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Best Practices in End-of-Life Care

Section 1: Introduction

This course is designed to empower social workers with the specialized skills necessary to support individuals and families as they navigate the complexities of end-of-life experiences. You'll learn to conduct targeted biopsychosocial assessments, which aid hospice and palliative social workers in identifying the social, emotional, and practical needs unique to patients and families.

Through patient-centered care planning, this CE will explore ways to advocate for clients, offer holistic pain management, and provide meaningful palliative and hospice education. The course also covers effective communication strategies for discussing sensitive topics like patient prognosis, Advanced Directives, MOLST/POLST, Code Status, and memorial planning, helping the social worker to approach these conversations with empathy and clarity. Additionally, the learner will gain insight into essential grief counseling techniques, explore anticipatory grief interventions, learn how to conduct bereavement risk assessments, and reinforce the importance of interdisciplinary collaboration to ensure person- and family-centered holistic care with a social work lens.

By the end of this course, the learner will be equipped with the practical knowledge and confidence to support clients and their loved ones through one of life's most challenging phases with professionalism, compassion, and integrity.

Section 2: Social Work Role in End-of-Life Care

The social worker's role in end-of-life care is pivotal in providing comprehensive support to patients, families, and caregivers navigating the complex emotional, psychological, and logistical challenges that arise during this time (Thiel et al., 2021). In hospice care, social workers serve as essential case managers, coordinating care for both patients and families to ensure comprehensive support throughout the end-of-life journey. They assess and address the holistic needs of patients and families—emotional, social, financial, and spiritual—through regular biopsychosocial assessments and personalized care plans. Social workers are instrumental in connecting families to necessary resources, which may include counseling services, community support groups, financial aid, and respite care for caregivers. Caring for a terminally ill loved one takes a significant amount of time. Still, it is emotionally exhausting, and there are systems in place that are covered by the **Medicare Hospice Benefit** that can assist caregivers with symptom management and with obtaining breaks when they need them from the essential responsibility of being the sole caregiver for a loved one.

“There are four levels of care which the **Medicare Hospice Benefit** covers, and Medicare makes daily payments based on these:

1. **Routine home care**: A day the patient elects to get hospice care at home and isn’t getting continuous home care. A patient’s home might be a home, a skilled nursing facility (SNF), or an assisted living facility. Routine home care is the level of care provided when the patient isn’t in crisis.
2. **Continuous home care**: A day when the patient gets hospice care in a home setting that isn’t an inpatient facility (hospital, skilled nursing facility (SNF), or hospice inpatient unit). The care consists mainly of nursing care on a continuous basis at home. Patients can also get hospice aide, homemaker services, or both on a continuous basis. Hospice patients can get continuous home care only during brief periods of crisis and only as needed to maintain the patient at home. Some hospices do not have the staffing to provide continuous home care, so the patient is better served either in an inpatient respite placement or as general inpatient care, commonly referred to as GIP.

3. **Inpatient respite care**: A day the patient elects to get hospice care in an approved inpatient facility for up to 5 consecutive days to give their caregiver a rest.
4. **General inpatient care**: A day the patient elects hospice care in an inpatient facility for pain control or acute or chronic symptom management, which can't be managed in other settings (*Hospice | CMS*, n.d.)."

Medical/Hospice social workers also help patients and families navigate complex healthcare systems, clarifying options for pain management, palliative treatments, and advance care planning. They also educate patients and families on hospice philosophy. Along with a nurse case manager and physician/nurse practitioner, they help families and patients understand that hospice care is aimed at comfort measures only and not curative measures.

It is a common reaction of patients and families to want to seek curative care or call 911 in a crisis, as the dying process can be very intimidating and elicit significant fear for both the patient and the caregiver(s). They must be educated to call the hospice and not emergency services if the patient is being cared for in the home because the hospice nurse or administrator on call can handle most emergent situations in a terminal patient. If a patient goes to the hospital and is admitted, there must be a **hospice revocation.** When a hospice patient is admitted to the hospital for reasons beyond what hospice covers (e.g., for intensive treatments rather than symptom relief), hospice care funding and coverage may be paused or revoked. This helps avoid overlapping coverage between hospice care and other forms of acute hospital care. If a patient or their family desires hospitalization for treatment that goes beyond the hospice model, they can revoke hospice care to access these services. After discharge, they have the option to re-enroll in hospice, provided they still meet eligibility criteria.

By serving as a liaison with healthcare providers, social workers ensure that care aligns with patients' and families' needs and wishes, providing a stable point of contact throughout the process. Their work helps to ease the emotional and logistical burdens on families, making end-of-life transitions as supportive and respectful as possible. From a therapeutic and counseling standpoint, social workers are pivotal in providing compassionate counseling to help patients and families address grief, anticipatory loss, and complex decision-making, often using therapeutic approaches like **Trauma-Focused Cognitive Behavioral Therapy (TF-CBT)** and **Cognitive Processing Therapy (CPT)** to address trauma, anxiety, and distress (Liu et al., 2019).

Social workers also play an essential role in facilitating discussions about Advance Directives and **POLST (Physician Orders for Life-Sustaining Treatment)** or **MOLST (Medical Orders for Life-Sustaining Treatment)** with patients and their caregivers during end-of-life care. These conversations are often challenging, as they involve decisions about life-sustaining measures, personal values, and medical preferences when a patient is nearing the end of life and has been diagnosed with a terminal illness. Social workers must approach these discussions with empathy and cultural sensitivity, helping patients and families express their wishes for future care clearly and confidently. An example of a MOLST (using the state of Maryland, for example) can be found here. The MOLST is completed by a physician, nurse practitioner, or other medical provider, and it is crucial that social workers understand the designations as they are not as simple as **DNR-Do Not Resuscitate** or **Full Code** (meaning all life-saving measures, including CPR, would be given). Some families opt for intravenous fluids, tube feedings or blood transfusions, and other treatments at the end of life, based on personal preference or cultural considerations.

Social workers also help educate patients and caregivers on the purpose of **Advance Directives**—legal documents that outline a person's healthcare preferences should they become unable to express them. By exploring the patient's values and beliefs, social workers help identify the type of care the patient prefers, guiding them through choices about resuscitation, intubation, artificial nutrition, and comfort care. Social workers also explain **POLST/MOLST forms** mentioned above, which are actionable medical orders that specify the patient's treatment preferences, ensuring these decisions are honored across healthcare settings (Russell & Quaack, 2021). Another type of document that is legally enforceable is the **Five Wishes Advance Directive Document**, which is widely known for being easy to follow, understand, and complete. An excellent patient education tool, it provides a conversation framework that covers medical, emotional, spiritual, and communication wishes (*About Five Wishes · Five Wishes*, n.d.).

Through this process, social workers provide support to caregivers, easing feelings of uncertainty and guilt that may arise from making these choices on behalf of a loved one. They ensure that both patients and families feel informed and empowered, fostering a sense of control and peace during a vulnerable time.

Section 3: Case Study: Advanced Care Planning

James Mitchell, a 58-year-old man diagnosed with terminal brain cancer, has been under palliative care following a significant decline in his cognitive and physical abilities. James has decided to stop pursuing curative care and has opted for comfort measures only, so he consents to hospice care. James has a supportive family, including his wife, Susan, and their two teenage children, Emma and Michael, who are deeply involved in his care. Despite their devotion, neither James nor his family has addressed formal end-of-life planning, and there are no existing documents, such as a living will or a designated **Medical Power of**

Attorney (MPOA). Without clear directives, the family finds themselves uncertain about how to proceed with James' care, especially as his condition progresses.

During an in-depth conversation with the social worker, James and his family expressed their concerns about his condition but revealed they haven't given much thought to formalized end-of-life documentation. When the social worker raises the topic of Advanced Care Planning (ACP), they seem unfamiliar with the terms and the implications of lacking a clear plan. They assume that Susan, as his spouse, would naturally make decisions if James were unable to speak for himself. The social worker gently explains that, while this is often the case, without documented preferences and designated roles, it can lead to unnecessary conflicts, stress, and, sometimes, legal complications if family members have differing opinions.

Section 3 Reflection Questions

1. How can the social worker assess the level of understanding and awareness a patient and their family have regarding end-of-life planning and hospice philosophy?

2. What are effective ways to explain these complex concepts, such as Advanced Directives, Medical Power of Attorney (MPOA), or Five Wishes, if the family is unfamiliar with them while honoring the dignity and sensitivity of the situation?

3. Spend some time reviewing and listing two assessments (apart from the biopsychosocial assessment) that might be helpful in making sure a patient and family's cultural, spiritual, and emotional state are honored in the Advanced Care Planning process (ACP). When choosing assessment tools, consider patient and family dynamics as well as **risk and protective factors** and **coping mechanisms.**

Reflection Questions Answers/Explanations

1. There are some key methods a social worker can use to assess the Mitchell family's understanding and awareness. Ask **open-ended questions** such as, “What have you heard about advance directives or living wills?” and “What concerns do you have about hospice care and planning for this stage of care?” The **teach-back method** is a key way a social worker could assess this. The **teach-back method** is a communication strategy in which a social worker or healthcare provider asks the patient or family to explain the information just discussed in their own words. This method ensures that the family accurately understands critical concepts, and it allows the provider to clarify any misunderstandings in real time (Shersher et al., 2020).

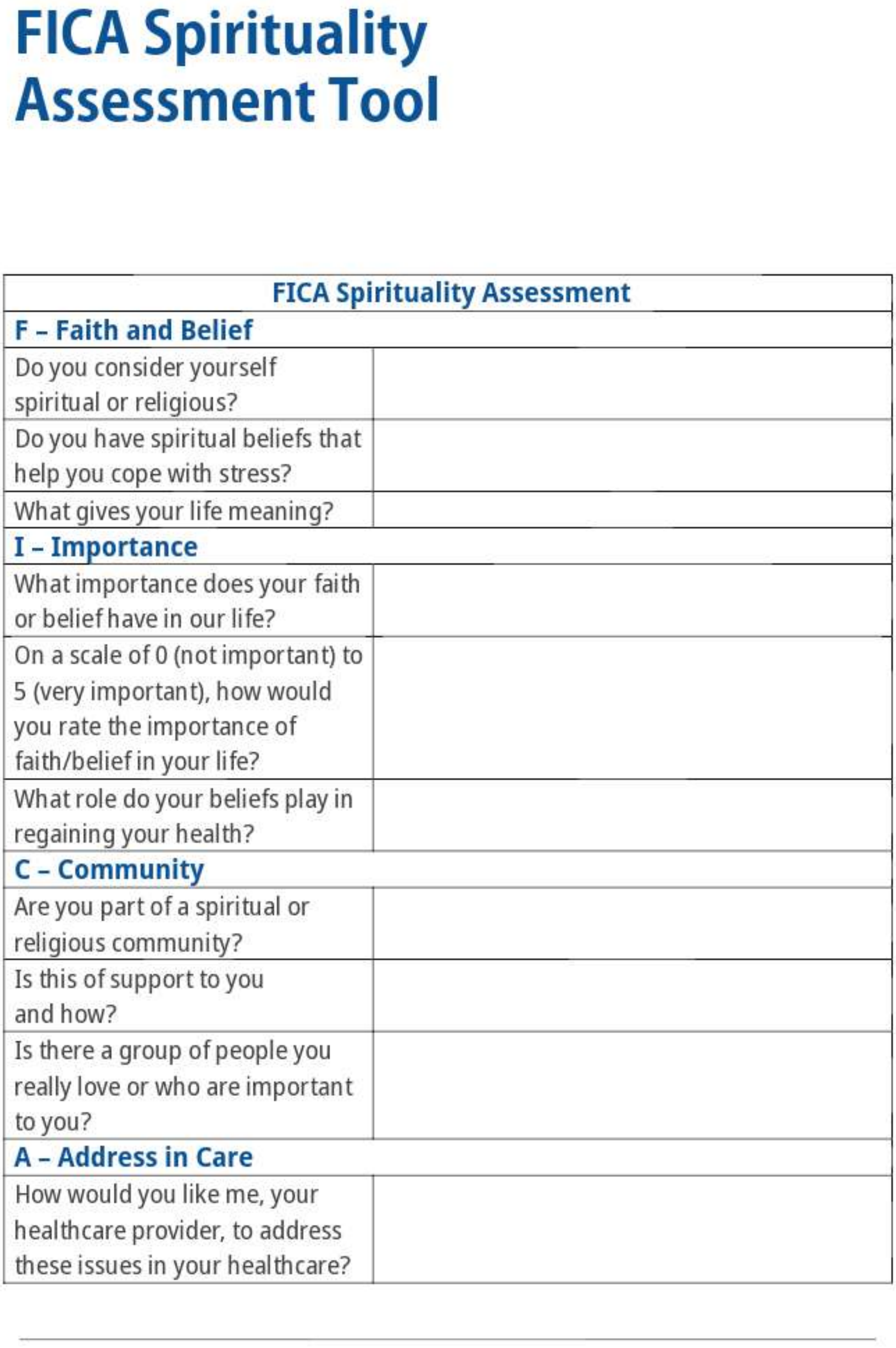
2. Using simple and respectful language while avoiding complex medical jargon is essential when conversing with families and patients about the end-of-life planning process. For example, a clinician might explain Advanced Directives as "a document where you can write down the types of medical care you would or wouldn’t want if you couldn’t tell the doctors yourself." Emphasize that these choices help honor the patient’s wishes, making it clear these decisions are about supporting dignity and control. Another way in which a social worker might explain these concepts is by using visual aids such as pamphlets, diagrams, or easy-to-read summaries, as these help a family digest the information at their own pace. Visual aids for **Five Wishes**, for instance, might list out each “wishes” in the document (e.g., comfort, medical treatment, how they want to be remembered) so they can follow along visually, as the social worker explains. Those visual aids for Five Wishes are available here: **https://www.fivewishes.org/five-wishes-sample.pdf.** A video that explains **Five Wishes** is also available on Youtube.

3. Spirituality has been found in some families and patients to lighten the burden of advanced care planning at the end of life (Vigna et al., 2020). This is why spiritual care is part of the holistic model of hospice care. Social workers can use a **FICA assessment** to gain insight into what, if any, cultural or spiritual beliefs may influence their views on end-of-life planning. These tools help assess how their beliefs align or conflict with sensitive aspects of end-of-life planning. Often, there is a collaboration between the social worker and the chaplain in conducting a FICA Assessment. Either professional is qualified to conduct this assessment. **(see next page for a standard FICA Spirituality Assessment adapted from Puchalski, 2021).**

Section 4: Understanding Anticipatory Grief Interventions

Anticipatory Grief is defined as the experience of grief that occurs before an impending loss on the part of the patient and family/caregiver(s). Patients facing terminal illness often experience anticipatory grief as they confront the reality of their mortality. They may mourn the loss of future experiences, relationships, and unfinished goals. Emotions include fear, sadness, anger, and acceptance. Caregivers, including family members, experience anticipatory grief as they witness the decline of their loved one and manage the associated emotional and physical challenges. They may fear role changes, loss of a shared future, and many mixed emotions (Singer et al., 2022). During this emotional adjustment process, the social worker must establish rapport with the patient and their caregivers so that interventions can be provided. Interventions for **anticipatory grief** include:

- Education and normalization
- Counseling and validation



FICA Spirituality Assessment Tool

FICA Spirituality Assessment	
F – Faith and Belief	
Do you consider yourself spiritual or religious?	
Do you have spiritual beliefs that help you cope with stress?	
What gives your life meaning?	
I – Importance	
What importance does your faith or belief have in our life?	
On a scale of 0 (not important) to 5 (very important), how would you rate the importance of faith/belief in your life?	
What role do your beliefs play in regaining your health?	
C – Community	
Are you part of a spiritual or religious community?	
Is this of support to you and how?	
Is there a group of people you really love or who are important to you?	
A – Address in Care	
How would you like me, your healthcare provider, to address these issues in your healthcare?	

- Conversation facilitation between caregiver(s)/family members and the patient
- Guidance on Life Review activities and/or legacy activities, including planning for a memorial service.
- Provision of resources and referrals to support groups to alleviate caregiver stress

Before the introduction of a second assessment tool used in **anticipatory grief** and bereavement, let's review a couple of social work terms using an end-of-life perspective. In hospice social work, **Risk and Protective Factors** refer to the elements that can either increase or decrease the likelihood of complicated grief or adverse outcomes following a bereavement. These factors help social workers assess the potential challenges or supports that may affect how individuals and families cope with loss. Research by Asmat et al. (2024) found that understanding both risk and protective factors enables social workers to provide tailored support and interventions.

Asmat et al. (2024) define **Risk factors** as characteristics or conditions that increase the likelihood of complicated grief or maladaptive responses to loss. They help social workers identify individuals who may need more intensive support during bereavement and during the anticipatory grieving stage of end-of-life interventions. Key bereavement risk factors include:

- **Preexisting Mental Health Issues**: A history of mental health conditions, such as depression, anxiety, or substance use disorders, may make grieving more challenging.
- **Sudden or Traumatic Death**: Unexpected or violent deaths, such as accidents or suicides, can intensify grief and lead to unresolved emotional distress.

- **Limited Social Support**: A lack of friends, family, or community support can leave individuals isolated, making it harder to cope with grief.
- **Unresolved Past Losses or Trauma**: Previous unresolved grief or trauma can resurface, complicating the current grieving process.
- **Economic or Caregiving Burden**: Financial stress or a significant caregiving role for the deceased may compound grief with feelings of insecurity or overwhelming responsibility.

Asmat et al. (2024) explain **Protective factors** as strengths or supports that help individuals manage grief healthily and reduce the risk of complicated grief. These factors can foster resilience, assisting individuals to adjust to life after loss. Key protective factors include:

- **Strong Social Support**: A supportive network of family, friends, or community can provide emotional comfort, practical help, and a sense of belonging during bereavement.
- **Positive Coping Mechanisms**: Healthy coping strategies, such as exercise, journaling, meditation, or counseling, can assist individuals in processing their grief constructively.
- **Prior Resilience and Adaptive Skills**: People with a history of successfully managing adversity may be better equipped to cope with grief.
- **Religious or Spiritual Beliefs**: Belief systems can offer meaning, comfort, and a sense of continuity, providing a framework for understanding loss.
- **Access to Counseling or Support Services**: Timely professional support can prevent complicated grief by offering tools and resources to navigate emotional challenges.

- **Preparation and Anticipatory Grief**: When death is expected, anticipatory grief work may help family members begin processing their loss in advance, which can ease the transition.
- **Intense Attachment to the Deceased**: Positive attachment to the deceased often provides motivation to honor them after their death, and doing so promotes positive resilience.

On the next page, Morris et al. (2019) developed this specific **Bereavement Risk Assessment Tool (BRAT)** shown as an example, and this is the other crucial assessment social workers use when forming a care plan for the patient and family to manage grief (both anticipatory and bereavement). This assessment type allows social workers to target specific interventions based on the aforementioned risk and protective factors.

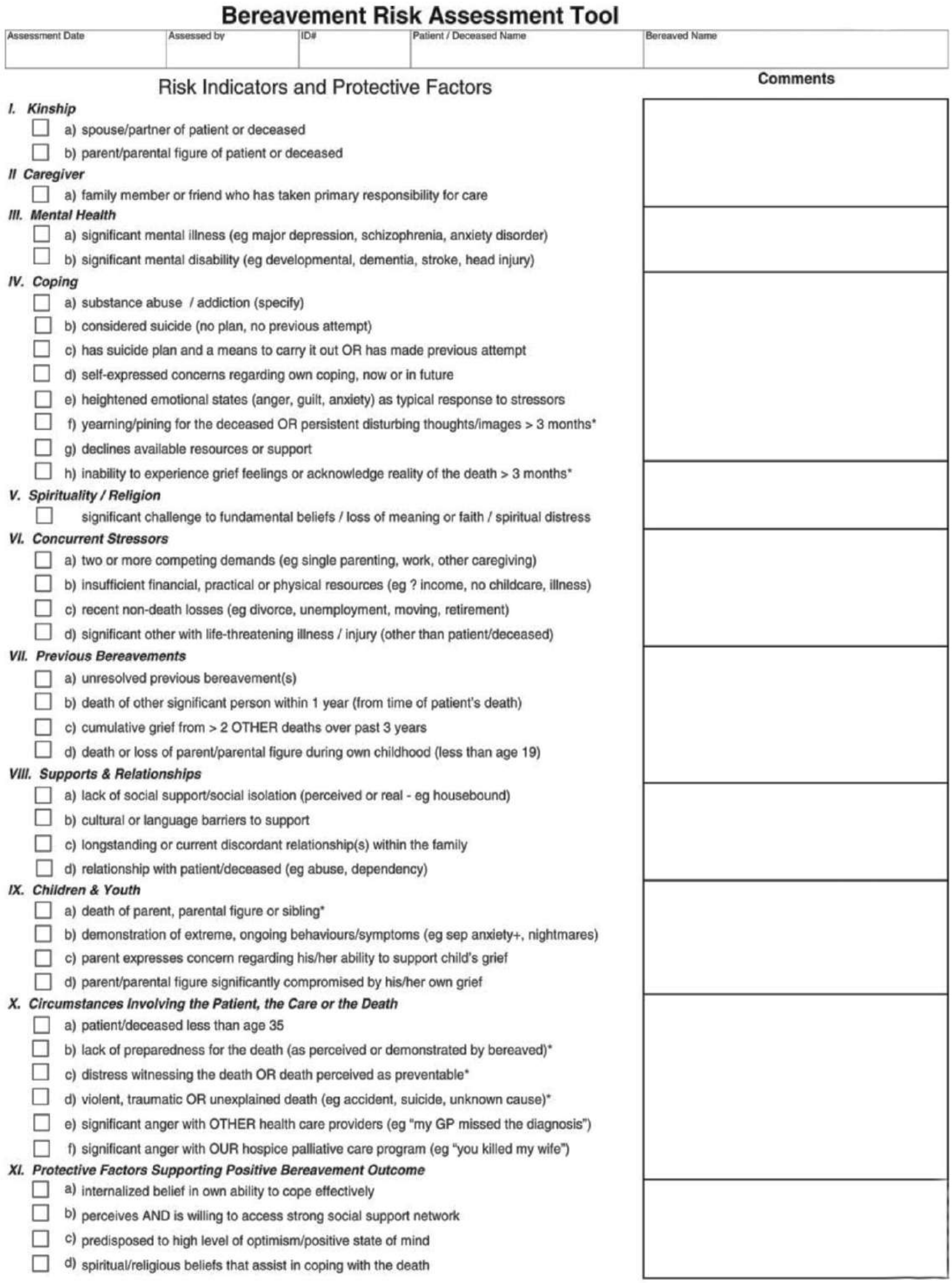
Because the nature of grief is fluid and it ebbs and flows, even as death is anticipated, the Bereavement Risk Assessment should be completed as the patient and family care progresses, and it is recommended to be completed at each visit, especially as the disease advances and the end becomes near.

Section 5: Scoring the Bereavement Risk Assessment Tool

Using the assessment tool above, the scoring is relatively straightforward and helps guide social work interventions for categories related to the bereavement process. Areas of assessment include kinship, mental health history, coping strategies, spiritual distress, and prior losses (as back-to-back or other losses in close proximity can vastly influence risks for **Prolonged Grief Disorder**).

To calculate an overall bereavement risk score, each risk factor identified in the assessment is documented. Higher scores reflect a greater need for intervention and support. Protective factors such as optimism, strong social support networks, and positive coping mechanisms are also included to offset some of the high-risk indicators, enabling a balanced and holistic view of bereavement risk.

Using the BRAT as an assessment tool enables social workers to customize bereavement support plans based on both the identified risks and protective factors. By systematically assessing these areas, the social worker can ensure that family members receive the appropriate level of support and resources in line with their unique needs. This assessment can be longitudinally tracked throughout the course of the family being in service. It helps the hospice social worker coordinate care with other professionals in the community and communicate the results of the BRAT assessment to the bereavement team or professional. That role is often held by a person trained in counseling, social work, marriage and family therapy, psychology, etc.



Bereavement Risk Assessment Tool

Assessment Date	Assessed by	ID#	Patient / Deceased Name	Bereaved Name

Risk Indicators and Protective Factors

Comments

I. Kinship

- ☐ a) spouse/partner of patient or deceased
- ☐ b) parent/parental figure of patient or deceased

II Caregiver

- ☐ a) family member or friend who has taken primary responsibility for care

III. Mental Health

- ☐ a) significant mental illness (eg major depression, schizophrenia, anxiety disorder)
- ☐ b) significant mental disability (eg developmental, dementia, stroke, head injury)

IV. Coping

- ☐ a) substance abuse / addiction (specify)
- ☐ b) considered suicide (no plan, no previous attempt)
- ☐ c) has suicide plan and a means to carry it out OR has made previous attempt
- ☐ d) self-expressed concerns regarding own coping, now or in future
- ☐ e) heightened emotional states (anger, guilt, anxiety) as typical response to stressors
- ☐ f) yearning/pining for the deceased OR persistent disturbing thoughts/images > 3 months*
- ☐ g) declines available resources or support
- ☐ h) inability to experience grief feelings or acknowledge reality of the death > 3 months*

V. Spirituality / Religion

- ☐ significant challenge to fundamental beliefs / loss of meaning or faith / spiritual distress

VI. Concurrent Stressors

- ☐ a) two or more competing demands (eg single parenting, work, other caregiving)
- ☐ b) insufficient financial, practical or physical resources (eg ? income, no childcare, illness)
- ☐ c) recent non-death losses (eg divorce, unemployment, moving, retirement)
- ☐ d) significant other with life-threatening illness / injury (other than patient/deceased)

VII. Previous Bereavements

- ☐ a) unresolved previous bereavement(s)
- ☐ b) death of other significant person within 1 year (from time of patient's death)
- ☐ c) cumulative grief from > 2 OTHER deaths over past 3 years
- ☐ d) death or loss of parent/parental figure during own childhood (less than age 19)

VIII. Supports & Relationships

- ☐ a) lack of social support/social isolation (perceived or real - eg housebound)
- ☐ b) cultural or language barriers to support
- ☐ c) longstanding or current discordant relationship(s) within the family
- ☐ d) relationship with patient/deceased (eg abuse, dependency)

IX. Children & Youth

- ☐ a) death of parent, parental figure or sibling*
- ☐ b) demonstration of extreme, ongoing behaviours/symptoms (eg sep anxiety+, nightmares)
- ☐ c) parent expresses concern regarding his/her ability to support child's grief
- ☐ d) parent/parental figure significantly compromised by his/her own grief

X. Circumstances Involving the Patient, the Care or the Death

- ☐ a) patient/deceased less than age 35
- ☐ b) lack of preparedness for the death (as perceived or demonstrated by bereaved)*
- ☐ c) distress witnessing the death OR death perceived as preventable*
- ☐ d) violent, traumatic OR unexplained death (eg accident, suicide, unknown cause)*
- ☐ e) significant anger with OTHER health care providers (eg "my GP missed the diagnosis")
- ☐ f) significant anger with OUR hospice palliative care program (eg "you killed my wife")

XI. Protective Factors Supporting Positive Bereavement Outcome

- ☐ a) internalized belief in own ability to cope effectively
- ☐ b) perceives AND is willing to access strong social support network
- ☐ c) predisposed to high level of optimism/positive state of mind
- ☐ d) spiritual/religious beliefs that assist in coping with the death

Fig. 1. Bereavement Risk Assessment Tool (BRAT).

Prolonged Grief Disorder is the only diagnosable grief disorder by the DSM V-TR. “For a diagnosis of prolonged grief disorder, the loss of a loved one had to have occurred at least a year ago for adults and at least six months ago for children and adolescents. In addition, the grieving individual must have experienced at least three of the symptoms below nearly every day for at least the last month prior to the diagnosis.

Symptoms of prolonged grief disorder include:

- Identity disruption (such as feeling as though part of oneself has died).
- A marked sense of disbelief about the death.
- Avoid reminders that the person is dead.
- Intense emotional pain (such as anger, bitterness, and sorrow) related to the death.
- Difficulty with reintegration (such as problems engaging with friends, pursuing interests, and planning for the future).
- Emotional numbness (absence or marked reduction of emotional experience).
- Feeling that life is meaningless.
- Intense loneliness (feeling alone or detached from others).(APA, 2022).”

Additionally, a family or caregiver may be at an increased risk of this disorder if they have other mental health comorbid conditions such as PTSD, depression, or anxiety. If the death of the loved one occurred without appropriate comfort medications dosed in the patient and they passed away through aspiration or another traumatic manner, this is an additional situation that can complicate grief. It is essential for the clinician to be aware of all circumstances surrounding the death, and it is imperative that when a patient is nearing the end of life, social work visits and other team visits should be made more frequent to offer the needed support for the caregivers. If elected, chaplains can also provide spiritual support along with the RN case manager on the team.

Section 6: Hospice Interdisciplinary Team Collaboration

Medicare guidelines mandate that the interdisciplinary team/group (IDT/IDG) is required to meet at least every **15 days** for each hospice patient. This ensures a hospice patient's care plan is updated and reviewed so that it meets the patient's current needs as well as the family/caregiver's current needs and wishes. This is how hospice teams ensure that patient- and family-centered care is provided. Perspectives and insights from the team members allow for the management of symptomatology, which may be complex. Usually, a bereavement professional is an integral part of the team in order to ensure continuity of care once the patient has passed away, and follow-up services for the family/caregiver(s) are warranted. This clinician can be a social worker, therapist, licensed marriage and family therapist, or licensed professional counselor. Other professionals mandated by the Medicare hospice guidelines include a physician or nurse practitioner, RN case managers, social workers, and chaplains. This allows for a team approach to the management of the physical, emotional, social, and spiritual needs of the patients and their families.

Section 7: Defining Bereavement Services

Medicare has special provisions with the hospice benefit that bereavement services be offered to families and/or primary caregivers of hospice patients for

up to 13 months following the patient's death. Often, the first year after the loss is the most difficult, and the intent is to cover special dates, anniversaries, or times of remembrance that may trigger intense grief, emotions, and reactions. The specific services vary depending on the hospice organization, but they may include grief counseling, support groups, and check-ins to help families adjust and process the emotions associated with their loss (Becker et al., 2023).

Bereavement support can vary but often includes the following components, as Moran (2020) explains.

- **Individual and Grief Counseling Services:** In these sessions, social workers or other licensed counselors provide one-on-one and/or family services that aim to help the clients develop healthy coping skills.
- **Support Groups**: Often, these groups are categorized by relationship type, age group, and/or gender and sexual orientation. For instance, this social worker course writer aided in the facilitation of a Living with Loss Spouse/Partner Group wherein the focus was broken into four parts: a meditation/reading, psychoeducation on some part of bereavement theory (which was aimed at creating an understanding that the attendees' feelings were expected), a time for optional sharing guided by topical discussion questions or cognitive behavioral therapy interventions (CBT), and a closing activity. In the first session (usually 8-10 meetups), we often shared the video from NBC, "How Grief Affects Your Brain And What To Do About It." Another resource that has proven helpful is https://www.whatsyourgrief.com, which was written by social workers who have extensive experience in evaluating, developing, and managing complex and prolonged grief across many populations. The site also includes professional development courses, as well as courses for the bereaved.

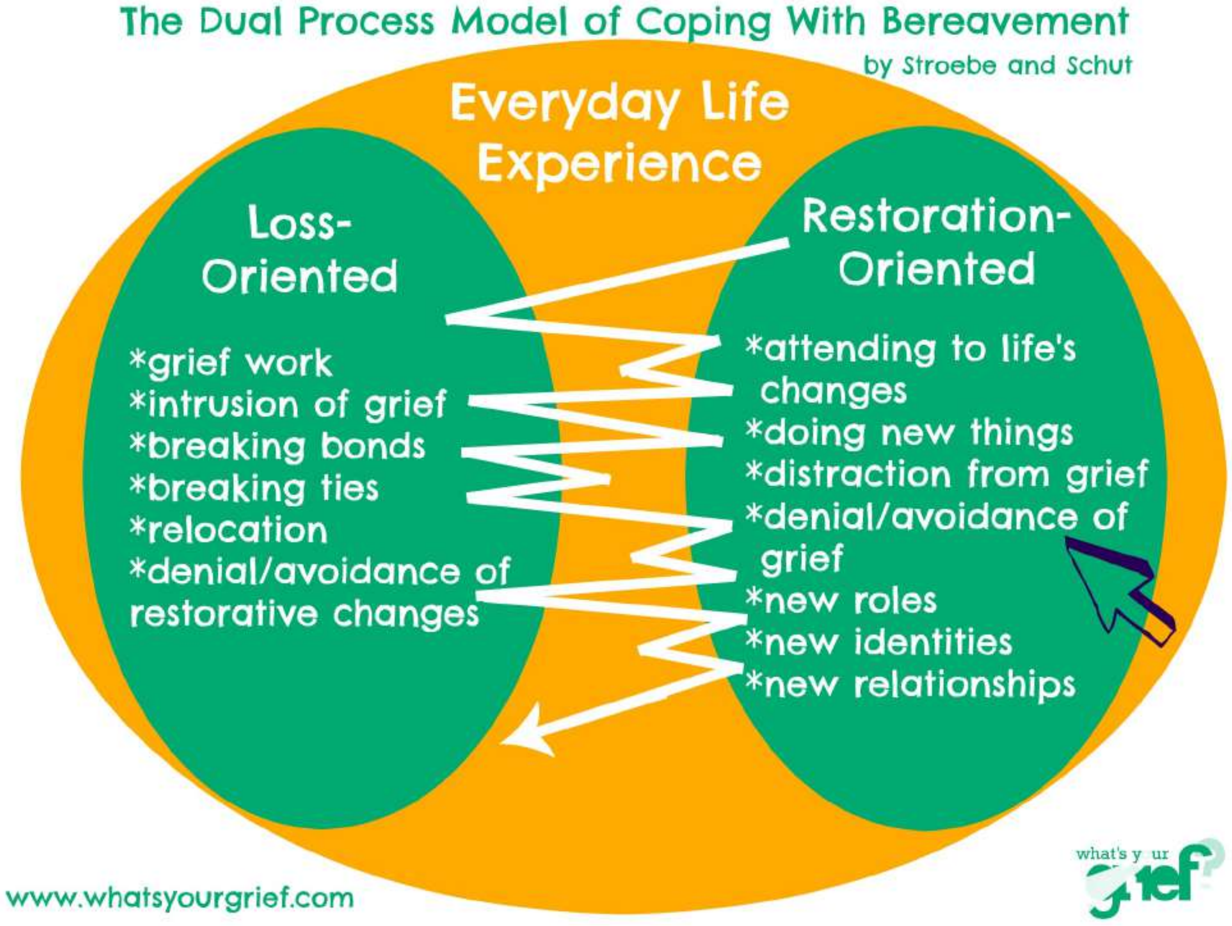
- **Educational Services**: An essential component of grief is to understand the where, when, why, and how. These are often found in literature developed by the National Hospice and Palliative Care Organization (NHPCO).
- **Periodic Check-ins**: Bereavement phone calls are an essential part of any hospice program. These calls are often completed by counselors or volunteers, as 5% of all hospice services are required to be completed by volunteers. Usually, after the "business of death," such as the funeral, insurance settlements, etc., things begin to slow down, and these calls help identify high-risk individuals/families that may require more extensive intervention.
- **Specialized Support During Holidays/Key Dates**: It is a well-known fact that grief intensifies when special dates arise. Often, bereavement programs provide calls on these dates.
- **Spiritual Support**: This is provided by chaplains with the hospice agency or by outside clergy if the family elects to utilize this support.
- **Practical Assistance**: This type of support often includes case management services such as searching for financial assistance (as perhaps the primary financial provider was the loss) and help with childcare, housing, food, mental health, and other needs.

Section 8: Bereavement/Grief Models and Their Implications

This section of the program will include the three predominant theories used to understand the unique nature of grief from the patient's and caregivers' point of view. Historically, grief models relied solely on the **Kübler-Ross model**, which (Corr, 2020) and other researchers in the field assert is an outdated viewpoint to apply to all types of grief. This model is more appropriate to apply to the terminal patient's dying process, so this will be discussed first in this section. Next, the contemporary models of grief that apply to the family/caregivers of patients at the end-of-life stage will be discussed. The five stages of grief reported by Kübler-Ross are **denial, anger, bargaining, depression, and acceptance,** and these are recognized as stages the terminal patient goes through but are no longer the gold standard in grief amongst caregivers/family (Ross et al., 2019). It also must be noted that not all patients go through these stages in any particular order, nor do all patients experience every stage before they die; some never come to acceptance, and this makes the work of the social worker and other clinicians crucial in counseling a patient and holding space, being sensitive and compassionate as well as presenting an attitude of active/reflective listening as just like grief, this process has a different timing for every patient.

- **Denial** is the initial reaction that terminal patients often go through, which is when they refuse to accept their prognosis, and this is a common defense mechanism.
- **Anger** is almost self-explanatory, but patients often feel anger toward their medical situation, and they ask questions like, "Why Me?"
- **Bargaining**: In this stage, many patients try to make deals with their higher power, themselves, or others, and they hope to avoid the loss and/or postpone the inevitability of a terminal disease.
- **Depression**: This stage is often marked with a realization of the prognosis by the patient, even though it brings intense sadness and hopelessness.
- **Acceptance**: In this final stage, the patient generally comes to terms with the end-of-life prognosis.

Shelvock (2022) asserts that psychological research on caregiver/family grief shows that it does not follow any specific timeline, which is why one of the most applicable models of grief is William Worden's **Dual Process Model**. This model states that there is an oscillation back and forth between a loss orientation process and a restoration orientation process. This highlights how there are good days and bad days when grieving. The following graphic from http://www.whatsyourgrief.com is a visual representation of the model and is a depiction of how we move back and forth between loss orientation and restoration of our lives.



Guldin and Leget (2023) posit that “the literature showed a high degree of consensus on descriptions of grief reactions within physiological, emotional, cognitive, social, behavioral, and spiritual/existential domains through The Integrated Model of Grief and Loss.” Some clinicians refer to this as the **PEMSS Model of Grief**. The five dimensions are very similar, but they simplify the integrated model, and the descriptions are **Physical, Emotional, Mental, Social, and Spiritual**.

Section 8 Case Study: A Caregiver's Journey Through the Dual Process Model of Grief

Sarah Johnson, age 50, is the primary caregiver for her husband, Mark, who has recently passed away after a two-year battle with Amyotrophic lateral sclerosis (ALS), also known as Lou Gehrig’s Disease. Sarah has been intensely involved in his care, managing both the physical and emotional aspects of his illness and supporting their two teenage children. After Mark's passing, Sarah experiences a profound sense of loss but also relief that his suffering has ended. Clinically, applying the **Dual Process Model of Grief**, she reverts back and forth through loss-oriented responses and restoration-oriented responses such as:

Loss-Oriented Grief Responses

- **Emotional Reactions**: Sarah often finds herself overwhelmed with grief. She longs for Mark and feels incredibly guilty about her sense of relief after his passing. She has moments of intense sorrow, especially when recalling memories or special milestones/anniversaries. She questions her decisions about his care and experiences, and she wonders if she did everything she could to try and save his life. She also questions if she treated him with all the love she should have in the end, as his care was highly tiresome, and sometimes she recalls responding to his needs with impatience.

- **Ruminating on the Past**: She repeatedly goes through moments in Mark's last days and replays conversations and caregiving actions, feeling guilty that she didn't spend enough time with him due to her other life responsibilities.

Restoration-Oriented Grief Responses

- **Adjusting to New Roles**: Since Mark's death, Sarah has been responsible for managing all household responsibilities and supporting her children emotionally and financially. She struggles to adjust to life without Mark's presence and the shift in family dynamics. She often finds herself depressed and stressed because she must handle her needs and financial needs and help support her children through their own grief of losing their father at such pivotal ages.

- **Focusing on Her Own Needs**: Occasionally, Sarah feels a sense of personal freedom and relief after years of caregiving. She has moments of enjoying activities she had set aside, such as reconnecting with friends or exercising. It seems as though she is grieving usually and not experiencing symptoms that align with the earlier discussion on **Prolonged Grief Disorder**. However, there are times when she feels she or her children might need the support of a grief counselor. The thought remains in the back of her head, and she is unsure if her grief is normal or if she is developing mental issues due to the intensity of her emotions at times.

- **Building a New Identity**: However, even with periods of emotional intensity, Sarah is beginning to recognize her identity beyond being Mark's caregiver. This includes planning for her future, considering returning to work and rebuilding her social life.

Sarah wavers between these loss-oriented and restoration-oriented responses, which is characteristic of the **Dual Process Model**. This fluctuation is natural and represents the balance between addressing the pain of loss and re-engaging with life.

Section 8 Reflection Questions

1. What therapeutic approaches can Sarah use to assist her in the expression of her grief, and how might tools like memory-building/life review or journaling assist her?

2. How can the social worker facilitate Sarah's efforts to engage in self-care activities and help her rebuild her social networks (for support)?

3. How can the social worker educate Sarah on the natural process of wavering between grief and restoration (clue: research the Dual Process Model)?

4. How might the social worker support Sarah's relationship with her children as they grieve together and what family-centered interventions might apply?

Section 8 Reflection Questions Answers

1. The social worker should use psychoeducation on the grieving process, educating Sarah about normal grief reactions. There are many journaling activities online within websites such as http://www.whatsyourgrief.com and other sites that the social worker could use to facilitate life review/ prompt journaling responses. Sometimes, even having her show photos of special memories and enabling a life review can be therapeutic.

2. Specific therapeutic interventions such as Cognitive Behavioral Therapy (CBT) can address her feelings of guilt and self-doubt. These interventions often come with homework between therapy sessions so that it reinforces what is discussed in therapy should she decide to seek additional grief counseling.

3. The social worker should help Sarah by normalizing her fluctuating emotions and helping her understand that these feelings (loss and restoration-oriented activities) are necessary for her healing, as seen in the **Dual Process Model**. The nature of grief is that it ebbs and flows, much like waves, and showing Sarah that her wavering emotions are not abnormal is essential for her to continue to heal. As discussed earlier, **Prolonged Grief Disorder** does not become an issue for adults until the aforementioned criteria are met.

4. As we know, adolescents have different emotions than adults so they may experience grief differently. Some interventions that may support the teens and the family are creating a safe space for open communication by encouraging family meetings. Some hospices offer specific supportive peer groups, so finding those is essential for teens to connect with other peers who have had similar losses, and it can help them feel validated. Also, teens may benefit from creative outlets such as art or music as well as journaling. Both Sarah and her children can engage in legacy-building activities such as writing letters to the deceased or creating a memory book or collage. Using tangible ways for them as a family to honor their father/husband's memory can help make meaning out of the loss.

Fostering Professional Resilience and Preventing Compassion Fatigue

Compassion fatigue, often referred to as the "cost of caring," is a state of emotional and physical exhaustion resulting from prolonged exposure to the suffering of others. It is a particular risk in hospice social work, where professionals are continually immersed in end-of-life care and trauma. This condition can manifest as reduced empathy, emotional apathy, irritability, insomnia, or even physical fatigue, which ultimately undermines both professional effectiveness and personal well-being (Ratcliff, 2024). Social workers experiencing compassion fatigue may feel detached from their patients, struggle to connect emotionally, or experience decreased job satisfaction, motivation, and overall mental health.

Recognizing the early warning signs of compassion fatigue is critical. Symptoms, such as heightened irritability, difficulty concentrating, or a sense of emotional numbness, signal the need for timely intervention. Left unaddressed, compassion fatigue can lead to full-fledged burnout, impairing the ability to provide high-quality care to patients and support their families. Social workers must adopt a proactive approach to managing these challenges in order to sustain their emotional resilience and maintain professional integrity.

Preventing compassion fatigue necessitates both individual and organizational efforts. Self-care is paramount, with strategies such as mindfulness practices, engaging in regular physical activity, maintaining healthy sleep habits, and setting clear emotional and physical boundaries. These practices allow social workers to replenish their energy and build emotional resilience. Moreover, cultivating a robust personal support system outside of work can provide a safe space to process emotions and gain perspective.

On an organizational level, fostering a culture of support and understanding is equally critical. Employers can offer training programs that focus on recognizing and mitigating compassion fatigue, provide access to professional supervision, and encourage mental health days to allow for recovery. Structured debriefing sessions can also offer social workers an outlet to process challenging cases and alleviate feelings of isolation. Regular opportunities for peer support, such as team-building activities or small group discussions, further enhance the sense of community and shared understanding among staff (Gallagher & Cooper, 2023).

Incorporating these measures into the practice of hospice social work not only enhances the personal well-being of practitioners but also ensures that patients and their families receive the compassionate, high-quality care they deserve. For those entering the field of end-of-life care, understanding the risks of compassion fatigue and learning to foster resilience are essential components of professional preparation.

Ultimately, fostering resilience in social work is not just about protecting professionals—it is about preserving the heart of hospice care. Social workers who feel supported and equipped to manage the emotional demands of their roles are better able to offer meaningful, empathetic care to those facing life’s most challenging moments. By prioritizing resilience and compassion for ourselves, we ensure the sustainability of a workforce dedicated to providing peace, dignity, and comfort to those at the end of life, even in the most challenging circumstances.

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