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Understanding and Managing End of Life Symptoms: A teaching guide for the primary caregiver

By

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Supervised by Dr. Christine Nelson-Tuttle

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Abstract

The goal of hospice is to support patients and the family or friend who has taken on the role of the caregiver. The majority of care provided in the home to the ill patient is provided by informal caregivers with limited experience. Emotional and physical strain can cause caregiver breakdown even to the most capable caregiver. Caregivers become over whelmed and panic when they are expected to monitor, interpret, and make decisions, in providing direct care.

There are tremendous expectations of the caregiver in the home setting. The home healthcare hospice nurse should provide teaching materials and information to support the patient and caregiver in formulating decisions related to symptom control, which affects quality of life.

Through surveying hospice nurses and receiving expert opinions, a caregiver symptom guide and daily symptom diary has been developed. The symptom guide focuses on the most problematic symptoms frequently experienced by hospice patients: pain, fatigue, breathlessness, cough, congestion, anxiety, agitation, delirium, anorexia, nausea, and constipation.

Keywords: hospice, caregiver, symptoms, pain, knowledge
Understanding and Managing End of Life Symptoms: A teaching guide for the primary caregiver.

Introduction

Home is where family and friends care for their loved ones. As the population ages, older people will require care in the home. By the year 2020, 23% of the North America’s population will be 60 years or older. (Stoltz, 2004) In 2010, an estimated 1.3 million American’s age 65 years and older with life-limiting illnesses received hospice services, with approximately 40% of them cared for in private residences. (Lau, 2012). The hospice nurse makes home visits, but the informal caregivers, family and friends, provide most of the direct patient care. Hospice nurses are the primary source of information and play a significant role in educating and supporting caregivers in the home. However evidence shows that only 59% of home hospice patients receive education in medication and symptom management. (Masin-Peters, 2010). The importance of relationship building between the hospice provider and caregiver is crucial in developing trust and confidence with each other to facilitate learning. Currently there are no national clinical standards detailing the hospice nurses role in assisting caregivers with multiple responsibilities associated with medication and symptom management. The National Patient Safety Goals for home and hospice care, developed by the Joint Commission (NPSGS, 2013) state that hospice providers should explain all prescription medications to the patient and/or family at the time of enrollment but provide little guidance on the method or content of the explanation of the medication. (NPSGS, 2013) There is no direction related to symptom management education. Practice standards in medication and symptom management are left to the judgement of the hospice nurse.
The Caregivers Perceptions

Caregivers report feeling inadequate and unprepared for approaching symptoms that will occur in the dying patient. Evidence indicates that caregivers are more competent when they have formal support. Providing support for a loved one at the end of life can be a satisfying experience when caregivers have the necessary knowledge. Lounderback (2000) found that caregivers reported pride in their abilities to meet a challenge, an increased sense of self worth, a greater closeness to their loved one, and an enhanced sense of meaning, and pleasure in their role as a caregiver when provided education related to symptom management. Caregivers frequently express feelings of inadequacy and quilt when attempting to care for their loved ones. These feelings lessened when they were provided the knowledge required to care for their loved one.

The purpose of developing the Understanding and Managing End of Life Symptoms teaching guide is to provide the caregiver and patient a resource to guide them in symptom management.

Results from surveying nurses

The Nursing Perceptions of Hospice Caregivers Symptom Management Knowledge Level survey was provided to 19 hospice nurses who are employed by a not for profit home care agency providing home hospice care in Rochester, New York. The hospice nurses were asked 6 questions related to caregiver knowledge and asked to rank 12 end of life symptoms. The twelve symptoms were determined based on common symptom clusters that occur at the end of life. Esper (2005) noted combinations of symptoms occurring in relation to each other can have a detrimental effect on overall patient outcome and may often be synergistic to one another. Limited research has been conducted to define which symptoms occur within clusters.

The data validated that home hospice nurses believed that caregivers would be receptive to learning. The hospice nurses survey indicated that more educational materials are needed
within the first 48 hours of a patient being enrolled in the hospice program. The data confirmed that 89% of the nurses believed caregivers do not feel confident in managing the symptoms of their loved one and 100% of the nurses have witnessed caregivers becoming overwhelmed because of poorly controlled symptoms. Seventy-nine percent of the nurses felt additional educational material needed to be provided in the home. The hospice nurses ranked end of life symptoms most likely to be poorly controlled during the first 2 weeks on hospice services. Fifty-seven percent of the hospice nurses ranked pain as the highest symptom poorly controlled. Thirty-seven percent of the hospice nurses ranked confusion as the second most common symptom observed. Six out of the 19 hospice nurses placed agitation, anxiety, and cough as the third most common symptom. The ranking of end of life symptoms along with caregiver perceptions validated the need to provide a teaching guide related to symptom management.

The development of the teaching guide

When developing the "Understanding and Managing End of Life Symptoms teaching guide", a review of the adult learning theories was necessary. Adult learners are independent, self-directing, have various experience, integrate learning into everyday, are interested in immediate problem centered approaches and are motivated. (Abela, 2009). Adult learners require the mutual respect of the teacher and need to be viewed as equal. Motivation is another important aspect of adult learning. The teacher is the motivator and needs to evaluate what the learner needs in order to progress forward. Goddu(2012) offers an interesting skill teaching concept:

**Overview:** introduction to why the skill is needed and it’s relevance in the area of concern.

**Demonstration without comment:** allows the learner to observe the skill or listen to the content.
**Demonstration with comment:** allows the breakdown of the information or skill into manageable portions with the learner asking questions.

**Verbalization:** the learner talks through the skill or content with the teacher.

**Practice:** the learner executes the skill.

The adult learner requires encouragement and praise after each step from the teacher.

The educational cycle requires assessing the needs of the learner, setting educational objectives, choosing and using a variety of methods, and assess if learning has occurred.

In developing the teaching guide, the concepts of adult learning theory were used as a basis for establishing guidelines for teaching in the home.

### Guidelines for home teaching

| Establish trust                          | Emphasize the role of the nurse and working together. Verbalize you care.  
|                                       | Explain the 24/7 triage center, provide phone numbers.  
|                                       | Treat the caregiver as a team member, ask for their opinion, and ask if they agree with the plan.  
|                                       | Establish trust by listening and addressing all concerns each visit.  
|                                       | Build a rapport; review each visit, the issues addressed. |
| Provide information                    | Provide teaching materials at first visit, begin teaching.  
|                                       | Provide instruction verbally, in written form, or demonstration.  
|                                       | Use simple terms and repeat information.  
|                                       | Explain the importance of the information provided.  
|                                       | Prepare caregiver for the future events that may or may not happen.  
|                                       | Assess the caregiver ability to learn and at what level.  
|                                       | Re-emphasize the care givers role and responsibilities during teaching. |
| Promote self confidence                | Provide encouragement and praise.  
|                                       | Have caregiver demonstrate skills.  
|                                       | Remind caregiver of their success; don’t focus on errors, up lift the caregiver.  
| Offer instruction/relief               | Teach symptom management |
The teaching guide

The teaching guide focuses on 4 categories of symptoms. Pain, fatigue, and breathlessness. Cough and congestion. Anxiety, agitation, and delirium. Anorexia, nausea/vomiting, and constipation. The teaching guide describes characteristics of each symptom, additional symptoms found at the end of life, and the purpose of common medications used in hospice care. The teaching guide provides information to the caregiver on techniques to use when assessing the patient. The teaching guide contains a 31 day to day symptom diary to be used to document symptoms. The caregiver can review questions with the patient to assist in determining the frequency of the symptoms. The hospice nurse would then review the symptom diary each visit. The following plan was recommended as the teaching guide schedule to optimize learning opportunities without overwhelming the caregivers.

Day 1 The teaching materials will be provided to the caregiver/patient at the initial hospice opening. The hospice nurse will instruct the caregiver/patient to review the material over the next 24-48 hours.

Day 3 A hospice nurse will visit the patient and caregiver to provide instruction on how to use the teaching guideline. The hospice nurse will provide symptom teaching, review medications, demonstrate techniques, and answer questions. The hospice nurse should expect the
caregiver/patient to be able to provide feedback indicating they are increasing their knowledge base. The hospice nurse needs to listen, address all caregiver concerns, and review the hospice nurses role.

Day 6 The hospice nurse will reinforce teaching and answer questions while reviewing the symptom diary. The hospice nurse will focus on current symptoms the patient has experienced and how to manage those symptoms. Addressing all of the caregiver concerns.

Day 10 The hospice nurse will review the symptom diary, reinforce teaching materials, answer questions, and address all of the caregiver concerns and review the plan for the patient.

Day 14 The hospice nurse will continue to provide teaching related to ongoing and new symptoms the patient experiences. Caregiver teaching will continue throughout the patients time on hospice.

Reevaluation, reinforcement, and encouragement are key factors in the caregivers ability to learn and have success in symptom management of the patient on hospice. The responsibility lies with the home care hospice nurse to provide the educational tools and teaching to the caregiver. The teaching guide can be a useful tool that the hospice nurse can provide to the caregiver.

Expert Review

The teaching guide was reviewed by three experts in hospice care. Each of them have 20 years or greater experience in the field. One of the experts is a hospice nurse educator. The experts were provided a likert scale to describe their opinions on the teaching guide. They all strongly agreed the guide is easy to read, communicates concepts and ideas clearly, is well organized and will be easy to follow for the caregiver. The experts felt the guide has longevity, can be customized for the patient and is strongly worthwhile. One of the hospice experts felt the
teaching guide would benefit newly hired hospice nurses and the content will enhance the caregivers knowledge. The hospice experts thought the day to day diary would not only assist the caregiver but provide accurate data for the nurse since often the caregiver and patient can only recall the current days issues. The day to day diary will enable the hospice nurse a more accurate idea of what symptoms and issues are occurring. The hospice experts stressed the teaching guide will only be effective if the nurse spends time with the caregiver teaching effectively. Overall the feedback concerning the teaching guide was positive.

**Conclusion**

Significant gaps exist in caregiver knowledge related to care and symptom management of patients near the end of their lives. One of the most important goals of the hospice nurse and caregiver is to decrease the suffering through symptom control. Symptoms can be managed in the home when caregivers are provided tools to improve their knowledge base. There are many complex issues a caregiver faces when agreeing to care for their loved one in the home. The caregiver is dealing with physical, psychosocial, and emotional issues for themselves and the dying patient. Obtaining the knowledge they require to care for their loved one can be overwhelming and challenging. The Understanding and Managing End of Life Symptoms teaching guide allows the hospice nurse the ability to teach the caregiver the basic knowledge to combat end of life symptoms in the home and improve the quality of life for the dying patient.
References


