Current practice in oncologic nursing

Peterson · Kellogg

Mosby's Current Practice and Perspectives in Nursing Series

VOLUME ONE

Current practice in oncologic nursing

Edited by

BARBARA HOLZ PETERSON, R.N., M.S.N.

Nurse Practitioner, Ambulatory Care,
Veterans Administration Hospital,
Seattle, Washington

CAROLYN JO KELLOGG, R.N., M.S.

Academic Counselor,
University of Washington School of Nursing,
Seattle, Washington

The C. V. Mosby Company

Saint Louis 1976

Printed in the United States of America

Distributed in Great Britain by Henry Kimpton, London

Library of Congress Cataloging in Publication Data

Main entry under title:

Current practice in oncologic nursing.

Bibliography: p.
Includes index.
1. Cancer nursing. I. Peterson, Barbara Holz, 1941- II. Kellogg, Carolyn Jo, 1946-
[DNLM: 1. Neoplasms—Nursing. WY156976]
RC266.C87 610.73'6 75-31734
ISBN 0-8016-3791-0

VH/VH/VH 9 8 7 6 5 4 3 2 1

Current practice in oncologic nursing

Contributors

JUDITH ATWOOD, R.N., M.N.
Clinical Nurse Specialist, I.C.U./C.C.U., Harborview Medical Center,
Seattle, Washington

PATRICIA BLESSING, B.S.
Madison Public School Hospital Teacher, University of Wisconsin Hospitals,
Madison, Wisconsin

MICHAEL CHOUINARD, M.D.
Assistant Professor, Department of Medicine, Section of Hematology/Oncology,
St. Louis University, St. Louis, Missouri

CONSTANCE MARY CLARK, R.N., M.S.N.
Clinical Nurse Specialist, Neurosurgery and Urology, St. Joseph Mercy Hospital,
Ann Arbor, Michigan

JOSEPHINE KELLY CRAYTOR, R.N., M.S.
Associate Professor of Nursing and Associate Director for Oncology Nursing,
University of Rochester Cancer Center,
Rochester, New York

CAROL L. CROFT, R.N., B.S.N.
Staff Nurse, Tumor Institute, Swedish Hospital Medical Center,
Seattle, Washington

JOYCE ANN HARLEY DOAN, R.N., B.S.N.
Clinical Coordinator, Cancer Lifeline, Inc., Seattle, Washington

MARYLIN JANE DODD, R.N., M.N.
Instructor, University of Washington School of Nursing,
Seattle, Washington

GEORGE J. HILL, II, M.D.
Professor of Surgery, Department of Surgery, Washington University–Barnes Hospital, St. Louis, Missouri

JEANETTE KOWALSKI, R.N., M.S.N.
Instructor, St. Louis University School of Nursing and Allied Health Professions, St. Louis, Missouri

CAROLYN A. LIVINGSTON, R.N., M.N.
Instructor, University of Washington School of Nursing, Seattle, Washington

VICKI ELIZABETH LONG
Senior Nursing Student, University of Washington School of Nursing, Seattle, Washington

CYNTHIA ALLISON MANTZ, R.N.
Nurse Oncologist, Department of Surgery, Washington University–Barnes Hospital, St. Louis, Missouri

P. M. MacELVEEN, Ph.D.
Assistant Professor, Department of Psychosocial Nursing, University of Washington School of Nursing, Seattle, Washington

JANET ALMETER McNALLY, R.N., M.S.
Nurse Clinician, Research Project, Strong Memorial Hospital, Rochester, New York

MARGARET LAWLEY MORSE, R.N., M.S.
Clinical Nursing Specialist, Pediatric Hematology-Oncology, Riley Hospital for Children, Indiana University Medical Center, Indianapolis, Indiana

PEGGY JUNE NASLUND NELSON, R.N.
Nurse Oncologist, Department of Surgery, Washington University–Barnes Hospital, St. Louis, Missouri

MAUREEN B. NILAND, R.N., M.S.
Assistant Professor, University of Washington School of Nursing, Seattle, Washington

ANN ELISABETH PAULEN, R.N., M.S., F.A.A.N.
Clinical Nurse Specialist–Assistant Clinical Professor, University of Wisconsin Center for Health Sciences, Madison, Wisconsin

DOLLY K. REINER, R.N., M.N.
Psychotherapist, private practice, New York, New York

ANNIE STOKES SAKAGUCHI, R.N., M.N.
Head Nurse Clinician, Breast Cancer Detection Center,
Virginia Mason Medical Center,
Seattle, Washington

SAUNDRA ELAINE SAUNDERS, R.N., M.S.N., M.S.Ed.
Clinical Nurse Specialist in Gynecology–Clinical Instructor,
University of Wisconsin Center for Health Sciences,
Madison, Wisconsin

ANNETTE R. TEALEY, R.N., M.S.
Clinical Nurse Specialist in Radiotherapy, University of
Wisconsin Center for Health Sciences,
Madison, Wisconsin

KATHLEEN M. THANEY, R.N., M.S.
Nurse Clinician, Radiation Oncology, University of Rochester Cancer Center,
Rochester, New York

MARGIE J. VAN METER, R.N., M.S.
Clinical Nursing Specialist in Neurosurgery, University Hospital,
Ann Arbor, Michigan

ELISE T. WEAR, R.N., M.S.
Clinical Nursing Specialist in Pediatric Hematology-Oncology,
University of Wisconsin Center for Health Sciences,
Madison, Wisconsin

SUSAN LYNN ZIMMERMAN, R.N., M.S.N.
Clinical Nurse Specialist, University Hospital, Seattle, Washington

To our children

Kirstin and Drew

Preface

Recent developments in cancer research have greatly revolutionized the care of the cancer patient, and nurses have been intimately involved in the coordination and delivery of this care. This book was designed with the cancer nursing specialist in mind but is also meant to update others who are involved with patients who have or had cancer as part of their diagnosis. Its purpose is to present the many roles nurses fulfill and the significant contributions they make from the detection clinic to terminal care at home.

In many cases the diagnosis of cancer no longer requires the totally pessimistic attitude often expressed by physicians, nurses, and the society in which we live. "Cures" in cancer are being made, life is being extended, and the disorganized cellular growth is being controlled. New approaches to treatment and an increased emphasis on finding efficient and effective detection methods have aided in this control. Communication with the general public to increase awareness and dispel fears has also contributed greatly.

Five broad categories are covered: (1) professional awareness, (2) screening and early detection, (3) therapy, (4) maximizing the quality of life, and (5) rehabilitation.

The theme throughout is on the nursing process, with pertinent assessment tools preceding the chapters to which they specifically apply. An additional focus is on openness in communication. New approaches to this are presented, such as contracting with the patient for the care desired.

To give a broad perspective the editors have selected contributors from seven states, representing fourteen cancer centers. These authors share valuable experience in dealing with the new approaches and treatments and demonstrate the genuine use of self needed to bring cancer patients to a dignified death. It is hoped that the reader will come away with increased awareness and reduced fear of the complex nursing care required by the patient with cancer. It is one of the most satisfying and challenging areas in which to become involved.

We would like to thank Ken Kellogg for his patience and encouragement and Pat Tilbian, Jennifer Andrys, and Gina Gross for their typing assistance.

Barbara Holz Peterson

Carolyn Jo Kellogg

Current practice in oncologic nursing

Contents

part I
PROFESSIONAL AWARENESS

The first two chapters were chosen for the introductory part of this book because both present the idea of openness. This openness of discussion with the patient of what was until recently a taboo subject is a vital concept. We as editors hope to encourage greater awareness of this concept on the part of health care professionals who work with cancer patients.

The following chapters, written by Dolly Reiner, Maureen Niland, and Judith Atwood, present some new and humanistic approaches in the care of patients who have cancer. Informed consent and contracting with patients for their daily care are challenging concepts for the nurse. Talking with patients about their problems in dealing with a disease that may be terminal has only recently been encouraged. In the past, patients who were dying were pitied. Staff persons complained that they did not know what to say to the dying person or his family. Many patients were not told their diagnosis, although everyone else knew. Death was a taboo subject until Kübler-Ross in the 1960s encouraged a change in this attitude.

Ms. Reiner discusses not only the challenge of telling the patient about his diagnosis but also the pros and cons of telling the patient the risks involved with the various courses of treatment of the disease.

Ms. Niland and Ms. Atwood present the idea of the patient's controlling the day-to-day care he receives by contracting with the staff.

1 The doctrine of informed consent
a therapeutic dilemma for nurses

DOLLY K. REINER

Malignant neoplasms are rated as the second highest cause of death in the United States, but cancer is the disease entity people fear most. So great is the national dread of cancer that many patients, faced with an undiagnosed life-threatening illness, smile with gratitude and relief when informed that cancer is not their problem. The anxieties and fears expressed by the person with a diagnosis of cancer can be readily understood when we realize that the average American is more fearful of cancer than any other disease or event, including nuclear war.[19]

Health care professionals assume that the human organism has little desire to quit life without trying whatever the art of medicine has to offer at his moment of need.[15] The therapies available for curing cancer are known to be inadequate for more than half the medically treated patients. Until cancer treatments become more effective, these patients, including those on research protocols, are provided with the temporary control of eventually failing therapeutic modalities.[16]

Indisputably, therapeutic research is a complex process. The need for scientists to bring research out of the animal laboratory into the clinical research area, employing human subjects, is axiomatic. With the knowledge that most experimental therapies are not major breakthroughs in cancer cure, the medical community has assumed that adequate explanation of the risks and hazards involved is sufficient for the patient, since he has elected to be treated. What might be determined adequate by a health professional is not necessarily deemed adequate by and for the patient.

A unique and emotional component of human experimentation has become an ethical and legal issue for nurse practitioners—the doctrine of informed consent. The central theme in biomedical research should be the value placed on human therapy, which includes the patient's right to know. With the existentialist view that life is meaningless unless one acts, the ethical problems presented by the doctrine of informed consent should be of increasing concern to the entire nursing profession.

ETHICS VERSUS ETIQUETTE

There are many important ethical theories dealing with human goals, motives, and conduct, ranging from selfish hedonism to altruistic social idealism, and from

utilitarianism to pragmatism. What is usually called nursing ethics is only nursing etiquette and has scarcely been concerned with ethical theory. It is necessary to make the distinction between the two. Nursing etiquette concerns the patterns of interpersonal relations among professionals, whereas nursing ethics is concerned with patient care and human value. Ethics is not an internal process but an external one, and thus it is a public process.[28]

The ethic taken frequently—albeit unconsciously—by members of the health professions is pragmatism. William James, expanding on Locke, held that experiment and experience promote an ethical behavior, and that whatever works out satisfactorily on trial or experimentation is good. Measured by any ethical theory, even pragmatism, experience still shows that the obligation remains with the members of the health professions to do everything they can on behalf of their patients' welfare.[26]

DOCTRINE OF INFORMED CONSENT

The structural responsibility within the system for the process of informed consent rests with the physician-researcher. Many investigators assume that patient-subjects understand the possible benefits and hazards inherent in the particular research protocol after informed consent has been obtained in compliance with the *Federal Register*.[33] Although the Department of Health, Education, and Welfare's regulation is fulfilled when the patient-subject's written consent is obtained, the patient-subject's human rights are not.

The abstract notion of self-determination, wherein each person has the inalienable right to pursue his own ends in his own way so long as he does not interfere with the rights of others or the community, is implemented by the requirement of consent in research protocols. However, how can a dying patient be said to exercise a free power of choice? The patient-subject, anxious and/or fearful because of a life-threatening disease, can have a very unique perception of experimentation. Can we say that we have recognized his right to make choices concerning his own life, both in quantity and quality? Does the patient-subject understand that he has control over his own being and can withdraw his consent at any time he chooses? It is highly questionable whether the patient-subject understands what he has consented to. Kübler-Ross,[24] in her many interviews with dying patients, reported that these patients have increasing difficulties in communication of all kinds and at all levels. The progression to the final stage of life, death, is fraught with anxieties, fears, and hopes. Most dying patients do not discuss death, but rather their expectation of living.[35]

Traditionally, the process of consent was used to differentiate between medical interventions that were legally permissible and those which would subject a physician to liability for an unauthorized procedure.[22] After World War II, a growing humanitarian ethic resulted in another viewpoint relative to the significance of personal informed consent and its implications for human research.[21] With the revelation of the Nazi atrocities perpetuated in the name of medical science at the

Nuremberg trials, physicians from around the world formalized ethical medical thought in the Nuremberg Code. In 1964 the World Medical Association elaborated yet another code of ethics on human experimentation which came to be known as the Declaration of Helsinki.[27] The Helsinki code is probably the nearest document to a universal ethical code presently in existence. It brought to the fore the patient's right to consent: "Consistent with patient psychology, the doctor should obtain the patient's freely given consent after the patient has been given a full explanation."[27] How freely is the consent given to a clinical researcher by a person who feels threatened by the prognosis of death? And what is meant by a full explanation that is consistent with patient psychology?

The criterion of consent has emerged in one guise or another in most discussions of human experimentation. The concept of consent has been much derided as unrealistic, artificial, fictional, difficult to obtain, and nonexistent.[8,10,31,36] It is important to recognize that the psychologic constraints or compulsions that operate on a seriously ill patient are different from those which affect a person volunteering his services for gain.[9] In the field of clinical research the Declaration of Helsinki distinguishes between research that is combined with professional care and that which is nontherapeutic.[27] A fundamental distinction must be recognized when the aim of the former is essentially therapeutic for the patient, and the primary objective of the latter is purely scientific and without therapeutic value to the person subjected to the research. Experiments on human beings fall into two categories:

1. Experiments for the immediate benefit of the human subject, with the welfare of that subject as an end in mind
2. Experiments in which human subjects serve as a means for collecting information intended for the future benefit of society[11]

The dying cancer patient on a research protocol can be placed in either category. All the factors that make human beings both accessible and necessary to experimentation also compromise the quality of their informed consent.

The courts have recently accepted a person's consent as being valid, evidencing a voluntary product of his free will, only if that consent is based on adequate information about the medical intervention, including its attendant risks.[22] An experiment, defined by Fox[7] as a process of systematically venturing into the unknown, indicates that an investigator cannot describe or predict all the discomforts, risks, and/or dangers to which a subject may be exposed. With the advances made in chemotherapy, a physician exercises a power heretofore unknown in medicine—that of manipulation of the intracellular and extracellular environment of the human organism. We remain ignorant of all possible potentialities of drugs for therapeutic cure or toxic side effects. Is valid and informed consent obtained, then, on the basis of inadequate information? Informed and/or valid consent still lacks legally specific construction and remains an ill-defined concept, although common law sets a high value on consent to physical invasions that threaten the social, biologic, or psychic integrity of the individual.