Raising the Bar for Bereavement Programming: Lessons Learned from COVID

Gary Gardia, LCSW, APHSW-C
ggardia@aol.com

1. One of the most important lessons we have learned lately is that if our top priority is in fact the provision of high quality care, then the only way to get there is through creative thinking.
   Thinking that is not exactly creative is "We have always done it this way" or "We don't provide this service but let me refer you to someone in the community who can." Many people nationally have confessed to taking the easy way out during COVID by saying 'We used to provide this service but we can't right now because of COVID.'" With all the technology available these days there really should be no more excuses. We can even be maximizing the use of the telephone. It requires creative thinking and a relentless drive to continually provide exceptional services regardless of the obstacles we face.

2. Who should supervise the provision of bereavement services?
   A hospice program is required to have "…an organized program of bereavement services furnished under the supervision of a qualified professional with experience or education in grief/loss counseling."

   Do you have documented grief/loss education/counseling experience?
   If you are the bereavement coordinator for your hospice program, do you feel you have the skills necessary to create a high level bereavement program? Are you confident with your grief/loss counseling skills? The truth is, we should never stop learning. There are new advances in this field happening all the time.
   Here is an excellent resource to consider:
   Grief Counseling and Grief Therapy, Fifth Edition: A Handbook for the Mental Health Practitioner – Grief Counseling Handbook on Treatment of Grief, Loss and Bereavement, Book and Free eBook by William Worden
   Springer Publishing Company; 5th edition (May 10, 2018)

3. Who should receive bereavement counseling and/or bereavement services?
   - Members of the patient's family
   - Significant members of the patient/family circle of support

   Note from Medicare: *To restrict bereavement counseling to a select few would discourage hospices from providing this service, thus harming the bereaved and the larger community. Therefore, we did not insert language limiting the definition of "bereavement counseling" to immediate family members.*
   Bereavement services….would be required to be made available to individuals identified in the bereavement plan of care up to one year following the death of the patient, and would reflect the needs of those individuals. When appropriate, residents and staff of a SNF/NF, ICF/ MR, or other facility would be offered bereavement services.
   How good are you as an organization at including all significant members of the person's circle of support in your bereavement services? We are there to meet the needs of the "bereaved" and maybe we don't work hard enough to see who we need to include? Here is a really good article about circles of support as they relate to person-centered care:
   Circles of Support
   https://personcenteredplanning.com/index.php/circles-of-support/

4. Who should be providing the counseling?

   § 418.64(d*), we require that counseling services, including bereavement counseling, are provided by or under the supervision of a qualified individual* with experience in grief or loss counseling. *Some hospices may use a social worker while other hospices may choose to use chaplains or volunteers to provide this service.*

   This flexibility allows hospices to meet the needs of their patients and families in a manner that works best for their needs and resources. Therefore, we are not prescribing who may or may not furnish bereavement counseling services.

   https://www.federalregister.gov/documents/2008/06/05/08-1305/medicare-and-medicaid-programs-hospice-conditions-of-participation

5. Medicare Definition

   Bereavement counseling means emotional, psychosocial, and spiritual support and services provided before and after the death of the patient to assist with issues related to grief, loss, and adjustment

   The revised CoPs speak a lot about bereavement counseling. The comments from reviewers and responses from Medicare provide a lot of insight into where Medicare is coming from and can significantly assist us in determining how to design our programs and services. I recommend you take the time to pull up the CoPs Final Rule document and then do a search using the words "bereavement", "bereavement counseling", "comprehensive assessment", "counseling", and/or "IDG" and review the conversations that have taken place. Very helpful!

   Centers for Medicare & Medicaid – Services 42 CFR Part 418 [CMS–3844–F] RIN 0938–AH27 - Medicare and Medicaid Programs:- Hospice Conditions of Participation

   https://www.govinfo.gov/content/pkg/FR-2008-06-05/pdf/08-1305.pdf

6. What should be included in the assessment and then incorporated into the plan?

   From the State Operations Manual Appendix M - Guidance to Surveyors: Hospice

   Social, spiritual and cultural factors *that may impact a family member or other Individual's ability to cope with the patient's death would include, but not be limited to:*

   - *History of previous losses;*
   - *Family problems;*
   - *Financial concerns;*
   - *Communication issues;*
   - *Drug and alcohol abuse;*
   - *Health concerns;*
   - *Legal and financial concern;*
   - *Mental health issues;*
   - *Presence or absence of a support system; and*
   - *Feelings of despair, anger, guilt or abandonment.*

   These issues may not be readily apparent during the initial bereavement risk assessment, but should be incorporated into the hospice plan of care if they become evident, and must be considered in the bereavement plan of care.

7. Individualizing the Plan
    1. Take responsibility for teaching team members how to conduct a thorough bereavement assessment
    2. In addition to other factors, be sure to include: past losses, past coping strategies, elements present for complicated grief, multiple losses, support system, added financial strain, spiritual distress, meaning and beliefs, relationship dynamics, suicidal ideation
    3. If the forms you are using are generic (check boxes) assure the person conducting the assessment is adding narrative notes, especially for higher risk assessments
    4. Ensure that the process is dynamic
    5. Collect ongoing information in IDG meetings
    6. Enlist a team member to assess for specific dynamics during routine visits
    7. Reassess soon after the death of the patient
    8. Remember that "bereavement assessment and counseling" begins at the time of admission and is an ongoing process

    One of the biggest complaints from Medicare surveyors is that plans-of-care are not individualized. In fact, it has been the #1 deficiency for the past 3 years. They are specifically talking about the primary patient care plan but how individualized are your bereavement plans and how often do you review and update them based on new information you receive?
    MEDICARE TOP TEN HOSPICE STANDARD SURVEY DEFICIENCIES COMPARISON
    file:///C:/Users/owner/Downloads/Survey_Deficiency_Compare_2018-2020.pdf

8. Questions to consider: (guidance for surveyors and you!)
    - *How and when do you incorporate the bereavement assessment into the comprehensive assessment?*
    - *What services do you provide to reflect the needs of the family and other individuals in the bereavement plan of care?*
    - *How do you evaluate the outcomes and effectiveness of the bereavement services you provide?*

    State Operations Manual Appendix M - Guidance to Surveyors: Hospice - (Rev. 200, 02-21-20)
    https://www.cms.gov/Regulations-and-Guidance/Guidance/Manuals/Downloads/som107ap_m_hospice.pdf

9. Components of and Exceptional Bereavement Program
    - An assessment of risk/needs happens at the time of admission (or before) and bereavement counseling occurs at the time of admission (or immediately after) as needed.
    - Would we wait for days to provide pain control when someone is in serous pain? Why would it be acceptable to wait when someone is suffering?
    - All services are available at the bedside and/or virtually
    - Including support groups, education and counseling
    - Mailings are just one of many interventions
    - People can receive the information that is in a mailing via telephone or zoom calls if they prefer.

- Mailings are updated at least annually based on preferred practice and most recent research.
- Mailings are tailored to specific age groups and community diverse populations (religions/cultures, LGBTQ, etc)
- Professional and lay volunteers are included in our services to assure the diversity of needs are met.
- Relationships are developed with community resource organizations to assist in connecting the bereaved with the services they need.
- Plans-of-care are clearly individualized, outdated regular and guide the services provided

Remember…this is my list. These are the items I would want to include in an exceptional program…although I have had many conversations with bereavement professionals over the years about this and have served in the role of bereavement program director for many years. I don't want anyone to panic or feel pressured when you read through this list. Just ideas and items to put on your to-do list.

10. And…
    - Bereavement professionals services as coaches and guides for team members (including nursing assistants and volunteers) beginning at the time of admission
    - All bereavement services are based on preferred practices and the most recent research available
    - Bereavement professionals are clear about common "grief and loss" misperceptions and provide ongoing education to staff and volunteers
    - Bereavement professionals are included in a significant way in staff and volunteer training and ongoing education

11. Risk Assessments and COVID-19

    Consider:
    - A strong social support network is an indicator of lower risk
    - Focusing on physical health promotes lower levels of risk (alcohol sales are at an all-time high right now)
    - experiencing multiple losses is an indicator of higher levels of risk
    - Depression, suicide risk and self-harm risks increase for the general population
    - Remember: someone might be considered low risk at the time of admission or death, but the added complications of COVID-19 dynamics can likely increase risk over time
    - Should we question any assessment that says a person is "low risk" during these times?
    - Is this a good time for you to be doing some staff training?

    Here is an excellent resource: Managing Bereavement around the Coronavirus (COVID-19)
    https://complicatedgrief.columbia.edu/wp-content/uploads/2020/04/Managing-Bereavement-Around-COVID-19-HSPH.pdf

12. Matching bereavement services to risk levels
    - A one size fits all approach can never be acceptable
    - Mailings alone are never an adequate intervention for people who are at medium to high risk
    - Be clear about how you approach suicidal ideation for people receiving your bereavement services
    - Bereavement counseling is required under the Medicare CoPs. How are you providing counseling to people who are high risk both before and after the patient's death?
    - Are you referring to another program's bereavement services?
    - Are you referring to community counselors instead of providing counseling?
    - One way to increase the services you provide is through the use of volunteers.

    While this article focuses on risk assessment in the hospital setting, there is a lot of excellent information about risk assessments here.
    Implementing a Bereavement Risk Assessment Tool in a Hospital Setting
    https://kuscholarworks.ku.edu/bitstream/handle/1808/27575/Parker_ku_0099D_15783_DATA_1.pdf?sequence=1
    And take a look at this one: Bereavement Risk
    https://nebula.wsimg.com/45620df4a7e9a9af5b70f108e0453ce3?AccessKeyId=1FFFFAA9A26D840005C3&disposition=0

13. Volunteers and Virtual Services in Bereavement
    - Bereavement services – support and assessment calls
    - Life skills for the bereaved
    - Virtual calls to teach basic skills such as check book balancing, cooking, shopping, etc
    - Professional volunteer calls (some examples are)
    - Bereavement counseling
    - Patient/family bereavement counseling prior to death
    - Family meetings – before/after death
    - Calls from psychologists/psychiatrists per plan-of-care
    - Conferencing calling support groups
    - Bereavement support groups
    - Bereavement education groups
    - Patients – bereavement support

14. And…
    - Social isolation connection calls
    - "Would this be a good time to chat for a few minutes?" letting people know we are available
    - Spiritual support "prayer calls"
    - Prayers that are compatible with patient/family beliefs
    - Guided meditation calls
    - Sit together in silence and then talk about thoughts/feelings
    - Plan-of-care update calls
    - Calls instead of mailings – support and education

17. From the World Health Organization (WHO):
    Mental Health and Psychosocial Considerations During the COVID-19 Outbreak (2020)
    https://www.who.int/docs/default-source/coronaviruse/mental-health-considerations.pdf

Additional Information and Resources

Core Services – CoP Final Rule

Bereavement counseling. The hospice must:

(i) Have an organized program for the provision of bereavement services furnished under the supervision of a qualified professional with experience or education in grief or loss counseling.

(ii) Make bereavement services available to the family and other individuals in the bereavement plan of care up to 1 year following the death of the patient. Bereavement counseling also extends to residents of a SNF/NF or ICF/MR when appropriate and identified in the bereavement plan of care.

(iii) Ensure that bereavement services reflect the needs of the bereaved.

(iv) Develop a bereavement plan of care that notes the kind of bereavement services to be offered and the frequency of service delivery.

418.64(d) Counseling services: Counseling services for adjustment to death and dying must be available to both the patient and the family. Counseling services must include but are not limited to the following:

418.64(d)(1)(i) Bereavement counseling. The hospice must: Have an organized program for the provision of bereavement services furnished under the supervision of a qualified professional with experience in grief/loss counseling.

418.64(d)(1)(ii) Make bereavement services available to the family and other individuals in the bereavement plan of care up to one year following the death of the patient. Bereavement counseling also extends to residents and employees of a SNF/NF, ICF/MR, or other facility when appropriate and identified in the bereavement plan of care

418.64(d)(1)(iv) Develop a bereavement plan of care that notes the kind of bereavement services to be provided and the frequency of service delivery. A special coverage provision for bereavement counseling is specified in § 418.204(c).

Final Rule CoPs: https://www.govinfo.gov/content/pkg/FR-2008-06-05/pdf/08-1305.pdf

Distance/Virtual Options for Bereavement Volunteers

- Bereavement services – support and assessment calls
- Life skills for the bereaved
    - Virtual calls to teach basic skills such as check book balancing, cooking, shopping, etc
- Professional volunteer calls (some examples are)
    - Bereavement counseling
    - Patient/family bereavement counseling prior to death
    - Family meetings – before/after death
    - Calls from psychologists/psychiatrists per plan-of-care
- Conferencing calling support groups
    - Bereavement support groups
    - Bereavement education groups
    - Patients – bereavement support
- Social isolation connection calls
    - "Would this be a good time to chat for a few minutes?" letting people know we are available
- Spiritual support "prayer calls"
    - Prayers that are compatible with patient/family beliefs
    - Guided meditation calls
    - Sit together in silence and then talk about thoughts/feelings

Bereavement Risk Assessment

<u>Low to Average</u>:

- Able to verbalize grief
- Able to verbalize and demonstrate coping strategies that make use of both inner resources and external sources of support
- Perceived adequate social support and coping and some of the following may still apply:
    - Sleep disruptions
    - Lack of energy
    - Feeling lethargic or apathetic about activities of daily living
    - Changes in appetite
    - Withdrawing from normal/usual social interactions and relationships
    - Difficulty concentrating
    - Questioning spiritual or religious beliefs
    - Feelings of sadness, anger, guilt, emptiness, etc. and still experiencing moments of joy/happiness at times

Moderate:

- Ambivalence and/or verbalizing a "disconnect" with feelings
- Feeling "numb"
- Alcohol use (not excessive at this point)
- Suicidal ideation without a plan or specific intent (lower risk)
- Lack of social support or disconnected from support due to lengthy caregiving situation
- Disruption of activities of daily living
- Aspects of high risk but with higher level of coping displayed

High Risk for Complicated Bereavement:

- Suicidal ideation with plan
- Signs of caregiver PTSD
- History of drug/alcohol abuse
- Excessive feelings of guilt or despair
- Poor coping skills
- Relationship with the person who has died that was angry or overly dependent
- Mental health challenges such as a mental health diagnosis and/or a family history of mental illness
- Strong pessimistic view of the world
- Ruminative coping (a pattern of excessively focusing on one's symptoms of distress)
- Challenging, difficult or problematic family dynamics
- Cumulative multiple losses, particularly if losses are very recent (Note: losses may include pet, job, divorce, etc.)
- Concurrent life crisis
- Financial problems, family discord
- Poor physical health
- Perceived or actual lack of social support; isolation

Bereavement Program Assessment/Checklist

Instructions: Read each statement and give yourself a rating of
A = Yes, definitely, almost always
B = Sometimes yes
C = Not sure about this one
D = We Could be better at this

Make notes for improvement in the right-hand column.

When completing this exercise first consider the following:
Brief definition: "Bereavement counseling means emotional, psychosocial, and spiritual support and services provided before and after the death of the patient to assist with issues related to grief, loss, and adjustment."

Assessment Statement	RATING	Thoughts
We are fully aware of our organization's policies and procedures, our state's hospice regulations, and standards established by healthcare/hospice accrediting organizations such as JCAHO and CHAPS, etc. regarding bereavement services.		
We are clear that the provision of bereavement services is a Medicare requirement and that bereavement counseling is part of the hospice's bundled daily payment rate.		
We provide bereavement counseling and support for up to one year following the death of the person who was ill as required by Medicare.		
In addition to services such as mailings, telephone calls and support groups, we also provide counseling as required.		
We conduct a dynamic bereavement assessment that is completed within five days of the completion of the hospice election statement and certification form		
The bereavement risk assessment is updated as frequently as the comprehensive assessment: no less frequently than every 14 days and at the time of each recertification.		
Our bereavement risk assessments include information related to:		

• History of previous losses; • Family problems; • Financial concerns; • Communication issues; • Drug and alcohol abuse; • Health concerns; • Legal and financial concern; • Mental health issues; • Presence or absence of a support system; and • Feelings of despair, anger, guilt or abandonment.		
Our bereavement plans are comprehensive, dynamic and individualized.		
Based on the bereavement risk assessment, we determine when a person is high, medium or low risk. We then tailor the plan to the specific level of risk. People in the medium and high risk categories receive interventions that are appropriate for that risk level according to professional standards and national best practices.		
We provide bereavement counseling both before and after the patient's death.		
We offer bereavement counseling and services to staff members of SNF/NF and/or ICF/MR facilities following each death. A statement to this effect is included in out contracts with them.		
We include all significant members of a patient's circle of support in our bereavement plans and follow-up services.		
While we know it is not required by Medicare, we have a bereavement staff member or representative included in IDG meetings.		
Our bereavement program is supervised by a qualified professional with documented experience in grief/loss		

counseling.		
Our bereavement/grief counseling is provided by one or more professionals/volunteers with documented experience in grief/loss counseling.		
We regularly evaluate the outcomes and effectiveness of our bereavement services and make changes/improvements based on those evaluations.		

References and More Resources

Shear, M Katherine. “Complicated grief treatment: the theory, practice and outcomes.” Bereavement care : for all those who help the bereaved vol. 29,3 (2010): 10-14. doi:10.1080/02682621.2010.522373

Internet Resources

The Dual Process Model of Coping with Bereavement: Rationale and Description by Margaret Stroebe, Henk Schut (First published in 2010)
http://wendyvanmieghem.com/wp-content/uploads/2012/08/dual-process-model-by-M.-Stroebe-.pdf

Cognitive Behavioral Therapy For The Death of a Loved One
By Michael Schreiner August 2015
https://evolutioncounseling.com/cognitive-behavioral-therapy-for-the-death-of-a-loved-one/

National Alliance on Mental Health (NAMI)COVID-19 Resource and Information Guide
https://www.nami.org/getattachment/About-NAMI/NAMI-News/2020/NAMI-Updates-on-the-Coronavirus/COVID-19-Updated-Guide-1.pdf

From the World Health Organization (WHO)
Mental health and psychosocial considerations during the
COVID-19 outbreak
https://www.who.int/docs/default-source/coronaviruse/mental-health-considerations.pdf

From the Centers for Disease Control (CDC)
Stress and Coping Related to COVID-19
https://www.cdc.gov/coronavirus/2019-ncov/daily-life-coping/managing-stress-anxiety.html?CDC_AA_refVal=https%3A%2F%2Fwww.cdc.gov%2Fcoronavirus%2F2019-ncov%2Fprepare%2Fmanaging-stress-anxiety.html

Online Support Groups:
Nuts and Bolts, Benefits, Limitations and Future Directions
By Juneau M. Gary & Linda Remolino
https://www.counseling.org/resources/library/Selected%20Topics/Cybercounseling/Gary-Digest-2000-07.htm

Choosing a Digital Services Platform
https://www.techsafety.org/choosing-a-platform

Medicare

Department of Health and Human Services
Centers for Medicare & Medicaid Services
42 CFR Part 418
Medicare and Medicaid Programs: Hospice
Conditions of Participation; Final Rule
https://www.govinfo.gov/content/pkg/FR-2008-06-05/pdf/08-1305.pdf

State Operations Manual Appendix M - Guidance to Surveyors: Hospice
fhttps://www.cms.gov/Regulations-and-Guidance/Guidance/Manuals/Downloads/som107ap_m_hospice.pdf

Supplemental Internet Articles

What It Means to be Focused on Quality Vs. Compliance
https://www.greenlight.guru/blog/quality-vs-compliance

Best Practices in Children's Bereavement: A Qualitative and Quantitative Analysis of Needs and Services
https://www.jpsmjournal.com/article/S0885-3924%2816%2930672-8/fulltext

American Counseling Association: Grief and Loss Resources
https://www.counseling.org/knowledge-center/mental-health-resources/grief-and-loss-resources

The Encyclopedia of Death and Dying: Grief Counseling and Therapy
http://www.deathreference.com/Gi-Ho/Grief-Counseling-and-Therapy.html

The Goals and Objectives of Mental Health Treatment Plans
https://www.icanotes.com/2018/08/24/guide-to-creating-mental-health-treatment-plans/

Why Is It Important to Have a Personalized Treatment Plan?
https://www.foundationsrecoverynetwork.com/important-personalized-treatment-plan/