you feel_____
I sense you are feeling **….**	Is that how you feel?
It sounds like what you are saying or feeling) is **….**	Am I on the right track?

Step 2 : Your Side of the Story

Explaining only your side of the dispute- the impact of the situation on you.

- Use of the statement: "When you ____ I feel ____"
- Being neutral and factual
- Example: "When you read the newspaper while I'm talking to you, I feel like you are not interested in what I have to say"
- First talk about behavior, followed by how that behavior affects you.
- "When you brush off arguments it makes me feel as though you are not taking my concerns seriously."

Step 3: Make a Request

- What would you like from them?
- "I would appreciate it if you would ____ in the future. Do you think that is reasonable?"
- Allow room for compromise here so that both parties are happy with the outcome.
- Deny the temptation to call people on lies (unless this is the issue). This will just escalate the argument and cause the person to react defensively. A more effective thing to do is to make sure the problem can be overcome in the future.

Step 4: Future

- Discussion of how this situation can be avoided in the future.
- Evaluating the problems that led up to the dispute; that can be addressed more proactively in the future.

(Markman & Stanley, 2010)

Pitfalls for Open Communication

- Bringing the conversation back to yourself.
- Going off on tangents. It's important to stick to relevant points.
- Bringing old issues into the argument. For example, "Well, last year you…."
- Speaking in a way that is not respectful. Be aware of your tone.
- Engaging in negative emotions. Instead reflect what you see neutrally. Use statements such as "you look very angry", instead of "you look pissed off." This helps others reflect on themselves, which usually leads to them calming down.
- Making judgment statements about what is being said. For example, saying "good for you" or "that was wrong."
- Being defensive, and saying "Do it yourself."
- Using 'you' statements. Instead, use 'I' statements- "I feel_____ ."
- Trying to convince the other person that your perspective is the 'right' one. Rather, try to view the dispute as two conflicting, but equally valid, perspectives.

Conclusion: Even while taking these steps, sometimes it may not result in the desired outcome.

- The other person may still act defensively or angrily.
- You may be dealing with someone who is unreasonable, however you can walk away confident that you did the best you could.
- "I was decent and it is not my fault that it didn't work out."

Communication Tips

- You can write a script for yourself.
- You and your significant other can come up with your own agreed upon rules and guidelines to an argument to which to refer. Sometimes writing out these instructions and having them in front of you when discussing is helpful because when stressed and/or angry they are markedly more difficult to remember.
- You do not have to have the argument in the moment that the problem arises. Sometimes it is beneficial to come back to it later when emotions are not as high.
- You can make a request to sit down in the future and formally talk about the issue. This indicates its importance.(Gottman, 2001)

Facilitated Role Play: Members of the group will now have time to brainstorm common points of contention that they have with significant people in their lives. Pick one that is transplant-specific and shared by the group. Have members pair up and pick one side of the dispute to practice open communication, then have them switch their position. Time permitting, debrief the role play experience from each perspective.

Exercise: Communication Role Play

Interpersonal Issue: Transplant patient does not look sick, but is. Energy levels are greatly impacted and therefore their ability to participate in their relationships is as well.

Person One: Sally (patient)

Person Two: John (friend)

Sally (patient) gets up in the morning and is feeling fatigued. She remembers she has plans with her best friend, John, for lunch whom she hasn't seen in a while because she has so many medical appointments. It becomes clear to her after her shower that she is going to have to cancel with him again. She calls John to let him know. John is frustrated and disappointed and feels that Sally is no longer there for him, yet she is able to always follow up on her own medical issues and appointments.

Home Work

Use the steps to open communication at least twice this week. Choose a time when you are feeling slightly distressed but not in crisis, to practice these skills.

Make a note of the changes you applied (ie tone, language) in order to communicate more effectively.

INTERPERSONAL RELATIONSHIPS & TRANSPLANT:
COMMUNICATION WITH HEALTHCARE PROVIDERS

WEEK SEVEN: 2 HOURS

Overview:

- **Check-In:** How was the week? How was the "steps to communication" homework?**(20 mins)**
- **Assertiveness:** Review power point **(30 mins)**
- **Break (10 mins)**
- **Pt-Doctor Communication:** Review power point (30 mins)
- **Hope/Spirituality and transplant:** Review power point (20 mins)
- **Relaxation Technique:** One of the following - Guided Imagery/Progressive Muscle Relaxation/ Breathing Exercise/Mindfulness Exercise **(5min)**.
- **Homework and check out**. **(5min)**.

Being worked-up and followed for a transplant requires individuals to have frequent interaction with the health-care system to assess and manage symptoms, adjust medications, and address mental health concerns. While this system is intended to have a person's best interest in mind, it can often times feel like an added stressor. In this way, transplant candidates deal with differing agendas of various health professionals and often feel shuffled around the busy schedules of doctors, nurses and allied health professionals. It is imperative in this process that patients have clear communication and assertiveness skills. They are their best advocate - the onus is on them to communicate their concerns and rally resources.

Without these tools, hospital visits can contribute to one's feelings of loss of control and helplessness.

Tips on Being Assertive with Healthcare providers

Assertiveness: Saying "no" when you want to say no.

Brevity is crucial. Be as brief as possible. Avoid giving explanations or long justifications.

Use the word "no" when declining. The word "no" has more power than the ambiguous statement "well I don't think so."

Limit the words "I'm sorry" when saying "no." Try to be conscious about using this phrase to excuse your refusal – it can distract from your real intent.

Buy time for yourself. Say, "Let me get back to you on that," or "I'll think about it."

Doctor-Patient Communication

1. Write down a few questions or make a list of what you want to talk about. This can be your prompt sheet. Make sure all of the topics you listed are covered in your appointment time.

2. Let the doctor know what is most important to you. The doctor needs to know what's important to you so that they can choose the best treatments with you.

3. Ask a friend or family member to be with you to take notes.

4. Ask your most important questions first.

5. If you don't understand, ask your doctor to repeat in a way that is clearer to you. Asking for clarification more than once is more than acceptable. Make sure you leave with a clear explanation.

6. To ensure that you do have a proper understanding, try paraphrasing what your doctor has told you in your own words. *"So what you are telling me is, my kidney is functioning better this week? Am I getting that right?"*

7. If you would like further information that your doctor cannot give you, ask where you can get the information you desire; resources or another health professional.

8. Take a small tape recorder with you and tell your doctor you would like to record the visit to help you remember.

9. Regard your doctor as your ally.

10. Go into each doctors' appointment assuming that ALL of your concerns are valid, this includes mental health concerns like low mood, hypervigilance, lack of sleep etc. Communication is key.
(Edgar, 2007)

Hope/Spirituality & Transplantation

Brainstorming with group: What brings you hope?

Arguably, the most important element in the transplant process is maintaining hope. When interviewing a panel of post-transplant patients about what helped them through the difficult process of organ transplant, hope was emphasized and agreed upon as the number one primary factor. Try to maintain a 'fighting spirit' throughout the process; characterized by optimism and self-determination (Tschuschuk, 2001)

Maintaining Hope in Difficult Circumstances

Hopeisnowhere

Hope is now here OR hope is no where

Some people find hope in spirituality. Spirituality can refer to a variety of things. Individuals can find spirituality through a close connection to the earth, through communion with others OR by adhering to an organized religion.

- Explore how spirituality plays a role in participants' life?

Home Work

1) Use the assertiveness guidelines to turn down a request.

2) Start a list of questions and concerns to use for your next doctor's appointment.

3) Practice a relaxation exercise everyday

4) Write a list of things you hope to do after transplant.

SUMMARY AND GROUP CLOSING

WEEK EIGHT: 2 HOURS

Overview:

Check-In: How has the week been? How do you feel about this being the last session? **(20 mins)**

- **Summarize Skills/ Highlight Progress:** Have members identify changes and 2 most important things they have taken from the group **(40 mins)**
- **Break (10 mins)**
- **Closing Exercise (40 mins)**
- **Debrief** and exchange of information **(10 mins)**
- **Resources (10min)**

Review Session

Stress

The stress response (sympathetic nervous system) involves the release of hormones (Cortisol and Adrenaline) into our system, allowing our bodies to react quickly to the perceived threat.

- Using coping strategies as a buffer between environmental stress and our stress response.

Problem -Focused Coping:

- Changing the situation by defining the problem, looking at alternative solutions, and then evaluating options in order to choose the best strategy
- Those who use PFC are shown to have longer graft survival, better quality of life, and less risk of anxiety/depression
    - Instrumental Support: Drawing on the help and advice of others on how to address a situation
    - Planning: Creating a strategy with steps to address the situation, use problem solving
    - Active Coping: Concentrating efforts on taking action in the situation to improve it
    -

Emotion -Focused Coping:

Not all situations can be changed, but how we *feel* about the situation can be changed

- Thinking about a situation effects how we feel
    - Acceptance: Accepting reality and learning to live with it

- Emotional Support: Deriving comfort and understanding from others
- Humor: Making fun of the situation
- Positive Reframing: Seeing a situation in a more positive light, looking for the good in a situation
- Spirituality: Finding comfort in spiritual beliefs/meditating
- Relaxation Techniques

Dysfunctional Coping:
Non-productive coping strategies used to alleviate stress:

The Dirty Half Dozen:

1. Behavioral Disengagement: Giving up any efforts in trying to deal with the problem
2. Denial: Refusing to believe in reality
3. Self-Distraction: Running to other activities to take one's mind off of the situation
4. Self-Blame: Criticizing oneself for things that happen
5. Substance Use: Using alcohol/drugs to mask negative emotions
6. Venting: Expressing negative feelings

- Combating Dysfunctional Coping: Remembering the importance of awareness; use problem-focused and emotion-focused coping strategies

Self-identity:
- "Illness Story":
  - Positive Reframing
  - Externalizing
  - Balanced Perception
- Societal Pressures: Deconstructing cultural expectations

Interpersonal Difficulties:
Effective Communication:

- Active Listening: Repeat, Rephrase, Reflect
- Empathizing: compassion, concern, share experience of another

- Collaborative Solution: Look at both perspectives in order to find a solution

Steps to open communication:

1. Their Side
2. My Side
3. Solution

Self Advocacy:

- Open/Assertive Communication: Way of getting your own needs met while respecting others; standing up for yourself without being aggressive.
- Assertiveness: Maintain boundaries, be direct.

Finding Hope & Spirituality:

- Discussion on the role spirituality takes in serving as a source of strength through adversity.

Exercise: Group Closure

- What is the most powerful thing you have learned over the sessions?
- Is there anything else you would have liked to discuss further?
- How will the future be different for you after this group?
- Inspirational Rocks: Request each participant to write one word on the rock that symbolizes their experience.
- Testimonials: Invite participants to submit to facilitators.

REFERENCES

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing.

Baranyi, A., Krauseneck, T., & Rothenhäusler, H.B. (2013). Overall mental distress and health-related quality of life after solid-organ transplantation: results from a retrospective follow-up study. *Health Quality of Life Outcomes, 8,* 11-15.

Beck, A., Rush J., Shaw, B., & Emery, G. (1987). *Cognitive Therapy of Depression.* New York. Guilford Clinical Psychology and Psychopathology.

Beck, J. S (2011*). Cognitive behavior therapy: Basics and beyond* (2nd ed.). New York, NY: Guilford.

Blumenthal, J. A., Babyak, M. A., Keefe, F. J., Davis, R. D., Lacaille, R.A., Carney, R. M., Freedland, K. E., Trulock, E., & Palmer, S. M. (2006). Telephone-based coping skills training for patients awaiting lung transplantation. *Journal of Consulting and Clinical Psychology*, *74,* 535-544.

Burns, David D. (1989). *The Feeling Good Handbook: Using the New Mood Therapy in Everyday Life*. New York: W. Morrow.

Carver, C.S. (1997). You want to measure coping but your protocol's too long: consider the brief COPE. *International Journal of Behavioural Medicine, 4,* 192-100.

Carver C.S., Scheier, M.F., Weintraub, J.K. (1989) Assessing coping strategies: a theoretically based approach. *Journal of Personality and Social Psycholology, 56,* 267-283.

Cooper, C., Katona, C., Livingston, G. (2008). Validity and reliability of the brief COPE in caregivers of people with dementia: the LASER-AD study. *The Journal of Nervous and Mental Disease, 196,* 838-843.

Cooper, C., Katona, C., Orrell, M., & Livingston, G. (2008). Coping strategies, anxiety and depression in caregivers of people with Alzheimer's disease. *International Journal of Geriatric Psychiatry, 23*, 929-936.

Corbett, C., Armstrong, M.J., Parker, R., Webb, K.,& Neuberger, J.M. (2013). Mental health disorders and solid-organ transplant recipients. *Transplantation, 96,* 593-600.

Cukor, D., Rosenthal, D.S., Jindal, R.M., Brown, C.D., & Kimmel, P.L. (2009). Depression is an important contributor to low medication adherence in hemodialyzed patients and transplant recipients. *Kidney International, 75,* 1223-1229.

DiMartini, A., Dew, M.A., Chaiffetz, D., Fitzgerald, M.G., Devera, M.E., & Fontes, P. (2011) Early trajectories of depressive symptoms after liver transplantation for alcoholic liver disease predicts long-term survival. *American Journal of Transplantation, 11,* 1287-1295.

Edgar, L. (2007). *Coping Skills for Life.* Quebec: Hope and Cope Wellness Centre.

Folkman, S., Lazarus, R.S., Gruen, R.J., & DeLongis, A. (1986) Appraisal, coping, health status, and psychological symptoms. *Journal of Personality and Social Psychology, 50,* 571-579.

Frazier, P. A., Davis-Ali, S. H.,& Dahl, K.E. (1995). Stressors, social support, and adjustment in kidney transplant patients and their spouses. *Social Work in Health Care, 21*, 93-108.

Gendlin, E. (1978). *Focusing*. New York: Random House.

Girdano, D. (1993). *Controlling Stress and Tension: A Holistic Approach* (4th Ed.). San Francisco CA: Benjamin Cummings.

Gottman, J. & Levenson, R. (1992). Marital process predictive of later dissolution: Behavior, physiology, and health. *Journal of Personality and Social Psychology, 63,* 221-233.

Gottman, J. (2001). *The Seven Principles for Making Marriage Work: A Practical Guide from the Country's Foremost Relationship Expert.* New York: Random House.

Gross, C.R., Kreitzer, M.J., Thomas, W., Reilly-Spong, M., Cramer-Bornemann, M., Nyman, J.A., Frazier, P., & Ibrahim, H.N. (2010). Mindfulness-based stress reduction for solid organ transplant recipients: a randomized controlled trial.

Alternative Therapies in Health and Medicine,16, 30-38.

Johnson, S. (2009). *Therapist's Guide to Posttraumatic Stress Disorder Intervention.* London UK: Elsevier Inc.

Kabat-Zinn, J. (2013) *Full Catastrophe Living Revised Edition: How to cope with stress, pain and illness using mindfulness meditation.* New York: Bantam Books.

Kabat-Zinnn, J. (1990). Full catastrophe living: Using the wisdom of your body and mind to face stress, pain and illness. New York: Delacorte.

Kiecolt-Glaser, J., Newton, T., Cacioppo, J., MacCallum, R., Glaser, R. & Malarkey, W. (1996). Marital conflict and endocrine function: Are men really more physiologically affected than women? *Journal of Consulting and Clinical Psychology, 64,* 324-332.

Kimmel, P.L., Peterson, R.A., Weihs, K.L., Simmens, S.J., Alleyne, S., Cruz, I., & Veis, J.H. (2000). Multiple measurements of depression predict mortality in a longitudinal study of chronic hemodialysis outpatients. *Kidney International, 57*(5)*,* 2093-2098.

Lawsin, C. (2008). *Coping Skills Training Intervention Manual for Cancer Patients.* Sydney Australia: Property of University of Sydney.

Lazarus, R.S., & Folkman, S. (1984). *Stress, Appraisal and Coping.* New York: Springer.

Linehan,M. (1993). *Skills Training Manual for Treating Borderline Personality Disorder: Diagnosis and Treatment of Mental Disorders (Diagnosis & Treatment of Mental Disorder)* New York: Guilford Press.

Lopes, A.A., Bragg, J., Young, E., Goodkin, D., Mapes, D., Combe, C., Piera, L., Held, P., Gillespie, B., & Port, F.K. (2002). Dialysis outcomes and practice patterns study (DOPPS). Depression as a predictor of mortality and hospitalization among hemodialysis patients in the United States and Europe. *Kidney International, 62*(1)*,* 199-207.

Markman, S., & Standley, S. (2010). *Fighting for your Marriage: A deluxe revised edition of the classic best-seller for Enhancing marriage and preventing divorce.* San Francisco. Jossey- Bass.

McMillan, S.C., Small, B.J., Weitzner, M., Schonwetter, R., Tittle, M., Moody, L.,& Haley, W.E. (2006). Impact of coping skills intervention with family caregivers of hospice patients with cancer: a randomized clinical trial. *Cancer, 106*, 214-222.

Myaskovsky, L., Dew, M.A., McNulty, M.L., Switzer, G.E., DiMartini, A.F., Kormos, R.L., & McCurry, K.R.(2006). Trajectories of change in quality of life in 12-month survivors of lung or heart transplant. *American Journal of Transplant, 6,* 1939-1947.

Neipp, M., Karavul, B., Jackobs, S., Meyer zu Vilsendorf, A., Richter, N., Becker, T., Schwarz, A.,& Klempnauer, J. (2006). Quality of life in adult transplant recipients more than 15 years after kidney transplantation. *Transplantation, 81,* 1640-1644.

Noohi, S., Khaghani-Zadeh, M., Javadipour, M., Assari, S., Najafi, M., Ebrahiminia, M., Pourfarziani, V. (2007). Anxiety and depression are correlated with higher morbidity after kidney transplantation. *Transplant Proceedings, 39,* 1074-1078.

Owen, J.E., Bonds, C.L., & Wellisch, D.K. (2006). Psychiatric evaluations of heart transplant candidates: predicting post-transplant hospitalizations, rejection episodes, and survival. *Psychosomatics,47*, 213-222.

Parr, E. & Mize, J. (2001) *Coping with organ transplant.* California: Avery

Perls, F. (1992). *Gestalt Therapy Verbatim.* Highland, NY: Gestalt Journal Press.

Prochaska, J. O. and C. C. DiClemente (1986). Toward a comprehensive model of change. In W. R. Miller & N. Heather (Eds.), *Treating Addictive Behaviors: Processes of Change* (3-27). New York: Plenum Press.

Roeder, E. (2004, January 1). From stress and Eros. Retrieved June 2, 2010, from http://www.stressanderos.org/problem-focused-coping.htm

Schneiderman, N., Ironson, G., & Siegel, S. D. (2005). Stress and health: psychological, behavioral, and biological determinants. *Annual Review of Clinical Psychology, 1,* 607- 628.

Sharp, T. (2002). The happiness institute: challenging automatic negative thoughts. Retrieved June 2, 2010, from http://www.thehappinessinstitute.com/freeproducts/docs.pdf

Siegel,R. (2009). *The Mindfulness Solution: Everyday Practices for Everyday Problems.* New York: Guilford Press.

Telles-Correia, D., Barbosa, A., Mega, I., & Monteiro, E. (2009). Importance of depression and active coping in liver transplant candidates' quality of life. *Progress in Transplantation*, 19, 85-89.

Tindall, J. (2008). *Peer Power, Book One: Workbook: Becoming an Effective Peer Helper and Conflict Mediator (*4th ed*.).*London England: Routledge.

Tolle,E. (2003). *Stillness Speaks.* Vancouver, Canada: Namaste Publishing.

Tsay, S. L., Lee, Y. C., & Lee, Y. C. (2005). Effects of an adaptation training programme for patients with end-stage renal disease. *Journal of Advanced Nursing, 50,* 39-46.

Tschuschke, V., Hertenstien, B, Arnold, R., Bunjes, D., Denzinger, R., & Kaechele, H. (2001). Association between coping and survival time for adult leukemia patients receiving allogeneic bone marrow transplantation: Results of a prospective study. *Journal of psychosomatic research, 50,* 277-85.

White, M., & Epston, D. (1990). *Narrative Means to Therapeutic Ends.* New York: W.W. Norton & Company.

Wolf, E. J., & Mori, D. L. (2009). Avoidant coping as a predictor of mortality in veterans with end-stage renal disease. *Journal of Health Psychology*, *28,* 330-337.

ABOUT THE AUTHORS

Tasneem Remtulla MSW, RSW has been practicing medical social work for twenty years at the Foothills Medical Center in Calgary, Alberta. For the last eighteen years she has worked at the Southern Alberta Transplant Program, specifically with the kidney and pancreas population. Tasneem holds a Bachelors degree in Sociology and Social Work, as well as a Masters degree in Social Work, and is registered with the Alberta College of Social Workers with restricted activity status. In her current role with the Southern Alberta Transplant Program, Tasneem provides individual counselling to patients both pre and post-transplant, as well as conducts psycho-social assessments providing recommendations and consultation to the transplant team regarding transplant candidacy and psycho-social preparedness. Additionally, Tasneem has participated in the development and facilitation of group interventions for those living with chronic and/or acute illness. Tasneem's scope of practice also includes patient teaching, staff education, patient advocacy, program/policy development and conducting social work transplant research. In recent years, Tasneem has also had the opportunity to present locally, nationally and internationally on embedded research and coping skills in the transplant population. Tasneem has a strong interest in biomedical ethics within the context of transplantation including exploration of the clinical and legal implications of transplant tourism.

Email: Tasneem.Remtulla@albertahealthservices.ca

Dee Miner MSW, RSW has been practicing medical social work for seventeen years at the Foothills Medical Centre in Calgary, Alberta. For the last 12 years she has worked at the Southern Alberta Transplant Program, specifically with the liver and lung transplant population. She holds a Bachelors and Masters degree in Social Work and is registered with the Alberta College of Social Workers with restricted activity status. In her current role with the Southern Alberta Transplant Program, Dee provides individual counselling to patients both pre and post-transplant. Additionally Dee completes comprehensive psychosocial assessments with recommendations regarding transplant candidacy, while participating in transplant listing discussions. Dee has participated in the development and facilitation of group interventions; both organ specific support groups, and group intervention to those living with chronic and/or acute illness. She has a keen interest, and skill in the assessment and

treatment of addiction within the context of transplantation. Dee's scope of practice also includes patient teaching, staff education, psychosocial support, patient advocacy, program/policy development and conducting social work transplant research. Lastly, she has had the opportunity to present locally, nationally and internationally on embedded research and coping skills in the transplant population.

Email: Dee.Miner@albertahealthservices.ca

Julie Anne Craig MSW, RSW practiced forensic social work for eight years through Alberta Health Services Forensic Adolescent Program. In this role, she provided individual and group psychosocial interventions to adolescents involved in the criminal justice system. Julie also conducted psychosocial assessments utilized by the Provincial Court of Alberta to inform adolescent sentencing. Julie attained her master's degree of social work at Wilfrid Laurier University, which coupled with her bachelor's degree of psychology and sociology from Queens University. Her education offered her a strong blend of research, analysis, and clinical social work skills. Prior to working in Forensics, Julie was employed by the Southern Alberta Transplant Program to conduct a literature review evaluating the impact of healthy coping skills in reducing depression and anxiety in pre-organ transplant patients as a basis for developing a group-therapy manual. The following six years she volunteered her time to assist with the research on this ongoing project that culminated in a publication and the Coping Skills Group manual.

ACKNOWLEDGEMENTS

We would like to extend our heartfelt appreciation and gratitude to our collaborative partners without whom this manual would not have been possible.

Thank you Dr. Lauren Zanussi (Department of Psychiatry, Alberta Health Services) for being our sounding board and for providing your clinical expertise, collaboration and guidance over the years.

Thank you Alberta Health Services Department of Allied Health and Alberta Health Services Southern Alberta Transplant Program (ALTRA) for encouraging and supporting innovation in clinical practice and program development.

We would also like to thank Dr. J.S Beck, Dr. M. Linehan(and Guilford Press) and Dr E Gendlin for granting us permission to use and/or reprint material from their respective practice, works and publications.