Nursing in Hospice and Terminal Care:

Research and Practice

Barbara Petrosino

ROUTLEDGE

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CONTENTS

National Hospice Organization

The National Hospice Organization was created to promote and maintain quality care for the terminally ill and their families. Formally established in 1978, NHO is an independent, non-profit, membership association devoted exclusively to hospice.

Nursing in Hospice and Terminal Care: Research and Practice

Introduction

In the past decade, health professionals have begun to carve a concept known as "hospice" out of health care. Hospice nursing in the United States can be considered to be in the neonatal stage of development, not really knowing that it is, *what* it is or even *if* it is a separate entity, much as the newborn infant. The research base for hospice nursing practice is even less developed (perhaps in the fetal stage). This special issue provides one effort in the long arduous developmental process. The first article identifies the components of hospice nursing and poses varied research questions to stimulate the evolution of each. The other articles make a contribution to the knowledge base of specific aspects of hospice nursing and provide the foundation for expanded research efforts.

Enhancing the quality of life of terminally ill persons has been identified as the primary *raison d'être* for the hospice movement. In her article, Martocchio explores the various meanings associated with quality of life such as death with dignity, healthy dying, and comfort care in terminal illness. She proposes that there are various patient agendas for enhancing one's quality of life and encourages our efforts to identify them.

The quality of life issue from the perspective of family caregivers and their perceptions of helpful nursing behaviors is addressed by McGinnis. She investigates ways to increase the effectiveness of terminal nursing care by looking at behaviors related to both the client's physical and psychosocial needs as well as the caregiver's psychosocial needs.

An examination of where and how nurses function in the hospice setting is presented by Burns and Carney. They describe the role of the nurse at various stages of hospice care. This study provides a basis for program design and for planning inservice education.

The problem of stress among hospice personnel has been given extensive attention in the recent literature. Vachon, a pioneer in this area of research, explores the myths and realities of stress in hospice settings and shoots down some of the "sacred cows" which lack scientific basis. This approach could encourage other researchers to

consider her framework for exploring myths and realities of symptom management and nursing interventions used in hospice care.

Hospice nursing care requires careful attention to the symptoms that patients develop in their terminal stage. Daeffler offers a thorough nursing care plan for dealing with the specific problems related to oral care of patients who are terminally ill. Hospice nurse researchers could explore other aspects of palliative care in a similar way in order to refine nursing practice in the hospice setting.

A rational and systematic process of assessment must precede meaningful interventions in all aspects of hospice care. Hymovich provides a framework for systematically assessing the needs of children and families and for providing interventions appropriate to the unique needs of each family with a terminally ill child.

The role of the family as caregivers is an essential focus of patient/family centered care. Kirschling presents her data to promote an understanding of the caregiving experiences of families with a terminally ill member.

Review of this collection of articles against the American Nurses' Association's definition of nursing, as expressed in their Social Policy Statement, is suggested. The focus of nursing is defined as "human responses to actual or potential health problems" (ANA. 1980, p. 9). Can this definition act as a framework for the development of hospice nursing? The answer to this question may help to clarify the identity of hospice nurses within the profession. Or, it may help to illuminate the weaknesses of the definition.

In order to build a scientific base for hospice nursing practice, the range of human responses to terminal illnesses must be explored and described. Testing the effectiveness of clinical nursing interventions intended to support positive human responses and those designed to alleviate problematic responses has to be carried out. Nurses in hospice care are being given these challenges. It is suggested that with each step of meeting the challenge, hospice nursing will make forward movement in its development toward maturity.

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Guest Editor

REFERENCE

ANA. (1980). "Nursing: A Social Policy Statement". Kansas City, MO. American Nurse's Association.

Research Challenges in Hospice Nursing

Barbara M. Petrosino

ABSTRACT. This article proposes that there are six major components of hospice nursing; individualization of care, availability of the nurse, patient-family control, anticipatory care, symptom control, rapid, effective nursing involvement, and interdisciplinary interactions. Each component is explored and a variety of research questions are posed in an attempt to identify the basis for the practice of hospice nursing.

Hospice Nursing in 1986 is alive and well. Many of the organizational and financial obstacles that faced hospices over the last ten years have begun to clear. Thus, hospice nurses can focus their entire energies on delivering care in a creative and thorough manner. The development of quality hospice care will depend on the refinement of its essential components. It is within this framework that it will, perhaps, be possible to address the often asked question, "Is hospice nursing different?" At this time the question is premature, perhaps even unimportant. Rather, the question should be, "How can we refine the components of hospice nursing and thus improve the quality of nursing care?"

The major components of hospice care have been highlighted in the literature as well as in discussion of hospice nursing practice (Baird, 1980; Blues & Zerwekh, 1984; Buckingham, 1980; Cohen, 1979). While they are subject to further clarification, for the purposes of this paper, the essential components of hospice nursing are identified as:

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—individualization of care
—availability of the nurse
—patient-family control
—anticipatory care
—symptom control
—rapid, effective nursing involvement
—interdisciplinary interactions

The components could be treated from a more philosophical or conceptual approach. However, this discussion focuses on each component from the practical perspective of nursing interventions.

The vehicle for refining these and/or other components of hospice nursing care is research. In some instances, high quality descriptive investigations are needed to identify such things as the specific characteristics of hospice patients' and families' needs, the nursing approaches that are being used, and the clinical experiences of nurses. In other instances, instruments need to be designed and tested, particular interventions need to be validated for use with hospice patients, and different approaches need to be measured and compared to determine the circumstances under which patient outcomes vary. There is a need for both qualitative and quantitative research efforts.

In the remainder of this article the essential components of hospice nursing are discussed briefly, and problem areas and research questions are posed for each. The intent is to stimulate thinking, discussion and research efforts.

INDIVIDUALIZATION OF CARE

The hospice nurse works with the patient and family to design a plan of nursing care that is distinctive for the patient and that fits his or her preferences and needs. This plan and its implementation is molded and altered primarily around the patient's values, characteristics and environment. There is less pressure to give emphasis to peripheral or external factors (e.g., institutional policies and routines) because the patient and the family are the central focus of attention.

Both published and unpublished testimonial-type case study examples indicate that individualized care is attempted, but there is little systematic research that has investigated the concept of in-

dividualized care and how it is achieved (Ajamian & Mount, 1981; Keaney, Hockley, & Morrison, 1982). For example, what does individualized care mean to patients? to families? to nurses? Do unbiased samples of patients find their nursing care adequately individualized to meet their needs? *How* do hospice nurses individualize care? What nursing needs are most or least likely to be adequately addressed in an individualized way? What nursing needs *require* an individualized approach for them to be effectively alleviated? With an increased data base about individualization of care, this rather abstract, but important, component of hospice care can be further refined and operationalized.

AVAILABILITY OF THE NURSE

Hospice nurses are expected to respond to the needs of patients and families as the needs occur. The nurse's availability to respond is intended to be a means for enhancing the sense of security of patients and families. In order for nurses to be sufficiently flexible to accommodate changes in the patient's situation, hospice nurses require control over the use of their time.

As the primary professional caregiver, the nurse determines the need for care at each interaction and remains with the patient for whatever time period is appropriate. The nurse also decides how time with the patient will be spent. The lack of institutional schedules and most other external time restrictions permits the nurse to focus on the patient's needs. The patient's and family's confidence in the availability of the nurse is intended to decrease their feelings of stress.

The availability of the hospice nurse from the perspectives of patients and families and nurses has received little investigation. How do hospice nurses use their time with patients? How do hospice nurses decide when and how they will be available to patients and families for particular nursing needs (e.g., physical care, teaching, listening)? Do the patient's and family's perceptions of the availability of the nurse influence their feelings of security and their ability to cope? Is there a relationship between the amount of time the nurse spends with the patient and family and their resolution of grief? Is there a "critical period" when availability of the nurse has a significant influence on coping and grief resolution? Does control over use of time influence the nurse's self-concept and her ability to cope with patient care demands?