Defining Preparatory Grief vs Depression: Tools and Strategies for Managing End of Life Emotions

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The Importance of Defining Preparatory Grief and Depression

Those who care for patients with terminal illness are vitally aware of psychosocial distress that can occur at any point in the disease trajectory. Symptoms of grief and depression can be a major cause of suffering and adversely affect quality of life (Block, 2000).

We want to offer a means to help differentiate what might be considered normal, preparatory grief and clinical depression.

“Distinguishing between grief and depression in seriously ill patients is vitally important, as the treatments differ” (Periyakoil, Kraemer, & Noda, 2012).
NASW Standards for Palliative & End of Life Care

ETHICS– treat all fairly, duty to do good, cause no harm, promote tolerance, respect, autonomy.

KNOWLEDGE– multifaceted roles of clinician, understand physical, social, and spiritual pain/suffering, range of settings and diagnosis with appropriate resources.

ASSESSMENT– comprehensive assessment to develop interventions and treatment plans based on past/current health, developmental abilities, spiritually, culture, support system, and past experiences. *mental health functioning including history, coping style, crisis management skills, and risk of suicide/homicide.

TREATMENT PLANNING– competence death and dying, grief theories and interventions based on assessments with competence in navigating network for appropriate referrals.

SELF-AWARENESS – individualization of client needs, work collaboratively as an interdisciplinary team, advocate, empowering the profession in its vital role.

DOCUMENTATION– ongoing documentation that reflects assessment, treatment offered, plan of care and assures continuity between settings.

INTERDISCIPLINARY TEAMWORK– collaboration with emphasis with the psych/social experience.

CULTURAL COMPETENCY– intergrade knowledge and about ethnicity, culture, value, religion, and economic factors.

EDUCATION/LEADERSHIP/TRAINING – professional development and offer expertise to individuals, groups, and organizations.

(National Association of Social Workers, 2004).
MN Statute: Treatment and Intervention Services

148E.225 TREATMENT AND INTERVENTION SERVICES.

§ Subdivision 1. Assessment or diagnosis.
A social worker must base treatment and intervention services on an assessment or diagnosis. A social worker must evaluate, on an ongoing basis, the appropriateness of the assessment or diagnosis.

§ Subd. 2. Assessment or diagnostic instruments.
A social worker must not use an assessment or diagnostic instrument without adequate training. A social worker must follow standards and accepted procedures for using an assessment or diagnostic instrument. A social worker must inform a client of the purpose before administering the instrument and must make the results available to the client.

§ Subd. 3. Plan for services.
A social worker must develop a plan for services that includes goals based on the assessment or diagnosis. A social worker must evaluate, on an ongoing basis, the appropriateness of the plan and the client's progress toward the goals.

§ Subd. 4. Records.
(a) A social worker must make and maintain current and accurate records, appropriate to the circumstances, of all services provided to a client. At a minimum, the records must contain documentation of:
(1) the assessment or diagnosis;
(2) the content of the service plan;
(3) progress with the plan and any revisions of assessment, diagnosis, or plan;
(4) any fees charged and payments made;
(5) copies of all client-written authorizations for release of information; and
(6) other information necessary to provide appropriate services.
(b) These records must be maintained by the social worker for at least seven years after the last date of service to the client. Social workers who are employed by an agency or other entity are not required to:
(1) maintain personal or separate records; or
(2) personally retain records at the conclusion of their employment.

§ Subd. 5. Termination of services.
A social worker must terminate a professional relationship with a client when the social worker reasonably determines that the client is not likely to benefit from continued services or the services are no longer needed, unless the social worker is required by law to provide services. A social worker who anticipates terminating services must give reasonable notice to the client in a manner that is appropriate to the needs of the client. The social worker must provide appropriate referrals as needed or upon request of the client.

Hospice Conditions of Participation

WE 15: “Hospice social work services are based on initial and ongoing assessments of the patient’s and family’s needs by a social worker from an accredited school of social work…”

WE 15.1: “Social work services include:”

1. “Identifying the patient’s and family’s psychosocial needs;”
4. “Providing interventions for specific symptom relief (e.g., fear, grief, depression, anger, etc.);”
5. “Screening for psychopathology and educating and intervening accordingly;”
DSM-5: Depressive Disorders

- “Depressive disorders include disruptive mood dysregulation disorder, major depressive disorder (including major depressive episode), persistent depressive disorder (dysthymia), premenstrual dysphoric disorder, substance/medication-induced depressive disorder, depressive disorder due to another medical condition, other specified depressive disorder, and unspecified depressive disorder” (American Psychiatric Association, 2013).

- Attention to symptoms of a major depressive disorder is vital to addressing a patient’s comfort.
DSM- 5: Major Depressive Disorder

Five (or more) have been present within a two week period and represent a change from previous functioning; at least one of the symptoms is either a depressed mood or loss of interest or pleasure.

- 1. Depressed mood most of the day, nearly every day, as either by subjective report (patient feels sad, empty, hopeless), or observation made by others (tearfulness)
- 2. Markedly diminished interest or pleasure in all, or almost all activities
- 3. Significant weight loss
- 4. Insomnia
- 5. Psychomotor agitation or retardation nearly every day.
- 6. Fatigue or loss of energy nearly every day
- 7. Feelings of worthlessness or excessive inappropriate guilt.
- 8. Diminished ability to think or concentrate, or indecisiveness, nearly every day.
- 9. Recurrent thought of death, recurrent suicidal ideation, with or without a plan.

(American Psychiatric Association, 2013)
Defining Preparatory Grief

“Preparatory grief will be defined as the *common, acute* responses to terminal illness experienced across individual domains (i.e., affective, behavioral, and cognitive) that may *temporarily* reduce QoL (Prost, 2017).

• Since anticipatory grief is often viewed as the experience of those family members ahead of a death, preparatory grief is often the term used by patients preparing for their own deaths.
• Similar to the experience survivors feel AFTER a death
• Grief = waves
• Self-image is still intact
• Can still find pleasure
• Sense of hope
  (Noorani & Montagnini, 2007).
Distinguishing Grief From a Major Depressive Episode

Grief

• Preparatory grief, over multiple losses, is a primary task of dying patients (Block, 2000).
• In grief, the predominant affect is feelings of emptiness and loss.
• Grief occurs in waves (Block, 2000).
• Self esteem is generally preserved (Block, 2000).
• Patients retain the capacity for pleasure (Noorani & Montagnini, 2007).
• Patients are able to look forward to the future (Block, 2000).
• Almost all terminally ill patients experience grief (Block, 2000).

Major Depressive Episode

• In depression, there is a persistent depressed mood and the inability to anticipate happiness or pleasure (Block, 2000).
• Symptoms of worthlessness, hopelessness, and excessive guilt may occur with depression (Block, 2000).
• Patients do not necessarily enjoy anything and have no sense of a positive future (Noorani & Montagnini, 2007).
• Depression is constant and unremitting (Pessin et al., 2005).
The Challenge of Finding an Effective Tool to Assess Depression in Hospice Patients:

Many commonly-used depression screening tools can result in false positives with hospice patients. The indicators that these tools use are often present in hospice patients due to their physical decline, such as:

- Decreased appetite
- Decreased social activities
- Difficulty sleeping
- Lack of energy
- Difficulty concentrating

(Periyakoil, et al., 2012)
The Palliative Grief Depression Scale (PGDS)

- Easy to use and concise
- Allows for self-rating
- Results are useful and applicable for a multidisciplinary care team
- The PGDS differentiates between grief and depression
- The underlying premise of the scale is that adaptive coping results from alternating between types of grief
- This adaptive coping allows for hope and new meaning in life

(Periyakoil, et al., 2012)
PGDS Definitions of Depression vs Grief

- **Depression** Persistent feelings of sadness and worthlessness and a lack of desire to engage in formerly pleasurable activities.

- **Loss-Oriented Grief (LOG)** When patients recognize that they have a serious and life-limiting illness, they experience a wide array of emotions, including numbness, shock, anger, separation anxiety, sadness, and despair. These can be thought of as primary stressors and are directly due to the patient's processing of losses due to the serious illness.

- **Restoration-Oriented Grief (ROG)** As seriously ill patients process the implications of their current losses, the focus of their hopes often shifts. Instead of a hope for cure, they may hope for quality time with family or good symptom management. They often try to find meaning in their current circumstances. They may place new importance on relationships in their life. They seek a new equilibrium.

(Periyakoil et al., 2012, Periyakoil et al., 2005)
### Polliative Grief Depression Scale used to measure the seriously ill patient’s loss oriented grief, restoration oriented grief, total grief and depression scores

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<thead>
<tr>
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**Total score per sub-scale**

- Total depression score = 
- ROG score =
- LOG score =
- Total grief score = (ROG+LOG)=
- Difference in grief score=(ROG-LOG)=

(VJ Periyakoil, MD., personal communication, March 12, 2018)
Scoring and Interpretation of PGDS:

Scoring and Interpretation of PGDS scores:

- LOG is scored positively with one point per true answer and zero points for a false answer and a score range=0 to 5.
- ROG is also scored positively with one point per true answer and zero points for a false answer and a score range=0 to 5.
- Depression is scored positively with one point per true answer and zero points for a false answer and a score range=0 to 10.

PGDS scores and implication on depression:

- If (ROG – LOG) < 0, patient is likely depressed.
- If (ROG – LOG) ≥ 0, and D score < 3, patient is likely not depressed.
- If (ROG – LOG) > 0 and D score ≥ 3, patient may be depressed.

(Periyakoil et al., 2012)
Scoring and Interpretation of PGDS:

PGDS total grief scores and implication on grief:

If (ROG+LOG) is low, the total grief currently experienced by the patient is low. Please note that grief varies with time and so it would be important to continue to track the patient’s grief as they progress through the illness. If (ROG+LOG) is high, this indicates increased grief and patient needs to be supported appropriately.

(Periyakoil et al., 2012)
Case Study

• Dorothy is a 72 year old widowed female with terminal cancer. She’s been living independently in an assisted living for several years and has been very involved in the community and activities there. Dorothy has been keeping to herself more and often chooses to eat her meals in her apartment. She reports that she has been feeling too tired attend her usual social activities.

• Dorothy is a widow. Her daughters and their families are very involved and supportive. She has visits from family several times a week. She seems to particularly enjoy holding her great-grandbabies.
Family concerns:

- Dorothy complains intermittently and can be negative.
- She’s tearful sometimes when family visits.
- Recently, Dorothy has accused her family of not visiting often enough and cries because she feels like a burden.
- Dorothy’s daughters report feeling like they can’t do anything right. They have encouraged her to eat in the dining room so she can socialize. Dorothy responds by saying she’s too embarrassed to be seen in her wheelchair.
- Family wonders if Dorothy is depressed and hopeless.
Hospice team observations:
• Dorothy spends supportive visits expressing frustration with the facility for not being attentive enough.
• Dorothy shared with the hospice chaplain that she is angry and saddened that she might not live to see the birth of her new great grandson, who is due in 5 months.
• Team members have noticed that Dorothy has lost interest in activities and is withdrawn.

Facility staff observations:
• Dorothy has become hostile toward them even though she’s been friendly with them for years.
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Total score per sub-scale

- Total depression score =
- ROG score =
- LOG score =
- Total grief score = (ROG+LOG) =
- Difference in grief score = (ROG-LOG) =

(VJ Periyakoil, MD., personal communication, March 12, 2018)
### Palliative Grief Depression Scale

The scale is used to measure the seriously ill patient's loss oriented grief, restoration oriented grief, total grief and depression scores. For true answers, enter 1 and for false answers enter 0 in the appropriate column.

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<td>5</td>
<td>1</td>
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- **Total Depression Score** = 0
- **ROG Score** = 5  
- **LOG Score** = 1  
- **Total grief score** = (ROG+LOG) = 6  
- **Difference in grief score** = (ROG-LOG) = 4
Dorothy’s PGDS Score:

RESULTS: Dorothy is likely not depressed. Dorothy appears to be experiencing restoration-oriented grief. ROG-LOG is greater than 0, and D score is less than 3.

PGDS scores and implication on depression:
If (ROG – LOG) < 0, patient is likely depressed.
If (ROG – LOG) ≥ 0, and D score < 3, patient is likely not depressed.
If (ROG – LOG) > 0 and D score ≥ 3, patient may be depressed.
Suggested Phrasing to Use When Documenting and Talking with Patients/Families

- “Patient appears to show depressive symptoms.”
- “Patient does not appear to show depressive symptoms.”
- “Patient reports feelings of depression.”
- “Patient’s behavior demonstrates feelings of depression.”
- “Patient appears to have a mixture of depressive symptoms and grief related symptoms.”
Communicating Results of the Scale to the IDG

Why is it important?

- Addressing comfort (including psychological suffering) is integral to hospice goals.
- Sharing results of our MH screening and addressing needs in an interdisciplinary team is fundamental to hospice philosophy.
- Care plan and goals can be addressed more accurately based on information gained from MH assessment.
- It’s an opportunity to highlight the value of hospice social workers and contribute to interdisciplinary care and pt comfort.
Communicating Results of the Scale to the IDG

How to share results of MH assessment:

- Reason for assessment
- Assessment tool used (and why until they are familiar with the PGDS)
- Score and what score means
- Implications of results
  - Provide patient, team, and/or family with results that patient does not appear to be depressed, but make plan to address concerns that were brought forward.
  - Does MD feel initiation of additional medications is needed.
  - Would therapies be useful (music, massage, aromatherapy)?
  - Is volunteer needed to decrease isolation?
  - Should spiritual care and/or social work increase frequency of support visits?
## Follow Up Strategies and Interventions

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<tr>
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<th>Restoration and Loss-Oriented Grief</th>
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<td>• Identify personal pattern of depression: severity, onset, duration</td>
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<td>• Consider a suicide assessment</td>
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<td>• Clarify goals around emotional health</td>
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<td>• Identify personal strengths, protective factors, and coping strategies with the patient</td>
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<td>• Determine if further intervention or therapeutic referral is needed</td>
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<td>• IDT to evaluate for psychotropic meds, if appropriate</td>
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<tr>
<td>• Validate feelings of loss, anger, guilt, sadness, relief</td>
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<td>• Normalize the process: people may swing between restoration and loss-oriented grief</td>
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<td>• Encourage “time-outs” from preparatory grief work <em>(Stroebe &amp; Schut, 1999)</em></td>
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<td>• Provide empathic listening and supportive presence</td>
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<td>• Encourage patients to name the loss (make it real)</td>
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<td>• Provide education to address fears about dying</td>
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<td>• Re-frame hope for the future</td>
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<td>• Differentiate healthy reactions and unhealthy reactions to grief (address cognitive distortions)</td>
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<td>• Reinforce family and social connections</td>
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<td>• Life review: integrate memories with meaning <em>(Metcalf, 2013)</em></td>
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Conclusion

• Clearly, people may experience grief and depression with serious illness at the end of life. While grief is a normal reaction to loss, as you have hopefully seen, depression is not a normal reaction.

• Accurate assessment and treatment is an opportunity to provide enhanced care for our hospice patients.
References


References


References


Thank You for Attending!

- Elizabeth.Bouman@allina.com
- Kelli.Kinney@allina.com
- Amber.Seikert@allina.com