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Best Practices of a Social Worker's Role in Supporting Family Caregivers Enrolled in Hospice Care

Jessie Wolf
Minnesota State University Mankato

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Jessie Wolf, LSW
 Department of Social Work
 Minnesota State University, Mankato

Agency Introduction

Mayo Clinic Health System-Mankato Hospice Department cares for patients and their families at the end of their life. The philosophy of hospice is to provide comfort and support during their particular journey. This is done by supporting the physical, emotional, and spiritual needs of the patient and family. The goal is never to hasten death. Hospice will provide supportive service in whatever setting they consider to be their home. This could be their home, nursing home, assisted living, or with family members. Occasionally, hospitalization is required to manage a patient's symptoms or transition to a new safe living arrangement. Patients can receive supportive services from their hospice social worker, chaplain, RN case manager, home health aids, volunteers, bereavement coordinator, hospice medical director, and triage nurses.

Purpose

The purpose of this project was to explore best practices are for hospice social worker's providing care to family caregivers enrolled in hospice. This project explored processes and assessment tools that other hospice agencies in rural Minnesota utilized while caring for the family members of hospice patients. The information obtained was used to provide recommendations to Mayo Clinic Health System- Mankato Hospice program to further improve the hospice programming and the social worker's role.

Literature Review

Often family caregivers consist of the client's spouse/partner and adult children. However, in some families the siblings, friends, or other relatives have also been caregivers (Wilder, Oliver, Demiris, Washington, 2008). The tasks performed by family caregivers often are medication administration, symptom management, assisting with personal cares, along with financial and legal management (Wilder et al., 2008). With all of those responsibilities family caregivers are at increased risk for depression, isolation, health problems, and an increase in mortality rates due to the added stress (McMillian et al., 2005). This demonstrates the need for hospice social workers to provide additional support to family caregivers to improve their quality of life (Wilder et al., 2008).

Methodology

This was qualitative study that explored how social workers can best serve family members who have a loved one enrolled in hospice. Unfortunately, there was limited literature available to provide guidance on how to best provide social work services with family caregivers. This study utilized a semi-structured phone interviews conducted with a 19 item instrument. By using semi-structured interviews the researcher was able to pursue and develop interview questions while maintaining the flexibility to expand on the participants responses. Interview questions focused on what processes were used to assess a family caregiver's need for resources and support. Once the need was identified questions were asked to identify process for how resource brokering occurred.

The Minnesota Department of Health (2010) has 111 hospice programs currently licensed to practice in Minnesota. The 111 programs were narrowed down to 67 by using the following criteria: programs located in rural communities; hospice programs that are licensed in Minnesota; and those that do not have access to hospice cottages. This criterion was selected as the researcher wants to select similar programs to Mayo Clinic Health System-Hospice program. One-third or 21 of these programs were selected at random to participate in this study. This random selection occurred by utilizing an Excel program assigning all eligible programs a random number, with interviews being conducted with the programs receiving the lowest numbers

Participants were selected based on the fact that they were currently employed in a hospice program located in Minnesota. After approval from Minnesota State University Mankato- IRB, interview appointments were arranged. Interviews were scheduled in advanced to increase ease in participants' schedules and participation.

Participant Demographics

Ten agreed to participate resulting in a 47.6% response rate. The other eleven agencies either did not respond or did not have a social worker. One did not have an active hospice program but were licensed by the MN DHS. Finally, during an interview with a participant it was discovered that another agency selected randomly was owned by the same cooperation. This agency was excluded from the sample.

Of the agencies who participated in this research project eight of them identified themselves as a rural agency. Only one agency had identified as being both rural and urban while one identified as urban. Nine of the participating agencies identified as a not-for profit while one identified as for-profit. Six of the agencies indicated they were not affiliated with a hospital while three were hospital affiliated and one had an affiliation with a hospital, nursing home and assisted living.

Table 1: Social Work Case Load

Agency Census per month	Number of social workers employed	Case load per social worker	Frequency of social work visits With patient & family
250-275	22- full time	25-30	<ul style="list-style-type: none"> 2/month with patient. Updates given to family after each visit.
204	7 - full time 1- Per diem 2-part time	35	<ul style="list-style-type: none"> 1/month with patient. RN primarily keeps family updated
110	4 - full time	Variable (not greater than 38)	<ul style="list-style-type: none"> 1/month with patient. Only meets with family face to face if they happen to be present at the time of visit
90-95	3 -all 32 hours per week	9-12	<ul style="list-style-type: none"> 2 to 3/month & as need with patient 1 to 2/month phone updates to family
70	7 - full time	10-15	<ul style="list-style-type: none"> 2/month & as needed with patient Meet with family when possible
50	1- full time	50	<ul style="list-style-type: none"> 1/month with patient Update per phone with family
14	1- full time	14	<ul style="list-style-type: none"> 1 to 2/month with patient. Family usually there too
10 to 15	1 - full time	10 to 15	<ul style="list-style-type: none"> 1 to 2/month & as needed Phone updates to family after each visit
10-30	1- full time	10-30	<ul style="list-style-type: none"> 1 to 4/month with patient Update per phone with family.
4	1- full time	4	<ul style="list-style-type: none"> 2/month with patient Family updates per phone or email

Implications for Practice

Caseload :

A significant challenge facing rural hospice social workers is case load size. The recommended guidelines for a full time social worker is between 20-30 patients (NHPCO, 2007) . This would average out to about 15 to 25 visits per week. Consideration needs to be made for travel time, documentation, acuity of the patient and family (NHPCO, 2007).

- Social workers working in rural agencies may have higher caseloads especially if they are the only social worker. This research study affirmed this statement
- The five participants who reported being the only social worker also had dual job responsibilities of being the bereavement and or volunteer coordinators.

Reimbursement:

Reimbursement rates are also a challenge. Medicare reimbursement tends to be the primary payor sources in rural hospice programs (Casey, Moscovice, Virnig, Durham, 2005). Medicare per diem rates are consistently lower in rural communities because rates are adjusted using a hospice wage index (Virnig et al., 2004).

- Some of those higher costs are associated with staff travel to patients' homes. It is not uncommon for a full time hospice social worker to drive as much as 1,000 miles per week (Haxton & Boelk, 2010).
- A related issue was lack of reimbursement when providing care to family members after the patient's death.
- Participants stated if a family needed the support often the agency would support the continued care. However, they would not receive compensation for support and resources used.

Data/ Results

Role of social worker:

- ❖ Participants identified their social work role in caring for hospice patients and their families as being end of life education, emotional support, assisting with resources, psychosocial assessments, and care coordination.
- ❖ Participants in smaller agencies reported that they took on multiple job responsibilities beyond their role as the social worker. Often those responsibilities and tasks were being the volunteer coordinator and bereavement coordinator.
- ❖ A participant who reported having 50 patients per month explained that she not only provided social worker support but was also the volunteer coordinator and bereavement coordinator.

Visits with Family:

- ❖ Participants were then asked if the visit is done by phone or in person. One participant stated she only did face to face visits with the family, while another participant stated they primarily did phone and email contact. Eight participants reported they did a combination of phone updates and face to face. Five of those eight stated they also would email family members updates on their visits with the patient.

Assessment:

- ❖ 70% of participants reported not having a formal assessment tool they used to assess families.
 - Often the information about the family is obtained through conversation during the patient assessment. If the family is not present the information about how the family is coping is through the lens of the client.
- ❖ 30% of participants reported that they have a bereavement assessment they do specifically for families but no other assessment tools.
 - All participants identified that the hospice team work together to provide support to the family. Support took the form of education of available hospice services, referrals to community resources, and emotional support.
 - It was evident that there is no consistent follow-up on resource brokering.

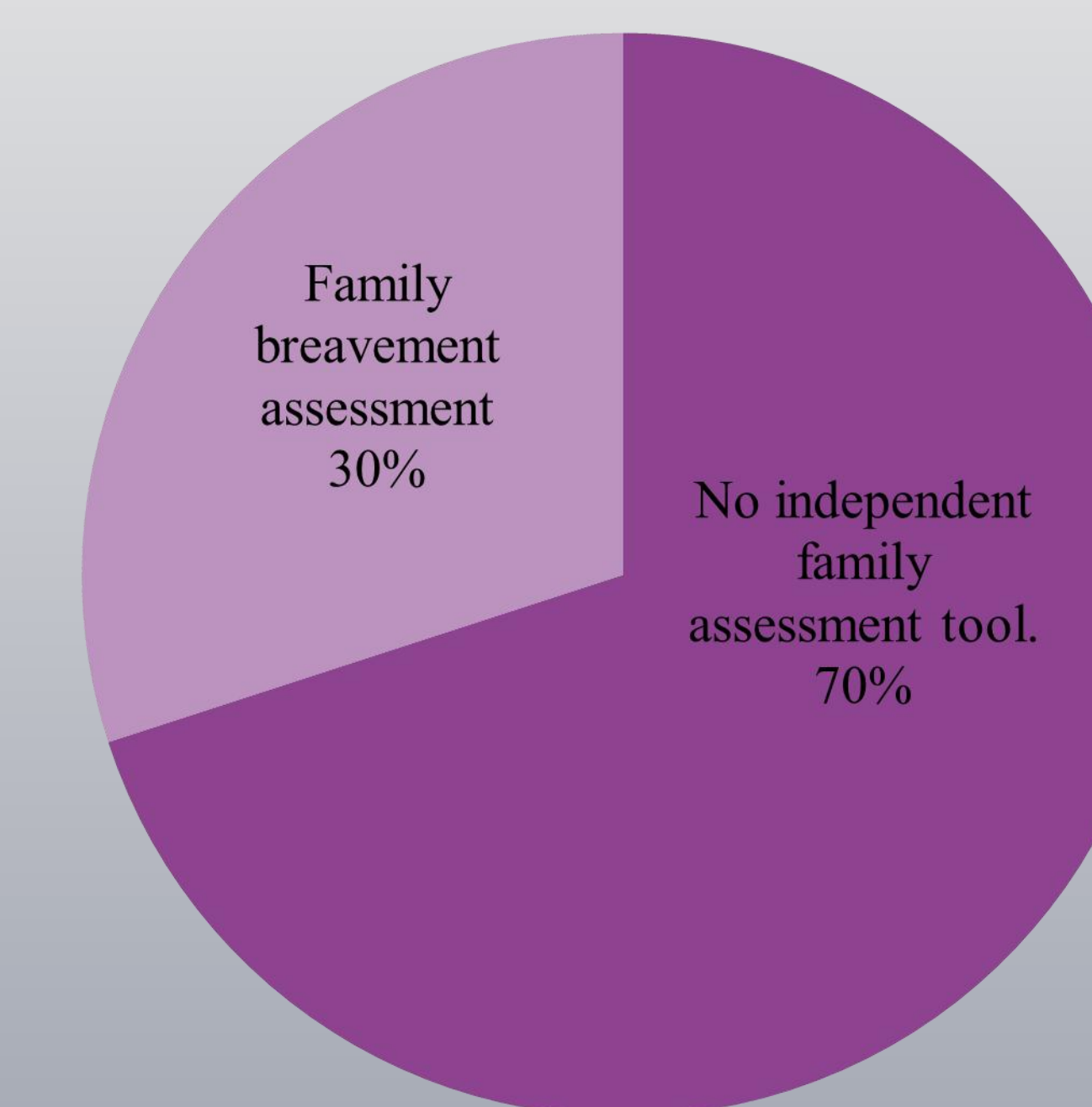
Social work involvement with the family after patient's death:

Three participants reported placing a phone call and mailing a card expressing condolences. During the phone call an introduction to bereavement services is made by the social worker. Four participants reported they are both the social worker and bereavement coordinator. They too provide information mailings, phone calls and attend patient visitation/funeral. One agency stated the chaplain takes over after the death and social work is no longer involved. One agency the social worker and chaplain shared the responsibilities.

Reimbursement:

- ❖ A common theme expressed by the participants of this study is frustration with reimbursement.
 - Medicare/insurance reimbursement rates are per diem basis no matter the acuity of care
 - Once patient dies Medicare/ insurance payments cease regardless of family caregiver's continued need for support

Figure 1: Family Assessment Tools



Recommendations

Hospice social workers currently have limited information on best practices in caring for family caregivers involved in hospice. As a result, there has not been formalized assessment tool or check list developed to assess the needs of the family. Often the family assessment is done informally through conversation during the patient assessment. The needs of the family may be different from what the patient perceives the needs to be. The family may not know what information to provide the social worker in order to receive the most comprehensive support available to them. Utilizing a formalized family assessment tool will provide a framework to enable social worker to thoroughly assess and engage the family caregivers.

The Mayo Clinic Health Systems-Hospice social workers should continue this research to develop their own formalized assessment tool which focuses on the family. If the tool is successful then disseminating the information with other hospice organizations to adopt into their programs.

