A Grief Recovery Outreach Program: Qualitative Study of Process and Change (Comparison of Grief Recovery Outreach Program and Prolonged Exposure Therapy)

Lynn M. Klimo, M.D., PGY IV, Elaine Henderson, M.Div., Joseph Varley, M.D., John Engel, Ph.D., Lura Pethtel, M.Ed.

(Original study)

Abstract

Objectives: This is a qualitative study to understand the experience that people have in the Grief Recovery Outreach Program. This is a group that is offered in many areas, in many different settings, around the world. It is a twelve week course to help people learn to cope with loss of many types. It has several components including education, fellowship and support, cognitive work, narrative work, and various other ways people learn to deal with grief. However, based on a literature review and an interview with a co-founder of the organization, there is no formalized research on the effectiveness of this group. This program is offered at Summa Health System St. Thomas Hospital, four times a year. This study was undertaken in order to understand trends of people's experience of the process of the group, the benefits or changes they experienced, as well as to create further questions for future research.

Methods: All the people who attended the Grief Recovery Outreach Program at St. Thomas hospital since it began here to the summer of 2003 were invited to participate in an interview. They were given research numbers in their letter to preserve anonymity. A total of 312 letters were sent out and there were 93 responses. With the help of Elaine Henderson M.Div., who facilitates the group, we grouped the names by gender, race, and socioeconomic background in order to obtain a heterogeneous sampling. Of those groups we randomly selected 14 people to invite to an interview. Due to an incomplete response of those 14 people, 6 more names were randomly selected and invited to participate. Of the 20 invited, I interviewed 8 people. Informed consent was obtained. The interviews were approximately one hour long, consisted of a short demographic sheet and an interview. The interview was audio-taped and transcribed. The data was analyzed for trends within question sets.

Demographics: Out of eight participants in this study, five were female and 3 were male, mean age was 60.4, seven were Caucasian and one African American, 50% were married, 25% divorced, one widowed, and one had a significant other. All had children, had some form of education, 50% were employed full time, 25% part time, 25% retired, and had a diverse range of incomes and religious backgrounds. They participated during various groups from 1999 to 2003 and there were a variety of losses represented.

Results: The results showed 100% (8 out of 8) of the interviewees reported an overall positive effect, that they would recommend the group, they use things they learned in the group elsewhere in their lives and they all felt some type of change had occurred. 100% of the sample felt safe at some point in the group, some for different reasons and at different times. The entire sample felt that reading out loud their assignments was a significant factor in their change. They were all able to report a variety of ways they had experienced this change as well as what aspects of the group they found most and least helpful. No one found anything unhelpful.

Discussion: This qualitative study indicates that attending the Grief Recovery Outreach Program is an overall positive experience that affects several areas of peoples' lives. It also appears that emotional abuse following loss has some role in the process of grieving. Even though there are other aspects of the group that were found to be helpful, the process of reading out loud assignments, called narrative in the literature, has a significant impact on the healing process. The group not only helps to provide a new way of understanding and coping with grief, but it also impacts other important areas of their lives.

The specific methods and outcome results of the study described in the abstract are detailed in a separate paper. This paper attempts to compare the Grief Recovery Outreach Program with Edna Foa's model of Exposure Therapy.

The Grief Recovery Outreach Program was developed primary out of the need of one man to deal with the grief over the death of his son in 1977. John W. James is the founder of the Grief Recovery Institute Educational Foundation, Inc. and first published the book, *The Grief Recovery Handbook*, in 1986. He had created a way of dealing with his grief that he first began sharing in funeral homes. He noticed that it helped many people and thus wrote the book. In 1998, Russell Friedman, after beginning as a volunteer at the Institute in 1987, became John's partner and together they revised *The Grief Recovery Handbook*, which has now been translated into at least five languages and is used around the world. The Institute also provides certification courses and workshops, and the Grief Recovery Outreach Program, which is being utilized by more than half a million people.

Grief, many people do not understand it and don't know how to deal with it. So, what is grief? It can be a normal reaction to a loss and it can also become pathological. In this article we will deal with a spectrum of grief reactions and one way to address them. We will also look at the similarities of a group treatment for grief with an individual treatment for trauma. When many people think about grief and 'loss', the things they consider are usually things such as death of a loved one, divorce, or loss of a job. However, loss can include many things. *The Grief Recovery Handbook* (Pg. 3) defines grief as "conflicting feelings caused by the end of or change in a familiar pattern of behavior". This can include a change in job, a move, loss of a pet, change in a life situation, finishing or beginning school, health issues, and many others. Some loss can also be related to a person's internal state, such as loss of esteem, respect, control, etc.

Another concept that the Grief Recovery Outreach Program emphasizes is that grief is not an intellectual process yet much of the time that is how we deal with it. People learn at a young age, from parents, family, school, media, and life events, that this is how to deal with grief.

Often people who have grief try to avoid it and other people try to comfort those grieving.

However, many of the things people say or do are not helpful to the grieving person. What occurs most often is that the things people learn are not helpful, and even not true. These are called "myths". People have learned they need to "be strong", "not cry", "just move on", and they hear "don't feel bad", you will be "better off without them", "there is always someone else", or "time will heal". These things do not facilitate the grief process. They usually stop it. Many people tend to "bury" feelings and grieve incompletely. The effects of this are great. It affects relationships, work, concentration, expression of emotions, and many other aspects of people's lives. People continue with their daily life and as other losses occur, they tend to accumulate and create more problems in their lives. They are often unaware that this unresolved grief has such an affect on their lives.

When a loss occurs or a trauma happens people cope with it in the ways that they have available to them. At times people need some assistance with the process of grieving or healing from trauma. Edna Foa developed a treatment for Post Traumatic Stress Disorder (develops in some people after trauma), which appears to have some components that are similar to the Grief Recovery Outreach Program. This treatment is called Prolonged Exposure Therapy. The following is a brief description of each treatment and the results experienced by participants. The results of the Grief Recovery Outreach Program are based on the qualitative study described in the abstract. The results described for the exposure therapy are based on this author's personal reading and experience performing the treatment.

Prolonged exposure therapy is a cognitive behavioral, brief therapy for people that have had traumatic experiences and are experiencing the symptoms of PTSD. It is a manualized therapy consisting of 10-12 weekly sessions, 1½ to 2 hours long with a therapist. The sessions involve education about symptoms a person may be experiencing and the process of both the response to trauma and the therapy, and two main components. The first is in vivo exposure which is done by the person between sessions. This involves identifying feelings, writing down situations, becoming aware of thoughts and changing the way a person thinks about certain situations. It also involves relaxation and a change in how people feel. The second component, prolonged imaginal exposure, occurs in the session and is exposure to the traumatic memory. This is accomplished by the person talking about the event (narrative) in

the first person repetitively in the session, having this story audio taped, and then listening to the tapes between sessions. Cognitive restructuring also occurs during this time to help the person gain an accurate perception of the event and their part in it. (See Table 1)

There are three main beliefs that a person has as a result of trauma that the therapy aims to address. There is a belief that the world is an unsafe place, that the person is 'incompetent' and can't cope, and that they are somehow responsible for what occurred. After a trauma these become generalized to many aspects of their lives. With exposure therapy these beliefs are reduced by disproving them through repeated anxiety reducing experiences.

The result of this therapy is that many people feel less anxious, are able to do things they were unable to do prior to treatment, feel more able to cope with situations, are able to identify thought patterns that may not be accurate and create a shift in them, and many of their emotional and/or physical symptoms they may have been experiencing reduce, among others. They begin to understand and gain a different perspective on their behavior and on a variety of other things due to the cognitive work done in therapy, and they gain a more realistic view of the event, their role in it and the world around them. This affects many different areas of their lives, including at home, work, relationships, and their internal state of well being.

The Grief Recovery Outreach Program has many similar components to Exposure therapy. The group runs for 12 weeks, each is 1½ hours long. It is manualized and facilitated by a certified group leader. It involves education about grief, written homework examining a person's beliefs about grieving, their loss history which often includes a loss that felt traumatic to the person, and retelling the history to the group (narrative). The written work involves graphs of loss history and a relationship which also includes some cognitive restructuring which occurs by including a balanced look at these events and an examination of the individual's responsibility in the relationship and a forgiving and amends process. (See Table 1)

Some of the results of completing this group are a greater sense of control over their emotions and sense of being able to cope, they feel more able to experience and express emotion, and, if they are experiencing anger or guilt, it is reduced. They gain an understanding and perspective of grief, their own histories, interacting with other people and how they cope, and a more realistic view of the relationship they work on with their graph. They also experience a reduction in emotional and physical symptoms. The effects of the group process are experienced in multiple aspects of their lives, personally, emotionally, cognitively, in relationships, at work, spiritually, and in "all areas" of their lives.

Table 1

Comparison of treatment modalities: Structure

GRIEF RECOVERY OUTREACH	PROLONGED EXPOSURE
PROGRAM	THERAPY
Facilitated Group	Individual CBT
12 Weeks, 1 ½ hour sessions	10 − 12 sessions, 1 ½ hours each
Book used as manual	Manual
Education, written work, narrative	Education, written work, narrative
Loss history & Relationship Graph	In Vivo and Exposure treatments
Balanced view of history/relationship	Cognitive restructuring
Incorrect ideas are habituated and lead to	Interpretations of events are responsible
unresolved grief and symptoms	for emotional reactions
Correct information, action, practice leads to	Becoming aware and modifying thinking,
change in processing of grief	habituating new behavior leads to change
	in emotional response and behavior

Table 2

Comparison of treatment modalities: Outcome

Grief Recovery Outreach Program	Prolonged Exposure Therapy
Have sense of being able to cope better	Feel more able to cope with situations
Reduction in emotional and physical symptoms	Reduction in emotional and physical symptoms
Gain understanding and perspective of grief, their own histories, other people	Gain understand and a different perspective on their behavior
Gain a realistic view of the relationship	Gain a realistic view of the event, their role in it and the world around them.
Feel more control over their emotions	Able to identify thought patterns that may not be accurate and create a shift in them
Able to experience and express emotion	Able to do things they were unable to do prior to treatment
Reduce anger and/or guilt	Reduce anxiety
Experience positive effects personally, emotionally, cognitively, in relationships, at work, spiritually, and in "all areas" of their lives	Experience positive effects including at home, work, relationships, and their internal state of well being, as well as, various other areas of their lives

The similarities are striking. There is emerging research that attempts to define normal grief, complicated grief, and traumatic grief, among others. Grief used in this research and in the DSM IV TR, as well as the term "bereavement", refers to the death of a significant person. However, grief and loss is defined in a much broader way in the Grief Recovery Outreach Program. *The Grief Recovery Handbook* (Pg. 3) defines grief as "conflicting feelings caused by the end of or change in a familiar pattern of behavior".

This includes many types of loss including death, divorce, a change in job, moving, and many others. The diagnostic line may be vague, but it seems that any loss has some component that can be loosely described by various aspects of the definition of "trauma", without fitting it into full diagnostic criteria. A comparison can be made between the experiences of someone who has experienced a loss and someone who has, by definition (DSM-IV-TR), experienced a trauma. A person who has had a loss has most probably experienced an event that has been painful and may have also involved feelings of fear or

helplessness. They may re-experience the loss in a variety of ways, through nightmares or dreams, illusions, or inability to stop thinking about the loss and excessive sadness at the memories. People may try to 'avoid' the pain of the loss by not talking about it or not going to places that remind them of the loss. They may only remember the "good things" about the person that was lost and not have the complete memory. They may feel 'numb' or feel distant from others and may not enjoy life the way they used to. They may feel 'guilty' about some aspect of the loss. They may experience physiological symptoms of hyper arousal such as sleep disturbance, irritability, and decreased concentration. These symptoms may affect their daily functioning and social interactions. These symptoms are similar to those that are listed in the criteria for post traumatic stress disorder (acute stress disorder based on duration). (See Table 3 and Table 4)

Table 3
Comparison of loss (grief) and trauma (PTSD)

	Loss (Grief)	Trauma (PTSD)
Response:	Pain, sadness, anger, guilt	Pain, guilt, anger, helplessness, fear
Experience:	Experienced loss, (grief as "conflicting feelings caused by the end of or change in a familiar pattern of behavior")	Experienced event involving death or serious injury or threat to physical integrity to self or others
Re-experience:	Dreams, nightmares, illusions, excessive thoughts or intense feelings brought about by memory	Intrusive thoughts, dreams, illusions, hallucinations, flashbacks, physiological distress to cues
Avoidance:	Don't talk about loss or go certain places, euphoric recall	Avoid thoughts, feelings, talking about, places, people, can't recall some aspect
Numbing:	Anhedonia, feel distant from others, isolate self	Anhedonia, detached, restricted affect, foreshortened future
Hyper-arousal:	Sleep disturbance, decrease concentration, irritability	Sleep disturbance, decrease concentration, irritability, hyper vigilance, startle

The duration of normal grief or bereavement (Table 5) is variable among cultures and is perceived as that which is deemed 'normal' for that culture. Proposed criteria for complicated and traumatic grief are dependent on a time period for diagnosis. (See Table 6 & 7) Acute stress disorder is defined by symptoms occurring within 1 month of the event and post traumatic stress disorder is diagnosed if the symptoms persist longer than 1 month.

Table 4

DSM-IV-TR criteria for PTSD (309.81)

A. The person has been exposed to a traumatic event in which both of the following have been present:

- 1. the person has experienced, witnessed, or been confronted with an event or events that involve actual or threatened death or serious injury, or a threat to the physical integrity of oneself or others.
- 2. the person's response involved intense fear, helplessness, or horror. Note: in children, it may be expressed instead by disorganized or agitated behavior.

B. The traumatic event is persistently re-experienced in at least one of the following ways:

- 1. recurrent and intrusive distressing recollections of the event, including images, thoughts, or perceptions. Note: in young children, repetitive play may occur in which themes or aspects of the trauma are expressed.
- 2. recurrent distressing dreams of the event. Note: in children, there may be frightening dreams without recognizable content
- 3. acting or feeling as if the traumatic event were recurring (includes a sense of reliving the experience, illusions, hallucinations, and dissociative flashback episodes, including those that occur upon awakening or when intoxicated). Note: in children, trauma-specific reenactment may occur.
- 4. intense psychological distress at exposure to internal or external cues that symbolize or resemble an aspect of the traumatic event.
- 5. physiologic reactivity upon exposure to internal or external cues that symbolize or resemble an aspect of the traumatic event

C. Persistent avoidance of stimuli associated with the trauma and numbing of general responsiveness (not present before the trauma), as indicated by at least three of the following:

- 1. efforts to avoid thoughts, feelings, or conversations associated with the trauma
- 2. efforts to avoid activities, places, or people that arouse recollections of the trauma
- 3. inability to recall an important aspect of the trauma
- 4. markedly diminished interest or participation in significant activities
- 5. feeling of detachment or estrangement from others
- 6. restricted range of affect (e.g., unable to have loving feelings)
- 7. sense of foreshortened future (e.g., does not expect to have a career, marriage, children, or a normal life span)

D. Persistent symptoms of increasing arousal (not present before the trauma), indicated by at least two of the following:

- 1. difficulty falling or staying asleep
- 2. irritability or outbursts of anger
- 3. difficulty concentrating
- 4. hyper-vigilance
- 5. exaggerated startle response

E. Duration of the disturbance (symptoms in B, C, and D) is more than one month.

F. The disturbance causes clinically significant distress or impairment in social, occupational, or other important areas of functioning.

Specify if: Acute: if duration of symptoms is less than three months

Chronic: if duration of symptoms is three months or more

Specify if: Without delay onset: onset of symptoms at least six months after the stressor

Table 5 Table 6

DSM IV TR – V 62.82 Bereavement	Proposed Criteria – Complicated Grief Disorder	
Clinical focus on reaction to death of loved	◆ Loss occurred at least 14 months ago (avoid	
one	anniversary reaction)	
◆ Some individuals present with MDD	◆ Intrusive Symptoms:	
symptoms	Unbidden memories or intrusive fantasies	
 Most individuals regard depressed mood as 	related to lost relationship	
"normal" after loss	Strong spells or pangs of severe emotion	
♦ Expression & duration vary among cultures	related to lost relationship	
♦ If symptoms greater than 2 mos. Than MDD	Distressingly strong yearnings or wishes	
♦ Following 6 symptoms not present in	that the deceased were there	
"normal" grief reaction (may be MDD)	 Signs of avoidance and failure to adapt 	
1. Guilt other than actions taken or not taken by	Feelings of being far too much alone or	
survivor at time of loss	personally empty	
2. Thoughts of death other than feeling they would be	Excessively staying away from people,	
better off dead or should have died with loved one	places, activities that remind person of	
3. Morbid preoccupation with worthlessness	deceased	
4. Marked psychomotor retardation	Unusual levels of sleep disturbance	
5. Prolonged & marked functional impairment	Loss of interest in work, social,	
6. Hallucinatory experiences other than thinking they	caretaking, or recreational activities to	
hear the voice or transiently see the deceased	maladaptive degree	
•		

Table 7

Proposed Criteria – Traumatic Grief		
Criterion A –1. Experienced death of a significant other		
2.Response involves intrusive, distressing preoccupation with deceased person		
Criterion B – Marked and persistent symptoms of:		
Frequent efforts to avoid reminders of the deceased		
2. Purposelessness or feelings of futility about the future		
3. Subjective sense of numbness, detachment, or absence of emotional		
responsiveness		
4. Feeling stunned, dazed, or shocked		
5. Difficulty acknowledging the death (disbelief)		
6. Feeling that life is empty and meaningless		
7. Difficulty imagining a fulfilling life without the deceased		
8. Feeling that part of oneself has died		
9. Shattered world view (lost sense of security, trust, control)		
10. Assumes symptoms or harmful behaviors of, or related to deceased person		
11. Excessive irritability, bitterness, or anger related to the death		
Criterion C – Duration at least 2 months		
Criterion D – Causes clinically significant impairment in social, occupational, or other		
important areas of functioning		

The qualitative study done at St. Thomas Hospital (Summa Health System) from January 2003 to April 2004, attempted to raise further questions for future studies. It asked questions regarding the group process, what was helpful to the participants, and what they perceived has or has not changed in their lives. The results were overwhelmingly positive for change and helpfulness of the group. Table 8 lists many of the things that people reported they experienced as changes after the group. Table 9 lists various health related changes that were mentioned during the course of the interviews. The participants were also asked about the process of the group and what they found helpful about the group. Three things emerged as helpful by most participants. These were the small group size, the reading and writing assignments, and most importantly to all people interviewed, was the ability to verbally share (narrative) their stories with the group without feeling judged and without interruption. These same components can be found in exposure therapy in one form or another. The details of the study and the outcomes are found in a separate paper.

Table 8

Change (Feelings of change reported by interviewees during the study.)

- Gained perspective on situations
- Better concentration
- Improved appetite and sleep
- Healthier lifestyles
- Improved interpersonal relationships
- Easier to identify emotions
- Better able to express emotions
- Feel better able to 'cope' and support themselves
- Gained 'awareness' of themselves, both their internal state of being and relating to others
- Able to listen better
- Feel able to help others
- More compassion
- Recognize grief easier and quicker
- Deal with grief more 'completely'

Table 9

Reported Heath Effects: "My health has improved"

- Decreased Headaches
- Decreased Blood Pressure
- Decreased "vague" symptoms
- Decreased Pain symptoms
- Decreased Incidental symptoms (leading to infection, time in hospital, accidents, health care utilization)
- Decrease Nightmares
- Decrease Panic Attacks
- Decrease Anxiety
- Decrease Depression
- Improved Concentration
- Improved Sleep
- Improved Eating Patterns
- Improved Exercise Patterns
- Improved Compliance

These observations lead to several interesting questions. Is the group treating simple grief? Are people in this group experiencing a form of complicated or traumatic grief? Does all grief, that has not been resolved, have some element that is similar to trauma? Do the myths that we learn through out life, promote unresolved grief that leads to a potential diagnosis of complicated grief? What is the Grief Recovery Outreach Program really treating, simple grief or complicated grief or something else? There is also the question about what type of loss is included in "grief". Since the research and the DSM are based on a definition of grief that only includes death, and the group and this qualitative study show effect with loss other than death, is it possible that grief is a broader category than is currently being used? With the positive outcomes from this qualitative study, the similarities to exposure therapy, and the interviewees reporting what they found to be most helpful and the most important changes in their lives, is the Grief Recovery Outreach Program actually a modified form of exposure therapy given in a group format?

It is clear that this group is helpful for many people, whatever form of grief they may be dealing with. Further studies are necessary to explore what specific types of grief might be

most helped by this format, what particular treatment this group is offering, and more specifically what outcomes are experienced by the participants. The goal of the founders of the Grief Recovery Outreach Program, "to deliver grief recovery assistance to the largest number of people in the shortest period of time," appears to be working. In light of the constraints that the insurance companies, the government, and time, among other things, has placed on health care professionals and patients, a group that can create such a positive change in people's lives, relationships, lifestyles, and health, would be a cost effective alternative or adjunctive treatment to individual psychotherapy (and/or primary care medicine).

References

- 1. American Psychiatric Association, DSM-IV-TR, APA, 2000.
- 2. Callahan, E, PhD, *Psychological Intervention for Unresolved Grief*, NCP Clinical Quarterly, 5(2/3), Summer1995.
- 3. Foa, E., Hembree, E., & Dancu, C., *Prolonged Exposure Manual, Revised Version*, Univ. of Pennsylvania, Jan. 2002.
- 4. Gentile, J. MD, *Pathological Grief*, Hospital Physician, 8(1):1-11, Feb. 2004.
- 5. Gilbert, K.R., *Taking a Narrative Approach to Grief Research: Finding Meaning in Stories*, Death Studies, 26:223-239, 2002.
- 6. James, J. W. and Friedman, R, *The Grief Index*, The Grief Recovery Institute, www.grief.net, 2003.
- 7. James, J. W. and Friedman, R, *The Grief Recovery Handbook*, revised Ed., Harper Perennial, 1998.
- 8. Neimeyer, R. A., *Narrative Strategies in Grief Therapy*, J. of Constructivist Psychology, 12:65-85, 1999.
- 9. Patton, M.Q., *Qualitative Evaluation and Research Methods*, 3rd Ed., Sage Pub., 2001.
- 10. Speedy, J, *The 'storied' helper: narrative ideas and practices in counselling and psychotherapy*, Eur. J. of Psychotherapy, Counselling, & Health, 3(2):361-374, Dec. 2000.
- 11. Thuen, F., Satisfaction with Bereavement Support Groups. Evaluation of the Norwegian Bereavement Care Project, J. of Mental Health, 4(5):449-511, Dec. 1995.