

SECOND EDITION

# Palliative Care Nursing

CARING FOR SUFFERING PATIENTS

Kathleen Ouimet Perrin, PhD, RN

Caryn A. Sheehan, DNP, APRN-BC

Mertie L. Potter, DNP, APRN-BC

Mary K. Kazanowski, PhD, APRN-BC, ACHPN



JONES & BARTLETT  
LEARNING



World Headquarters  
Jones & Bartlett Learning  
25 Mall Road  
Burlington, MA 01803  
978-443-5000  
info@jblearning.com  
www.jblearning.com

Jones & Bartlett Learning books and products are available through most bookstores and online booksellers. To contact Jones & Bartlett Learning directly, call 800-832-0034, fax 978-443-8000, or visit our website, [www.jblearning.com](http://www.jblearning.com).

Substantial discounts on bulk quantities of Jones & Bartlett Learning publications are available to corporations, professional associations, and other qualified organizations. For details and specific discount information, contact the special sales department at Jones & Bartlett Learning via the above contact information or send an email to [specialsales@jblearning.com](mailto:specialsales@jblearning.com).

Copyright © 2023 by Jones & Bartlett Learning, LLC, an Ascend Learning Company

All rights reserved. No part of the material protected by this copyright may be reproduced or utilized in any form, electronic or mechanical, including photocopying, recording, or by any information storage and retrieval system, without written permission from the copyright owner.

The content, statements, views, and opinions herein are the sole expression of the respective authors and not that of Jones & Bartlett Learning, LLC. Reference herein to any specific commercial product, process, or service by trade name, trademark, manufacturer, or otherwise does not constitute or imply its endorsement or recommendation by Jones & Bartlett Learning, LLC and such reference shall not be used for advertising or product endorsement purposes. All trademarks displayed are the trademarks of the parties noted herein. *Palliative Care Nursing: Caring for Suffering Patients, Second Edition* is an independent publication and has not been authorized, sponsored, or otherwise approved by the owners of the trademarks or service marks referenced in this product.

There may be images in this book that feature models; these models do not necessarily endorse, represent, or participate in the activities represented in the images. Any screenshots in this product are for educational and instructive purposes only. Any individuals and scenarios featured in the case studies throughout this product may be real or fictitious but are used for instructional purposes only.

The authors, editor, and publisher have made every effort to provide accurate information. However, they are not responsible for errors, omissions, or for any outcomes related to the use of the contents of this book and take no responsibility for the use of the products and procedures described. Treatments and side effects described in this book may not be applicable to all people; likewise, some people may require a dose or experience a side effect that is not described herein. Drugs and medical devices are discussed that may have limited availability controlled by the Food and Drug Administration (FDA) for use only in a research study or clinical trial. Research, clinical practice, and government regulations often change the accepted standard in this field. When consideration is being given to use of any drug in the clinical setting, the health care provider or reader is responsible for determining FDA status of the drug, reading the package insert, and reviewing prescribing information for the most up-to-date recommendations on dose, precautions, and contraindications, and determining the appropriate usage for the product. This is especially important in the case of drugs that are new or seldom used.

#### Production Credits

Vice President, Product Management: Marisa R. Urbano  
Vice President, Product Operations: Christine Emerton  
Director, Product Management: Matthew Kane  
Product Manager: Tina Chen  
Director, Content Management: Donna Gridley  
Manager, Content Strategy: Carolyn Pershouse  
Content Strategist: Paula-Yuan Gregory  
Director, Project Management and Content Services:  
Karen Scott  
Project Manager: Jessica deMartin  
Project Specialist: Erin Bosco  
Digital Project Specialist: Rachel DiMaggio

Senior Marketing Manager: Lindsay White  
Product Fulfillment Manager: Wendy Kilborn  
Composition: S4Carlisle Publishing Services  
Project Management: S4Carlisle Publishing Services  
Cover Design: Michael O'Donnell  
Senior Media Development Editor: Troy Liston  
Rights & Permissions Manager: John Rusk  
Rights Specialist: Maria Leon Maimone  
Cover Image (Title Page, Chapter Opener): Courtesy of  
Nance Trueworthy  
Printing and Binding: McNaughton & Gunn

#### Library of Congress Cataloging-in-Publication Data

Names: Perrin, Kathleen Ouimet, author. | Sheehan, Caryn A., author. |  
Potter, Mertie L., author. | Kazanowski, Mary K., author.  
Title: Palliative care nursing : caring for suffering patients / Kathleen  
Ouimet Perrin, Caryn A. Sheehan, Mertie L. Potter, Mary K. Kazanowski.  
Description: Second edition. | Burlington, Massachusetts : Jones & Bartlett  
Learning, [2023] | Preceded by Palliative care nursing / Kathleen Quimet  
Perrin ... [et al.], c2012. | Includes bibliographical references and  
index.  
Identifiers: LCCN 2021035885 | ISBN 9781284209822 (paperback)  
Subjects: MESH: Hospice and Palliative Care Nursing--ethics | Hospice and  
Palliative Care Nursing--methods | Terminal Care--methods |  
Pain--nursing | BISAC: MEDICAL / Nursing / Gerontology  
Classification: LCC R726.8 | NLM WY 152.3 | DDC 616.02/9--dc23  
LC record available at <https://lccn.loc.gov/2021035885>

6048

Printed in the United States of America

26 25 24 23 22 10 9 8 7 6 5 4 3 2 1

We dedicate this book to all our patients and their families. We have borne witness to their suffering—from psychological distress, from loss and bereavement, from countless and sometimes unfathomable physiological ailments. It is also dedicated to our nurse colleagues and the nursing students who have collaborated with us to provide nursing care. This book originated from our realization that, as nurses, we are fellow travelers with our patients and their families in their journey through suffering. When we give voice to both their suffering and our own, we can work together to alleviate it.

# Brief Contents

<b>Preface</b>	<b>xvii</b>
<b>Acknowledgments</b>	<b>xix</b>
<b>About the Authors</b>	<b>xxi</b>

<b>CHAPTER 1</b>	<b>Palliative Care and Its Role in Suffering</b> . . . . .	<b>1</b>
<b>CHAPTER 2</b>	<b>Suffering and Palliative Care Across the Continuum</b> . . . . .	<b>13</b>
<b>CHAPTER 3</b>	<b>Ethical Responsibilities and Issues in Palliative Care</b> . . . . .	<b>41</b>
<b>CHAPTER 4</b>	<b>Advance Care Planning Responsibilities</b> . . . . .	<b>77</b>
<b>CHAPTER 5</b>	<b>Difficult Conversations</b> . . . . .	<b>103</b>
<b>CHAPTER 6</b>	<b>Acute and Chronic Pain as Sources of Suffering</b> . . . . .	<b>121</b>
<b>CHAPTER 7</b>	<b>Palliative Care for Patients with Serious Illness</b> . . . . .	<b>141</b>
<b>CHAPTER 8</b>	<b>Suffering and Palliative Care at the End of Life</b> . . . . .	<b>167</b>
<b>CHAPTER 9</b>	<b>Grieving and Suffering</b> . . . . .	<b>199</b>
<b>CHAPTER 10</b>	<b>Spirituality and Suffering</b> . . . . .	<b>225</b>
<b>CHAPTER 11</b>	<b>The Search for Meaning in Suffering</b> . . . . .	<b>251</b>
<b>CHAPTER 12</b>	<b>The Nurse as Witness to Suffering</b> . . . . .	<b>275</b>

<b>CHAPTER 13</b>	<b>The Role of Healing and Holistic Nursing</b> .....	<b>303</b>
<b>CHAPTER 14</b>	<b>Conveying Comfort</b> .....	<b>323</b>
<b>CHAPTER 15</b>	<b>Inspiring Hope</b> .....	<b>347</b>
<b>Index</b>		<b>367</b>

# Contents

<b>Preface</b> .....	<b>xvii</b>
<b>Acknowledgments</b> .....	<b>xix</b>
<b>About the Authors</b> .....	<b>xxi</b>

## **CHAPTER 1 Palliative Care and Its Role in Suffering** ..... **1**

*Mary K. Kazanowski*

The Evolution of Palliative Care .....	2
The Nature of Suffering .....	3
Sources of Suffering .....	4
Physical Sources of Suffering .....	4
Psychological Sources of Suffering .....	4
Sociocultural Sources of Suffering .....	5
Developmental Sources of Suffering .....	6
Spiritual Sources of Suffering .....	7
Recognizing Suffering .....	7
Silent Sufferers .....	7
Assessing for Suffering .....	8
Nursing as Collaborators in Palliative Care .....	8
The Process of Suffering .....	9
Summary .....	10
Key Points .....	11
Exercise .....	11
Questions for Reflection and Journaling .....	11
References .....	11

## **CHAPTER 2 Suffering and Palliative Care Across the Continuum** ..... **13**

*Mertie L. Potter and Joshua Dion*

Introduction .....	14
Suffering in Various Cultures .....	16
Culture .....	16
Healthcare Disparities .....	18

Suffering in Children and Families . . . . .	19
Concerns . . . . .	19
Nursing Interventions . . . . .	26
Suffering in Families and Patients Diagnosed With Mental Health Issues and Substance Abuse . . . . .	27
Concerns . . . . .	30
Nursing Interventions . . . . .	30
Suffering in Individuals Identifying as Lesbian, Gay, Bisexual, Transgender, or Queer and/or Questioning (LGBTQ+) . . . . .	31
Suffering in Individuals With Cognitive Deficits or Impairments . . . . .	31
Concerns . . . . .	32
Nursing Interventions . . . . .	33
Suffering in Student Nurses and Nurses . . . . .	34
Self-Transcending Through Suffering . . . . .	36
Summary . . . . .	36
Key Points . . . . .	36
Exercise . . . . .	37
References . . . . .	37

### **CHAPTER 3 Ethical Responsibilities and Issues in Palliative Care . . . . . 41**

*Kathleen Ouimet Perrin*

Introduction . . . . .	42
Virtues of Nurses Providing Palliative Care . . . . .	43
Respect for Persons . . . . .	43
Veracity . . . . .	44
Beneficence . . . . .	45
Fidelity . . . . .	46
Ethical Dilemmas . . . . .	46
Tragic Circumstances . . . . .	47
Moral Distress . . . . .	47
Approaches to Decision Making in Ethical Dilemmas . . . . .	48
What Information Should Be Considered When Making a Decision? . . . . .	48
Who Should Be Involved in Making the Decision? . . . . .	48
How Should One Make a Decision and Choose a Course of Action? . . . . .	49
What Follow-up Is Necessary After a Decision Is Made? . . . . .	50
Ethical Dilemmas Frequently Encountered by Nurses . . . . .	50
Truth Telling . . . . .	51
Right to Choose or Decline Treatment at End of Life . . . . .	53

**viii Contents**

Dilemmas in Pain and Symptom Management . . . . . 55  
Dilemmas Surrounding Nutrition and Hydration at the  
End of Life . . . . . 58  
Prolongation of Life . . . . . 59  
Cardiopulmonary Resuscitation (CPR) and Do Not  
Resuscitate (DNR) Orders . . . . . 60  
Withholding and Withdrawal of Life-Sustaining Technologies . . . . . 61  
Active Assistance With Dying . . . . . 62  
Summary . . . . . 68  
Key Points . . . . . 69  
References . . . . . 72

**CHAPTER 4 Advance Care Planning Responsibilities . . . . . 77**

*Kathleen Quimet Perrin*

Introduction . . . . . 79  
Development of ADs: Legal/Ethical Underpinnings . . . . . 79  
Differences Between Advance Care Planning and Advance Directives . . . . . 80  
Types of Advance Directives . . . . . 81  
Current Status of Patient Self-Determination . . . . . 83  
Barriers to Advance Care Planning and Completion of Advance  
Directives . . . . . 85  
HCPs Concerns About Initiating AD Conversations . . . . . 85  
Sociocultural Barriers to Advanced Care Planning . . . . . 86  
Misunderstandings About Outcomes of Treatment or Choices . . . . . 88  
Advance Care Planning Strategies . . . . . 88  
Beginning the Process: Start Early, Revisit Often . . . . . 88  
Break the Ice for the Initial Discussion, Initiate the Discussion,  
and Obtain Permission . . . . . 89  
Define the Issues . . . . . 90  
Ask About Preferences for Specific Types of Treatment and/or  
a Surrogate to Make Decisions . . . . . 90  
Complete the ACP Process . . . . . 91  
Review the Decisions Regularly . . . . . 91  
Concerns That Arise During Implementation of Advance  
Directives . . . . . 92  
Concern: Are Patients' Advanced Care Decisions Stable? . . . . . 92  
Concern: Advance Directives Are Often Unavailable When  
Needed . . . . . 93  
Concern: Do Patients, Families, and Healthcare Providers Agree on  
How to Interpret an AD or POLST? . . . . . 94  
Concern and Strategy: Misunderstandings About What an AD Is and  
What Will Occur . . . . . 96  
Concern: Miscommunication . . . . . 97



Summary . . . . .	97
Keypoints . . . . .	98
Questions for Reflection and Journaling . . . . .	99
Exercises . . . . .	99
References . . . . .	100

## **CHAPTER 5 Difficult Conversations. . . . .103**

*Caryn A. Sheehan*

Introduction . . . . .	106
Which Conversations Are the Most Difficult?. . . . .	106
Communicating Clearly Matters: Benefits of Difficult Conversations. . . . .	107
Barriers to Effective Communication. . . . .	107
Early Discussions. . . . .	108
Later Discussions . . . . .	110
How to Begin the Conversation. . . . .	110
Setting the Stage for Difficult Conversations . . . . .	110
Becoming a Better Communicator. . . . .	111
Summary . . . . .	116
Key Points. . . . .	116
Exercises . . . . .	116
Questions for Reflection and Journaling . . . . .	119
References . . . . .	119

## **CHAPTER 6 Acute and Chronic Pain as Sources of Suffering . . . . .121**

*Caryn A. Sheehan*

Introduction—What Is Pain? . . . . .	122
Types of Pain . . . . .	122
Acute Pain Versus Chronic Pain . . . . .	122
Nocioceptive Pain Versus Neuropathic Pain . . . . .	123
Cancer Pain and EOL Pain Versus Chronic Nonmalignant Pain . . . . .	123
Scope of the Problem of Chronic Nonmalignant Pain . . . . .	124
Variables in Suffering With Pain . . . . .	124
Diagnosis: Chronic Pain . . . . .	124
Pain and Suffering Intertwine With Trust and Frustration . . . . .	126
Pain and Suffering and Functional Limitations . . . . .	126
Pain and Suffering and Isolation. . . . .	126
The Emotional Burden of Pain and Suffering . . . . .	127

Assessing Chronic Pain . . . . . 128  
Goals for People With Chronic Pain . . . . . 130  
Management of Chronic Pain and Suffering . . . . . 131  
    Barriers to Effective Management of Chronic Pain. . . . . 131  
    Options for Effective Management of Chronic Pain. . . . . 131  
    Physical and Behavioral Interventions. . . . . 132  
    Medications for Chronic Pain . . . . . 133  
Summary . . . . . 137  
Key Points. . . . . 137  
Exercise: One Day Spent Suffering With Chronic Pain . . . . . 137  
References . . . . . 138

**CHAPTER 7 Palliative Care for Patients With Serious Illness . . . . . 141**

*Mary K. Kazanowski*

Introduction . . . . . 142  
Chronic Obstructive Pulmonary Disease . . . . . 142  
    Treatment of Chronic Obstructive Pulmonary Disease . . . . . 143  
    Complications of COPD . . . . . 144  
    Symptom Management in Advanced COPD . . . . . 144  
    Prognosis . . . . . 145  
    Hospice . . . . . 145  
Heart Failure . . . . . 146  
    Treatment of Heart Failure . . . . . 146  
    Complications of Heart Failure. . . . . 147  
    Symptom Management in Advanced Heart Failure . . . . . 147  
    Prognosis . . . . . 148  
    Hospice . . . . . 149  
Alzheimer's Dementia . . . . . 149  
    Treatment of Alzheimer's Dementia. . . . . 150  
    Complications in Dementia . . . . . 150  
    Symptom Management in Dementia. . . . . 151  
    Prognosis . . . . . 151  
    Hospice . . . . . 151  
End-Stage Renal Disease . . . . . 152  
    Treatment of End-Stage Renal Disease. . . . . 152  
    Symptoms of Distress . . . . . 152  
    Prognosis . . . . . 153  
    Hospice . . . . . 154  
Additional Progressive Diseases . . . . . 154  
    Idiopathic Pulmonary Fibrosis . . . . . 154

Metastatic Cancer . . . . . 155  
 Advanced Chronic Liver Disease . . . . . 157  
 Parkinson’s Disease . . . . . 157  
 Amyotrophic Lateral Sclerosis . . . . . 158  
 Coronavirus Covid-19 . . . . . 159  
 Summary . . . . . 160  
 References . . . . . 162

**CHAPTER 8 Suffering and Palliative Care at the End of Life . . . . . 167**

*Mary K. Kazanowski*

Introduction . . . . . 168  
 Sources of Suffering at the End of Life . . . . . 169  
     Physical Suffering of the Person . . . . . 169  
     Emotional Suffering of the Person . . . . . 170  
     Spiritual Suffering of the Person . . . . . 172  
     Emotional Suffering of the Family . . . . . 172  
     Physical Suffering of Family . . . . . 173  
 Interventions to Assist With Persons Suffering at End of Life . . . . . 173  
 Prevalence of Symptoms at the End of Life . . . . . 176  
     Fatigue . . . . . 177  
 Pain . . . . . 177  
     Assessment of Pain at the End of Life . . . . . 177  
     Pharmacologic Relief of Pain at the End of Life . . . . . 178  
 Breathlessness or Dyspnea . . . . . 181  
     Pharmacologic Interventions for Dyspnea . . . . . 181  
     Nonpharmacological Interventions for Dyspnea . . . . . 182  
     Management of Oral Secretions . . . . . 183  
     Anxiety/Restlessness . . . . . 184  
     Nausea and Vomiting . . . . . 186  
     Urinary Discomfort . . . . . 187  
 Interventions to Assist the Family of a Person Near the End of Life . . . . . 187  
     When Death Occurs . . . . . 190  
     Bereavement . . . . . 190  
 Summary . . . . . 192  
 Key Points . . . . . 192  
 Visualization Exercise for End-of-Life Care . . . . . 193  
 Questions for Reflection and Journaling . . . . . 194  
 References . . . . . 195

**CHAPTER 9 Grieving and Suffering ..... 199**

*Mertie L. Potter*

Introduction .....	201
Interweaving of Suffering and Grieving .....	201
Traditional and Newer Models of Loss and Grieving .....	203
Traditional Models .....	203
Newer Models .....	205
Complicated Grief .....	206
Chronic Sorrow .....	208
Questions for Reflection .....	208
Developmental Needs .....	208
Infancy and Toddlers .....	210
Early Childhood .....	210
Late Childhood .....	211
Adolescence to Young Adulthood .....	211
Middle-Aged and Older Adults .....	212
Cultural Considerations Related to Loss and Grieving .....	212
Extraordinary Losses .....	213
Continuum of Grieving .....	213
Evidence-Based Practice .....	215
Communication and the Role of Nursing .....	215
With Patients and Families .....	215
With Colleagues .....	216
With Self .....	217
What to Say to a Grieving Person .....	217
Summary .....	218
Key Points .....	219
Exercises .....	219
References .....	220

**CHAPTER 10 Spirituality and Suffering ..... 225**

*Mertie L. Potter*

Introduction .....	226
Definitions .....	227
Religion .....	227
Faith .....	228
Spirituality .....	229
Spirit–Mind–Body Connection .....	229
Connectedness Between Religion, Faith, and Spirituality .....	230
The Relationship Between Spirituality and Suffering .....	231

Student Questions . . . . .	232
Coping . . . . .	232
Faith . . . . .	233
God . . . . .	234
Nurses Sharing Feelings and/or Crying . . . . .	235
Nursing Interventions . . . . .	235
Assessment of Patient’s Spirituality and Religion . . . . .	237
Alleviating Spiritual Suffering Within the Nurse . . . . .	239
Major World Religions . . . . .	240
Spiritual Assessment . . . . .	240
Christianity . . . . .	241
Islam . . . . .	242
Hinduism . . . . .	243
Buddhism . . . . .	244
Judaism . . . . .	244
Nursing Interventions That Promote Spiritual Care and Alleviate Suffering . . . . .	245
Summary . . . . .	247
Key Points . . . . .	247
Exercise . . . . .	247
References . . . . .	247

**CHAPTER 11 The Search for Meaning in Suffering . . . . . 251**

*Kathleen Quimet Perrin*

Introduction . . . . .	254
Shattering of Global Meaning . . . . .	255
The Search for Meaning . . . . .	255
Ways to Find Meaning . . . . .	256
Attributes of Holocaust Survivors . . . . .	256
Illness as a Source of Suffering . . . . .	257
Logotherapy in the Search for Meaning in Illness . . . . .	257
Learning the Meaning of the Illness to the Patient . . . . .	258
Silent Sufferers . . . . .	258
Finding a Voice . . . . .	259
Wounded Storytellers . . . . .	259
Value of Stories/Narratives . . . . .	260
Aesthetic Experiences . . . . .	262
Is Suffering All Bad? . . . . .	264
Feminist Response . . . . .	264
Do We Contribute to Suffering? . . . . .	265
Responses to Suffering . . . . .	265
Summary . . . . .	268

**xiv Contents**

Key Points . . . . . 268  
Exercises . . . . . 268  
Questions for Reflection and Journaling . . . . . 269  
References . . . . . 272

**CHAPTER 12 The Nurse as Witness to Suffering . . . . . 275**

*Kathleen Ouimet Perrin*

Introduction . . . . . 276  
Bearing Witness/Not Bearing Witness. . . . . 276  
    Ethical Aspects of Bearing Witness . . . . . 277  
    Not Bearing Witness. . . . . 278  
    Communication Strategies Nurses Use With Suffering Patients. . . . . 279  
Morse's Model of Patient Suffering . . . . . 281  
    Enduring . . . . . 282  
    Emotional Suffering . . . . . 285  
What Do Nurses Do With the Suffering They Have Witnessed? . . . . 286  
    Findings from Nurses Working With AIDS Patients . . . . . 286  
    Threats to Healers. . . . . 287  
    Nurses' Narratives About Patient Suffering . . . . . 290  
    Compassion Fatigue and Burnout. . . . . 291  
    Summary of Nurses' Responses to Suffering . . . . . 294  
    Student Nurses' Responses to Patient Suffering. . . . . 294  
    Student Nurses' Experiences of Bearing Witness. . . . . 294  
    Faculty Responses to Student Suffering. . . . . 295  
Summary . . . . . 297  
Key Points. . . . . 297  
Exercise: Witness to Suffering . . . . . 298  
Questions for Reflection and Journaling . . . . . 298  
References . . . . . 299

**CHAPTER 13 The Role of Healing and Holistic Nursing . . . . . 303**

*Maureen A. Gaynor*

Introduction . . . . . 304  
Concept of Healing. . . . . 305  
Holistic Nursing . . . . . 305  
    Definition of Holistic Nursing. . . . . 306  
    Holistic Nursing Theories. . . . . 306  
    Comparison and Contrast of Allopathic and Holistic Models of Care . . . . . 307  
Presence. . . . . 309  
The Science of Psychoneuroimmunology . . . . . 309

Implications of Mind–Body Interactions . . . . . 310  
     Relaxation Response . . . . . 311  
     Complementary/Alternative/Integrative Therapies . . . . . 312  
 Tending to the Nurses’ Spirit . . . . . 317  
 Ethical and Legal Issues . . . . . 318  
 Summary . . . . . 319  
 Key Points . . . . . 320  
 References . . . . . 320

**CHAPTER 14 Conveying Comfort . . . . . 323**

*Kathleen Quimet Perrin*

Introduction . . . . . 324  
 Why Should Nurses Focus on Providing Comfort? . . . . . 325  
 Assessment of Patient Comfort . . . . . 327  
 Patients’ Comfort Needs . . . . . 328  
     Suffering From Care . . . . . 329  
     Meeting Patient Expectations for Care and Comfort . . . . . 329  
 Comfort Strategies . . . . . 331  
     Characteristics of Comfort Strategies . . . . . 331  
     Dependence of Comfort Strategies on Patient Suffering State . . . . . 332  
 Comforting Interaction as a Model of Nurse–Patient Relationship . 338  
     Development of Nurse–Patient Relationship . . . . . 338  
     Dynamic Nature of Nurse–Patient Relationship . . . . . 338  
 Summary . . . . . 339  
 Exercise: A Comfort Shawl Project . . . . . 340  
 Key Points . . . . . 339  
 Questions for Reflection and Journaling . . . . . 341  
 References . . . . . 344

**CHAPTER 15 Inspiring Hope . . . . . 347**

*Caryn A. Sheehan*

Introduction . . . . . 349  
 Definitions of Hope . . . . . 350  
 Related Concepts . . . . . 350  
 Benefits of Hope . . . . . 351  
 Hope, False Hope, and Suffering . . . . . 352  
 Hopelessness . . . . . 353  
 Development of Hope . . . . . 353  
 Assessing Hope . . . . . 355  
 Including Hope in Nursing Practice . . . . . 356

**xvi      Contents**

Practice Suggestions . . . . . 356  
Conclusion . . . . . 358  
Key Points . . . . . 358  
References . . . . . 361

**Index . . . . . 367**



# Preface

At some critical juncture in all our professional lives, perhaps while we were students, perhaps as practicing nurses, all of us have realized that our patients are suffering. Sometimes they are suffering from a disease process, sometimes from adverse effects of the treatments we administer, and sometimes from the psychological distress that accompanies a disease.

Jacqueline Merry Stout described how she learned this lesson when, as a new nursing student, she was assigned to care for a woman who the day before had had bilateral mastectomies. When Jacqui entered the room, the patient was dressed beautifully, knowledgeable about her disease, smiling, and “not in need of a thing.” When Jacqui asked her patient how she was coping with her diagnosis of breast cancer and her surgery, the patient responded, “Oh, I’m handling it so well. Everyone keeps telling me that they can’t believe how strong I am and how well I am dealing with everything.” However, as Jacqui began to assess her patient and prepare her for discharge, a powerful doubt developed: What if the woman she was caring for was presenting a fragile façade covering up being truly terrified? Jacqui was sure there was something that she should be doing and felt she had failed because she could not discover what it was.



Courtesy of Jacqueline Merry Stout, MSN, RN. The final definitive version of this figure has been published in the *Journal of Holistic Nursing*, 25(3). Sage Publications Ltd./Sage Publication, Inc. All rights reserved.

As Jacqui wheeled the patient to an elevator and it began to descend to the lobby where the patient's husband was waiting, a great change came over the patient. Her shoulders slouched forward and she cupped her head in her hands. Tears streamed down her cheeks as she wept silently. Jacqui stopped the elevator, put a hand on the patient's shoulder, and just stood there while the patient cried. When she was finished, the patient wiped the tears from her eyes, proudly lifted her head, and nodded she was ready. Jacqui opened the elevator doors and wheeled her down the hall to her husband.

After this event, Jacqui wondered, What could she have done for her patient? Was having someone "just be there" what the patient needed most? While reflecting on the experience, Jacqui created the star-shaped box in the photo above to represent this patient. The box is a beautiful star-shaped box with exquisite pink paper and a lovely bow. Yet when you open it, you see ribbons in disarray, each marked with a powerful emotion, in stark contrast to the neat, "perfect" exterior.

Jacqui left the hospital that day fearing that she had failed her patient. How many times have any of us left after a long day wondering what else we might have done if only we had had a chance? In his discussion of nurses and their response to suffering, Jameton (1983) said, "I envision hospitals as places of suffering and I see nurses sweeping it all up. Then I wonder what they do with all that suffering after they have gathered it up." *Palliative Care Nursing: Caring for Suffering Patients, Second Edition* is intended to assist nurses to reflect on the suffering, tragedies, and sometimes horror they see in the clinical setting and to work through some of their own feelings and reactions. It is also intended to highlight the role that palliative care plays in caring for individuals and families with serious illness.

This book was also developed to assist nurses in finding answers to Jacqui's questions. How do we identify a patient who is suffering? How do we assess whether our patient (and/or her family) is coping with the event? How can we identify the sources of our patients' suffering when we believe they are putting up a façade? What can we do to alleviate patient suffering? How can we convey the extent of the suffering to the other members of the healthcare team and advocate excellent palliative care for our patients? This book was developed with the intention of helping nurses improve their ability to recognize the suffering of others and respond to it so that optimally they could relieve or alleviate patients' distress.

## Reference

Jameton, A. (1983, June). Panel Discussion at the National Endowment for the Humanities Summer Institute in Nursing Ethics, Medford, MA.

# Acknowledgments

We wish to acknowledge our families who have provided us with the love and support that has sustained us throughout our nursing careers, but especially as we worked on this project.

Thank you to my husband, Robin, and my parents, Marie and Charles Ouimet, for challenging me to reach beyond what I thought I could do.

*Kathleen Ouimet Perrin*

Thank you to all of my family members, especially Thomas, Zac, and Molly, who are my greatest inspiration and continued source of love and hope.

*Caryn A. Sheehan*

Thank you to my husband, Fred, for his continued role modeling of faith, peace, and joy on our journey together, and for his constant encouragement and support of my professional endeavors.

*Mertie L. Potter*

Thank you to my husband, Glenn, and my colleagues in palliative care, who consistently support me in assisting patients with serious illness.

*Mary K. Kazanowski*

We wish to acknowledge our nursing students, from whom we have learned so much. We continue to be impressed with their ability to empathize with suffering patients and their families as well as their level of compassion and commitment to alleviate suffering. Specifically, we wish to acknowledge and thank the following former students who allowed their projects and/or papers to be included in this book.

Preface	Jacqueline Merry Stout, MSN, RN	Preface Case Study and Photo
Chapter 2	Erica Lopes Cabral, MSN, FNP-BC	Case Study 2-1 and Student Project Photo
Chapter 3	Marysa Morin Duffy, BSN, RN	Student Project Poem
	Kathleen Masterson, BSN, RN, CMSRN	Case Study 3-1
	Megan A. Jacques, BSN, RN	Case Study 3-2
Chapter 4	Annie Dechant Ames, BSN, RN	Student Project Photo

*(continues)*

**xx Acknowledgments**

Chapter 5	Cecilia Mercadante, BSN, RN	Case Study 5-1 and Student Project Photo
	Caroline Trickett, BSN, RN, OCN	Case Study 5-2
Chapter 6	Katie Powers Cuozzo, MSN, RN	Case Study 6-1 and Student Project Photo
Chapter 8	Kristina Michaud, BSN, RN	Student Project Photos
	Megan K. McMahon, MSN, RN, CCRN, CPNP-AC	Case Study 8-1
Chapter 9	Angelina Markarov Skorupski, BSN, RN	Student Project Poem
Chapter 10	Emily Brown, BSN, RN	Student Project Photo
Chapter 11	Kristen Raymond, BSN, RN, PCCN	Case Study 11-1
	Shannon Vasas, BSN	Student Project Poem
Chapter 12	Kaitlin Forsythe, BSN, RN, CCRN	Student Project Photo
	Shaylin Lawrence, BSN, RN	Case Study 12-1
	Erin E. McDonough, DNP, AGACNP, CCRN-CSC	Case Study 12-2 and Poem
Chapter 13	Adelina Katzounos, BSN, RN	Case Study 13-1 and Student Project Photo
Chapter 14	Megan K. McMahon, MSN, RN, CCRN, CPNP-AC	Case Study 14-1 and Student Project Photo
	Madelyn Cantarow, MS, BSN, RN	Case Study 14-3 and Student Project Photo
Chapter 15	Jessica Ford, BSN, RN	Case Study 15-1 and Student Project Photo

We also want to acknowledge our colleagues Laurie Tyer, who assisted us by writing the exercise at the end of Chapter 8, “Suffering and Palliative Care at the End of Life,” for both editions of this book, and Sylvia Durette who assisted with the development of Chapter 10, “Spirituality and Suffering,” for the first edition.

# About the Authors

Kathleen Ouimet Perrin, PhD, RN, is Professor Emerita of Nursing at Saint Anselm College, Manchester, New Hampshire, where she has taught courses in critical care nursing, professional nursing, understanding suffering, and evidence-based practice to baccalaureate and RN to BSN students. She received her bachelor's degree from the University of Massachusetts, Amherst; her master's from Boston College; and her doctoral degree from the Union Institute, Cincinnati, Ohio. Her primary areas of interest and publication are critical care nursing, ethical issues, nursing history, and suffering experienced by patients and healthcare providers.

Caryn A. Sheehan, DNP, APRN-BC, is Professor of Nursing at Saint Anselm College, Manchester, New Hampshire, where she teaches geriatric and medical/surgical nursing to baccalaureate nursing students. She received her bachelor's degree from Saint Anselm College; her master's from Boston College; and her doctoral degree from Case Western Reserve University, Cleveland, Ohio. Her primary areas of professional interest, publication, and practice include technology in nursing education, men's health, oncology, hospice, chronic pain, gratitude, and quality of life.

Mertie L. Potter, DNP, APRN-BC, PMHNP-BC, PMHCNS-BC, is Professor Emerita of Nursing at Massachusetts General Hospital Institute of Health Professions (The MGH Institute) in Boston, Massachusetts. She currently counsels and prescribes for patients across the life span at Merrimack Valley Counseling Association in Nashua, New Hampshire, and continues to precept psychiatric mental health nurse practitioner (PMHNP) students from The MGH Institute. She received her bachelor's degree from Simmons College, Massachusetts; her master's from the University of Michigan; her doctoral degree from Case Western Reserve University, Cleveland, Ohio; and her certificate in Family PMHNP Post Master's Certificate Program at Rutgers University, New Jersey. Her special interest areas are grieving, spirituality, body–mind–spirit health, nursing theory, suffering, medical missions, and open consultation with patients and PMHNP students.

Mary K. Kazanowski, PhD, APRN-BC, ACHPN, is a nurse practitioner on the Palliative Care Team at Elliot Hospital. She received her bachelor's degree from Saint Anselm College, New Hampshire; her master's from Boston University; and her doctoral degree from Boston College. Her special interests are in symptom management and the implementation of palliative and hospice care into the healthcare system.

## Chapter Contributors

Joshua Dion, DNP, ACNP-BC, RN-BC, is an Assistant Professor and Track Coordinator for the Adult Gerontology Acute Care Nurse Practitioner Program at The MGH Institute of Health Professions (IHP) in Boston, Massachusetts. Joshua also has an independent pain management practice in Bedford, New Hampshire, that he

started in 2007 and manages both acute and chronic pain conditions. He received his bachelor's degree in Exercise Science from the University of Massachusetts at Amherst; his master's degree in nursing from the MGH IHP; and his doctoral degree from Northeastern University, Massachusetts. Joshua's special interest areas are opioid analgesics for pain control, interventional pain management, and alternative treatments for pain.

Maureen A. Gaynor, MSN, APRN, PMHCNS-BC, AHN-BC, currently practices in an outpatient community mental health center (CMHC) in Kingsport, Tennessee, as a psychiatric nurse practitioner. She received her nursing diploma from Pilgrim State Nursing School, New York; her bachelor's degree from New York Institute of Technology; and her MSN from Stony Brook University, New York. She also specializes in holistic nursing modalities. Her interests include integrative-holistic nursing, mental health, and the promotion of self-care and well-being.