Contents

List of contributors  page ix
Acknowledgments xiii

1 Introduction to Outcomes Assessment in Cancer  1
Joseph Lipscomb, Ph.D., Carolyn C. Gotay, Ph.D., and Claire Snyder, M.H.S. (The Editors)

Health-related quality of life in cancer: general concepts and generic measures

2 Definitions and conceptual models of quality of life  14
Carol Estwing Ferrans, Ph.D., R.N., F.A.A.N.

3 Assessing health status and quality of life of cancer patients: the use of general instruments  31
Pennifer Erickson, Ph.D.

4 The roles for preference-based measures in support of cancer research and policy  69
David H. Feeny, Ph.D.

Assessing health-related quality of life during treatment

5 Quality of life in breast cancer: what have we learned and where do we go from here?  93
Patricia A. Ganz, M.D., and Pamela J. Goodwin, M.D., M.Sc.
6  Measuring quality of life in prostate cancer: progress and challenges
Mark S. Litwin, M.D., M.P.H., and James A. Talcott, M.D., S.M.

7  The science of quality-of-life measurement in lung cancer
Craig C. Earle, M.D., M.Sc., and Jane C. Weeks, M.D.

8  Treatment for colorectal cancer: impact on health-related quality of life
Carol M. Moinpour, Ph.D., and Dawn Provenzale, M.D., M.S.

9  Instruments to measure the specific health impact of surgery, radiation, and chemotherapy on cancer patients
Michael J. Barry, M.D., and Janet E. Dancey, M.D.

Assessing health-related quality of life across the cancer continuum

10 Short-term outcomes of chemoprevention, genetic susceptibility testing, and screening interventions: What are they? How are they measured? When should they be measured?
Jeanne S. Mandelblatt, M.D., M.P.H., and Joe V. Selby, M.D., M.P.H.

11 Evaluating quality of life in cancer survivors
Brad Zebrack, Ph.D., M.S.W., and David Cella, Ph.D.

12 Assessing health-related quality of life at end of life
Betty R. Ferrell, Ph.D., F.A.A.N.
Measuring the experience and needs of cancer patients and caregivers

13 Patient advocate perspective on health-related quality of life issues with prostate cancer survivors
(Col. Ret.) James E. Williams, Jr. 286

14 Measuring the patient's perspective on the interpersonal aspects of cancer care
Charles Darby 290

15 Needs assessment in cancer
David H. Gustafson, Ph.D. 305

16 Assessing the subjective impact of caregiving on informal caregivers of cancer patients
Claire Snyder, M.H.S. 329

Methodological considerations in applications to cancer outcomes research

17 Practical considerations in outcomes assessment for clinical trials
Diane L. Fairclough, Dr.P.H. 346

18 Statistical issues in the application of cancer outcome measures
Jeff A. Sloan, Ph.D. 362

19 The clinical value and meaning of health-related quality-of-life outcomes in oncology
David Osoba, B.Sc., M.D., F.R.C.P.C. 386

20 Cross-cultural use of health-related quality of life assessments in clinical oncology
Neil K. Aaronson, Ph.D. 406

Modern psychometric theory in cancer outcomes research

21 Item response theory and its applications for cancer outcomes measurement
Steven P. Reise, Ph.D. 425
22 Applications of item response theory to improve health outcomes assessment: developing item banks, linking instruments, and computer-adaptive testing
Ronald K. Hambleton, Ph.D.

23 Subscales and summary scales: issues in health-related outcomes
Mark Wilson, Ph.D.

Assessing the economic impact of cancer

24 On the definition and measurement of the economic burden of cancer
Mark C. Hornbrook, Ph.D.

25 Cost-effectiveness analysis in cancer: toward an iterative framework for integration of evidence from trials and models
Bernie J. O'Brien, Ph.D.

Research and policy implications

26 Data for cancer outcomes research: identifying and strengthening the empirical base
Carolyn C. Gotay, Ph.D., and Joseph Lipscomb, Ph.D.

27 Use of health-related quality of life measures by industry and regulatory agencies in evaluating oncology therapies
Dennis A. Revicki, Ph.D.
28 Reflections on COMWG findings and moving to the next phase 568
Carolyn C. Gotay, Ph.D., Joseph Lipscomb, Ph.D., and Claire Snyder, M.H.S.

Invited papers

Invited Paper A The world of outcomes research: yesterday, today, and tomorrow 584
Bert Spilker, Ph.D., M.D.

Invited Paper B The ten Ds of health outcomes measurement for the twenty-first century 590
Colleen A. McHorney, Ph.D., and Karon E. Cook, Ph.D.

Invited Paper C The use of cognitive interviewing techniques in quality of life and patient-reported outcomes assessment 610
Gordon B. Willis, Ph.D., Bryce B. Reeve, Ph.D., and Ivan Barofsky, Ph.D.

Invited Paper D Industry perspective regarding outcomes research in oncology 623
Kati Copley-Merriman, M.S., M.B.A., Joseph Jackson, Ph.D., J. Gregory Boyer, Ph.D., Joseph C. Cappellari, Ph.D., M.P.H., Robert DeMarinis, Ph.D., Joseph DiCesare, M.P.H., R.Ph., M. Haim Erder, Ph.D., Jean Paul Gagnon, Ph.D., Lou Garrison, Ph.D., Kathleen Gondek, Ph.D., Kim A. Heithoff, Sc.D., Tom Hughes, Ph.D., David Miller, Ph.D., Margaret Rothman, Ph.D., Nancy Santanello, M.D., M.S., Richard Willke, Ph.D., and Bruce Wong, M.D.

Index 639