Master class in Palliative Care

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Bereavement-related Psychotherapies

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Outline

- Bereavement, grief, and mourning
- Palliative care / Family dynamic and palliative care
- Grieving: The five stages of grief / Normal grief / Complicated grief
- Major depression DSM V / Major Depression, change from DSM IV to DSM V
- Parental grief and depression
- Risk factors: Individual, social, family vulnerabilities
- Inventory of Grief and Loss Measures for Adults / for children
- Assess for normal/complicated grief
- Definition and purpose of Psychotherapy
- Counseling, coaching, and psychotherapy
- Candidates for bereavement related psychotherapies
- Main components of psychotherapy
- Types of psychotherapy
- What does the science say about grief psychotherapies
- Dealing with Family Caregivers
- Health professionals: BURN OUT
Bereavement, Grief, & Mourning

- **Bereavement** is the actual death of a close person (Zhang et al., 2006)

- **Grief** is a series of psychological and physiological reactions to this death (Zhang et al., 2006)

- **Mourning** is a series of grieving reactions that are publicly expressed and framed by culture and society (Payne et al., 1999)
Palliative Care

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (WHO)
Palliative Care (cont’d)

Palliative care for children is the *active total care* of the child's body, mind and spirit, and also involves giving support to the family.

- It begins when illness is diagnosed, and continues regardless of whether or not a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological, and social distress.
- Effective palliative care requires a *broad multidisciplinary approach that includes the family* and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centers and even in children's homes. (WHO; 1998a)
Family Dynamics & Palliative Care
King and Quill (2006)

- Life-threatening illnesses expose patient’s family to emotional distress, depression, and other mental disorders

- Most patients and families confronting end-of-life decisions want help in:
  - Communicating among each other
  - Strengthening family relationships

- Western medical training usually focuses on an individualistic approach, overlooking the family systems approach
End of life situation
or
Chronic illness onset

triggers grief process
The five stages of grief (Kubler-Ross, 1969)

1- Denial & Isolation: Denying the reality of the situation; avoidance; shock.

2- Anger: Directed toward objects, persons, or the deceased person with feeling of guilt.

3- Bargaining: Attempt to regain control; making a deal with a higher power to postpone the inevitable or go back in time; focus on the past in order not to feel painful emotions of the present.

4- Depression/natural response to death: Emptiness and sadness; apathy and exhaustion; sense of meaninglessness of life; death wishes.

5- Acceptance: Ready to cope with reality without the deceased; regaining sense of life
Normal Grief

Hypothesized Grief Resolution

Adjusted\textsuperscript{a} Mean\textsuperscript{b} Grief Resolution Scores Over Time

Average pattern of resolution in a sample of bereaved community-based participants of the Yale Bereavement Study (\(n = 281\)) (Zhang et al., 2006)
Complicated Grief  

Zhang et al. (2006)

6 months following the death, symptoms of normal grief are very similar to those of Complicated Grief / Major Depressive Disorder.

Persistence of the symptoms = Complicated grief

- anger,
- disbelief,
- hallucinations.
- self-esteem and sense of competence affected by the loss
- mourning behaviors
“Responses to a significant loss (e.g., bereavement, financial ruin, etc.) may include the feelings of intense sadness, rumination about the loss, insomnia, poor appetite, and weight loss which may resemble a depressive episode. Although such symptoms may be understandable or considered appropriate to the loss, the presence of a major depressive episode in addition to the normal response to a significant loss should also be carefully considered. This decision inevitably requires the exercise of clinical judgment based on the individual’s history and the cultural norms for the expression of distress in the context of loss”.
Major Depression
changes from DSM IV to DSMV

0 In the DSM-IV, bereavement was the only stressor excluded from a diagnosis of MDD in DSM-IV (while research and clinical evidence have demonstrated that bereavement can trigger MDD just like any other stressor can do)

0 Clinicians were asked to avoid diagnosing major depression in individuals within the first two months after the death of a loved one. This has been included in the “bereavement exclusion” section
<table>
<thead>
<tr>
<th>Major Depressive Disorder</th>
<th>Grief</th>
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<tr>
<td>Persistent depressed mood, inability to anticipate happiness or pleasure</td>
<td>Feelings of emptiness and loss</td>
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<tr>
<td>Depressed mood more persistent and not tied to specific thoughts or preoccupations</td>
<td>Dysphoria is likely to decrease in intensity over days to weeks and occurs in waves, dependent on the thoughts and reminders of the deceased (pangs of grief)</td>
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<td>Pervasive unhappiness and misery with no positive emotions</td>
<td>Pain may be accompanied by positive emotions and humor</td>
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<td>Self-critical and pessimistic ruminations</td>
<td>Thought content related to preoccupation with thoughts and memories related of the deceased</td>
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<tr>
<td>Feelings of worthlessness and self-loathing</td>
<td>Self-esteem is preserved, (in case there are any self-criticism, it is related to behaviors toward the deceased such as not visiting enough, not expressing love etc.)</td>
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<tr>
<td>Thoughts are focused on ending one’s life because of feeling worthless, undeserving of life, or unable to cope with the pain of depression</td>
<td>Thoughts about death and dying are generally focused on the deceased and the possibility of “joining” him/her</td>
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</table>
Parental grief and depression

- Rates of prolonged grief disorder (PGD) were similar to those reported in other bereaved populations (10.3%).

- 41% of parents met diagnostic criteria for grief-related separation distress.

- 22% of parents reported clinically significant depressive symptoms.

- Time since death and parental perception of the oncologist’s care predicted parental grief symptoms but not depressive symptoms.

- Perceptions of the child’s quality of life during the last month, preparedness for the child’s death, and economic hardship also predicted grief and depression outcomes.

*The importance of end-of-life factors in parents’ long-term adjustment and the need for optimal palliative care to ensure the best possible outcomes for parents.*

Prevalence and predictors of parental grief and depression after the death of a child from cancer. McCarthy MC, et al., 2010
Risk factors: individual vulnerabilities

- history of traumas
- Ongoing stressors
- younger age at the time of the trauma
- female gender
- premorbid personality characteristics and preexisting anxiety or depressive disorders
- repetition and/or previous traumas
- child abuse and childhood adversities.

- 10-15% of bereaved individuals develop complicated grief
Risk factors (cont’d): social vulnerabilities

- Absence or low social and family support
- Financial loss
- Educational and marital status
- Cultural believes and guilt
Risk factors (cont’d): family vulnerabilities

- Functional families = Supportive families: high levels of cohesiveness; conflict resolvers;

- Dysfunctional families: Hostile families: High conflict, poor expressiveness, low cohesion;

- Intermediate families: Moderate cohesiveness but still prone to psychosocial morbidity; functioning decreases in case of bereavement. (Kissane et al. 2006)

Despite tension during difficult times, cohesive families are more likely to be resilient.
To treat, we need to assess

How do we differentiate between normal versus complicated grief

The use of questionnaires and scales
Inventory of Grief and Loss Measures for Adults

- The Grief Cognitions Questionnaire (GCQ) (Boelen P. et al., 2005)
- Bereavement Risk Factor Questionnaire (Ellifritt, J. et al., 2003).
- The Texas Revised Inventory of Grief (Faschingbauer, T., et al., 1987)
- Perinatal Bereavement Grief Scale: Distinguishing grief from depression following miscarriage (Ritsher, J. & Neugebauer, N., 2002)
Inventory of Grief and Loss Measures for Children

- Inventory of Complicated Grief for Children (Dyregrov, A., et al., 2001)
- Inventory of Complicated Grief-Revised (ICG-R)-youth version (Melhem, N. 2007)
- The Person, Places, and Things that Your Child Misses (short and long forms) (Nader & Prigerson, 2006)
- An Inventory of People, Places, and Things that I Miss (Nader & Prigerson 2005).
Assess for normal/complicated grief

- The Inventory of Complicated Grief (ICG)/self-report (Prigerson, et al. 1995):
  - 19 statements concerning the immediate bereavement-related thoughts and behaviors. Likert scale with 5 response, ranging from “Never” to “Always.”
  - A score ≥ 25 = high risk for requiring clinical care.

- The Texas Inventory of Grief – Revised or TRIG/ self-report (Faschingbauer, 1981): “Present Feelings” index: 13 statements about various aspects of grief-related depression, such as acceptance of loss, crying and intrusive thoughts. Likert scale with 5 response, ranging from “Completely False” to “Completely True.”

- Other scales that assess for anxiety and depression.
Psychotherapy is a process through which persons or groups reach a better understanding of their internal mind state, and therefore are more empowered to think, feel, and do according to their freewill.

Psychotherapy refers to a variety of approaches and techniques used to help people better deal with their mental distress, emotional, and behavioral difficulties. It helps medical professionals, nurses, and psychologists to appropriately deal with family caregivers according to the specific grief stage they are passing through and the nature of the dynamics in their families.
Counseling, coaching, and psychotherapy

Counseling and coaching: support, explain, provide practical solutions.
Used in normal grief

Psychotherapy: Works on relations and interpersonal dynamics; works on internal psychological states.
Used in complicated grief
The person in a terminal stage of illness, being a child or an adult

The family members caring for patients with terminal illnesses

The healthcare providers: physicians and allied professions
Main components of psychotherapy

- Psychoeducation: stages of grief; family dynamics.
- Identification of thoughts, emotions, and reactions
- Identification of patterns of communication (most importantly in family therapies)
- Walking through the narrative account (similar to therapies for trauma)
- Processing thoughts, emotions, and reactions
- Reaching acceptance
<table>
<thead>
<tr>
<th>Type of Treatment</th>
<th>Characteristics</th>
<th>Stages</th>
<th>Aim</th>
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<tbody>
<tr>
<td><strong>Family Focused Grief</strong></td>
<td>- Brief, focused, &amp; time limited</td>
<td>- Assessment (1-2 sessions):</td>
<td>- Improving family functioning by exploring</td>
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<td><strong>Therapy</strong></td>
<td>- 9-18 months</td>
<td>- Detecting family problems</td>
<td>- communication, cohesion, conflict management</td>
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<td>- 4-8 sessions</td>
<td>- Formulating plan</td>
<td>-</td>
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<td>- 90 minutes’ duration</td>
<td>- Intervention (2-4 sessions):</td>
<td>- Sharing of illness story and other grief-related experiences</td>
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<td>- Working on plan</td>
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<td>- Termination (1-2 sessions):</td>
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<td></td>
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<td>- Consolidating new skills</td>
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<td>- Preparing to end therapy</td>
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<tr>
<td><strong>Interpersonal Therapy</strong></td>
<td>Time limited</td>
<td>- Assessment phase:</td>
<td>- Realistic evaluation of the relationship with the decease</td>
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<td></td>
<td>Psychodynamic approach</td>
<td>- Determining the suitability of IPT for the patient</td>
<td>(exploring negative &amp; positive aspects)</td>
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<td>Focuses on interpersonal relationships</td>
<td>- Educating patient on IPT</td>
<td>- Help the bereaved to improve social support system</td>
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<td>- Developing interpersonal formulation</td>
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<td>- Contracting patient to a specific number of sessions</td>
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<td></td>
<td></td>
<td>- Middle sessions:</td>
<td>- Engage in meaningful activities</td>
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<td>- Addressing problem areas using key IPT techniques</td>
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<tr>
<td></td>
<td></td>
<td>- Termination phase:</td>
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<td></td>
<td></td>
<td>- Reviewing progress</td>
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<td></td>
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<td>- Planning for future problems</td>
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</table>
| Integrative Cognitive Behavioral Treatment Manual for Complicated Grief (CG-CBT) | 20-25 sessions CBT approach | Includes relaxation techniques, Gestalt Therapy, Solution Focused Brief Therapy (SFBT), Multigenerational Family Therapy, and imagery work | Therapeutic alliance, stabilization, exploration, & motivation
- Psycho-education on complicated grief & social roles
- Discussing advantages & disadvantages of change
- Re-stabilizing family roles etc.
- Exposure & cognitive restructuring:
  - Exposure to painful emotions, dysfunctional thoughts
  - Working on changing dysfunctional thoughts & emotions
- Integration & Transformation:
  - Helping patient deal with future plans
  - Helping patient decide on a certain ritual dedicated to the deceased
| | | | Working on changing dysfunctional thoughts & emotions
| | | | Helping patients confront reality of death

| Complicated Grief Treatment | Interpersonal+ CBT Attachment theory | Introductory phase:
- Psych-education on normal & complicated grief
- Psycho-education on CGT
- Focusing on personal life goals
| | | Middle phase:
- Addressing attention to loss and restoration processes
| | | Termination phase:
- Reviewing progress, discussing future plans,
  And feelings about termination
| | | Working on maladaptive cognitive or behavioral avoidance
Internet-based CBT for Complicated Grief

**CBT approach**
- 2 weekly 45-minute writing assignments over 5 weeks

**Communication by e-mail**
- After every second essay, therapist provides patients with feedback & further instructions

**Introductory phase:**
- Exposure to bereavement cues:
  - Writing essays and expressing emotions and intruding thoughts about deceased

**Middle phase:**
- Cognitive reappraisal:
  - Writing a supportive letter to a imaginary friend passing through the same experience
  - Thinking about rituals, thinking about positive memories, strengthening social support etc.

**Termination phase:**
- Integration & Restoration:
  - Writing a letter to identify most important memories, assessing therapeutic process, discussing how to cope in the future

**Coping with bereavement**
<table>
<thead>
<tr>
<th>Interpretive group therapy</th>
<th>Short-term</th>
<th>90 minutes</th>
<th>12 weeks</th>
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</thead>
</table>
| Therapist is active, interpretive, transference focused | • Creating tolerable tense environment for discussion of conflicts and uncontrollable emotions  
• Conflicts & emotions discussed in the here-and-now experience  
• No immediate praise provided to the patient | • Improving insight about conflicts related to the death on both intrapsychic and interpersonal levels  
• Having tolerance for ambivalence toward deceased |

<table>
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<tr>
<th>Supportive group therapy</th>
<th>Short-term</th>
<th>90 minutes</th>
<th>12 weeks</th>
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</table>
| Therapist is active, non-interpretive, focused on patient’s current interpersonal relationships | • Creating comfortable environment for sharing common experiences and feelings  
• Receiving praise for efforts done at coping during session | • Enhancing the patients’ instant coping with their situation  
• Improving social support and problem solving |
What does the science say about grief psychotherapies
Family Focused Grief Therapy

Kissane et al. (2006) (RCT): FFGT (53 families) v/s control group (28 families):

- Non-significant differences in distress following 6 and 13 months
- Non-significant differences in depression and social adjustment
- Grief decreased similarly in both groups
Family Focused Grief Therapy (Cont’d)

Top 10% of families with the most distress, depression, and poor social adjustment were studied, results showed:

- Significantly more improvement in distress & depression in FFGT group after 6 and 13 months
- Non-significant differences in social adjustment

Sullen families in both groups were the most improved on depression and distress

Depression remained the same in hostile families in FFGT group, yet decreased in the control group

Intermediate families in FFGT group had lower conflict levels at 6 months than those in the control group

Hostile families in FFGT group deteriorated more in FFGT group than in control group over 13 months
Interpersonal Therapy

Reynolds III et al. (1999):
80 patients aged 50 and above with MDD before 6 months and after 12 months of the death of someone close to them

4 groups:
- Group 1: Interpersonal therapy + Nortriptyline (N=16)
- Group 2: Nortriptyline alone (N=25)
- Group 3: Placebo + Interpersonal therapy (N=17)
- Group 4: Placebo alone (N=22)

Results: Rate for remission reached:
- 69% in group 1 (highest rate)
- 56% in group 2
- 29% for group 3
- 45% for group 4
Complicated Grief Treatment

Pilot study (Shear et al. 2001):  21 patients
  0 8 dropped out after 1 or more sessions
  0 13 completed a one-month treatment

Results:

  Significant improvements in grief symptoms, anxiety, and depression were found in both completer and intent-to-treat groups
Interpersonal Psychotherapy/Complicated Greif Therapy

RCT - Shear et al. (2005): IPT (46 patients) v/s CGT (49 patients)

Results:
- The response rate was greater for complicated grief treatment (51%) than for interpersonal psychotherapy (28%; \(P = .02\))
- Time to response was faster for complicated grief treatment (\(P = .02\)). The number of sessions needed to treat was 4.3
Internet-based CBT for CG

Wagner et al. (2006): Internet-based CBT for CG (N=26)/waiting list control group (N=29)

Results:

- Intrusion and avoidance symptoms in the treatment condition significantly decreased compared to the control condition

- Decrease in failure to adapt in the treatment condition was significantly larger than that in the control condition

- Improvement depressive symptoms in the treatment group was larger than in the control group

- Improvement was maintained after 3 months follow up
Internet-based CBT for CG (cont’d)

Wagner and Maercker (2007): 1.5-year follow up study:

22 of the 26 participants of the original study participated (85%)

Results:

 Treatment gains related to intrusion, avoidance, failure to adapt, depression, and anxiety were maintained at 1.5-year follow-up
Interpretive v/s Supportive Group Therapies

RCT- Piper et al. (2001): study 2 personality characteristics interaction with the 2 types of group therapy

Personality Variables:

1- Quality of Objects Relations (QOR): refers to a person’s fixed pattern of interpersonal relationships (extending from primitive to mature)
   - Primitive QOR: when the person reacts to loss with extreme anxiety & affect. Develops dependence on that person
   - Mature QOR: when the person engages in relationships characterized by love, & concern. Ability to mourn and tolerate unattainable relationships

2- Psychological Mindedness (PM): A person’s ability to understand people and their problems in psychological terms
Interpretive v/s Supportive Group Therapies (cont’d)

Results related to grief symptoms:

- High QOR patients improved more in interpretative group therapy than in the other group
- Low QOR patients improved more in supportive group therapy than in the other group
- High PM patients improved more in both therapies

Results related to general symptoms (depression, anxiety, interpersonal distress, self-esteem, social dysfunction, physical dysfunction)

- Interpretive therapy was superior over supportive therapy
Interpretive v/s Supportive Group Therapies (cont’d)

Ogrodniczuk et al. (2002)

Investigated attachment to the lost person, QOR, and recent social role functioning as predictors of outcome for Interpretative & Supportive Group Therapies.

Results:

- A secure attachment to the lost person and a better social functioning were correlated with more decrease in grief symptoms and general symptoms in both therapies.

- Patients with higher QOR had a better outcome in Interpretive therapy.

- Patients with lower QOR had a better outcome in Supportive therapy.
In summary
Grief therapies are not efficacious for all grievers, they should be provided for children and adults with marked and persistent distress resulting from a loss.

Recent studies showed that therapies incorporating CBT techniques, such as cognitive restructuring and exposure, have had strong results in improving grief symptoms.

Pharmacotherapy, internet-based, family-based, and some other related interventions have shown preliminary promise, but insufficient research exist to validate their efficacy.

Grief therapies, in general, including CBT approaches are still not extensively studied.

A grief focused psychotherapy has better outcomes than more general psychotherapy approaches.

More randomized controlled trials should be conducted to support the efficacy of each of these therapies.
Dealing with Family Caregivers

- If provided with clear information from the medical team about the illness and available options, most families develop the capacity to share their feelings of grief and effectively collaborate to take the appropriate decisions.

- Disagreements could surface among family members if they receive ambiguous or opposing information from the medical team.

- It is highly recommended that the palliative care team facilitate communication among the medical professionals involved, to reach unanimity regarding prognosis and care options before sharing detailed information with the family.

King and Quill (2006)
Dealing with Family Caregivers (cont’d)

- Be ready to manage high level of family disorganization, conflict or instability

- Make efforts to have frequent communication between medical providers in order to avoid giving “mixed messages” that can lead to family conflict

- Have modest expectations regarding how much collaboration on decision making can be made in the family meeting
Dealing with Family Caregivers (cont’d)

- Arrange for family meetings that include all members

- Implement structure in family meetings to decrease conflict

- Set clear rules (e.g., everyone gets a chance to participate, anyone using abusive language or violent behavior will be asked to leave)

- Invite everyone to participate in turn, ask for each member’s opinion
Dealing with Family Caregivers (cont’d)

- Set firm limits on family arguments before verbal hostility escalates to violence (e.g., “I know you feel very strongly and we want to hear your point of view, but (shouting, cursing, blaming) will not be allowed in this meeting”)

- Have angry family members talk directly to you regarding their concerns rather than at other family members

- Avoid “taking sides” or mirroring family conflict

- Take time to debrief and support the family following a tense family meeting
Health professionals: watch your steps: BURN OUT

Burnout consists of three dimensions: emotional exhaustion, depersonalization (felt distance from others), and diminished personal accomplishment. Maslach (1982).
To prevent burn out

- Understand where the pressure comes from: life style, people, frustrations, etc.

- Too much to do, too little time: analyze personal expectations. Do I really have to do this now? What are the priorities?

- Improve assertiveness

- Protect the meaning of your job

- Talkgroup for team support


References


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