Handbook of Quality of Life in Cancer

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Editor

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This work is dedicated to Panayiotis Kassianos (1945–2006).

Preface

Is quality of life more important or is it quantity of life? Or is it up to the patient to decide? The evidence on the importance of quality of life (QoL) for patients, their lives and their treatment has been widely documented in the literature. There is considerable research on the role of QoL on general well-being, responsiveness to treatment and even longevity. Therefore, it is possible that QoL can even impact quantity of life. At the same time, there are a number of methodological considerations when measuring and assessing QoL with cancer patients. This handbook aims to fill a gap in the literature, collate evidence and bring world experts together to respond to a number of questions, among others, including:

1. What is QoL, why it is important and how is it assessed?
2. What are the theoretical and methodological considerations in assessing QoL with cancer patients?
3. How can QoL be utilised in routine clinical care?
4. How is QoL impacting different cancer populations in terms of site, age, gender and context?

The Handbook of Quality of Life in Cancer summarises current evidence and can be useful for a diverse readership. First, researchers who wish to use QoL assessment tools in clinical trials or other types of research studies. Second, healthcare practitioners including clinicians, nursing professionals, social workers, physiotherapists and psychologists, among others, who want to develop their understanding of how they can utilise QoL in their practice and its importance for the patients they care for. Third, commissioners who can understand why QoL may impact population health and the implications for costs of healthcare systems. Fourth, teachers and academics who can use the handbook to inform their teaching and prepare materials, exam questions or essay topics and facilitate debates in their teaching. Finally, students in diverse fields of study including medicine, nursing, psychology, social work, medical sociology, population health, epidemiology, medical statistics and others who can use the handbook for their studies and for their continuing professional development.

You can use this handbook in different ways that fit your learning purpose. We tried to summarise evidence in each chapter and provide elements that can help you to check your understanding of each topic and facilitate discussions with others either in a classroom or in practice. These elements include:

1. *Questions that can be used in teaching and to test learning*. These are questions that the authors of each chapter have considered carefully in order to help you to test and summarise your knowledge on each topic.
2. *A topic that can be used for discussion in teaching.* These topics are considered key for each chapter and can help facilitate debates and classroom interactive discussions as well as help you to consider issues that can be controversial or that can help develop your critical thinking on the topic.
3. *A 'further reading' list.* These lists are different than the reference lists for each chapter. The purpose here is to highlight what are the important publications for each topic so that you can easily expand your knowledge and identify further resources.
4. *A 'research in context' box* where authors have identified a key topic, publication or tool and have expanded on this with more details so that you can get further in-depth knowledge of a topic.

The first part of the handbook, *Concepts and Definitions*, is introductory and here you can read about important concepts and definitions. Concepts like QoL, health-related quality of life (HRQoL) and wellbeing are defined in Chap. 1, while Chap. 2 deals with what it means for patients to have QoL in relation to quantity of life.

The second part of the handbook, *Quality of Life Assessment*, deals with different aspects of assessing QoL of cancer patients. Generic tools like the WHOQOL group of tools are discussed in Chap. 3, while cancer-specific tools developed by the European Organisation for Research and Treatment of Cancer (EORTC) and the Functional Assessment of Chronic Illness Therapy (FACIT) measurement systems are discussed in detail in Chaps. 5 and 6, respectively. Chapter 4 outlines all aspects that should be considered when developing a cancer QoL assessment tool, and Chap. 7 outlines what should be considered when validating the tools. Modern technologies in assessing QoL are becoming more prevalent and will continue to be in the years to come. These are discussed in terms of using new technologies for QoL assessment in Chap. 8 and in terms of modern psychometric measurement and computerised adaptive testing in Chap. 9.

The third part of the handbook, *Best-Practice Elements When Assessing Quality of Life*, deals with best-practice elements of using QoL data. How the data can be analysed in clinical trials and beyond is discussed in Chap. 10, and how data can be presented visually to communicate these to patients and clinicians is discussed in Chap. 11. Subsequently, Chap. 12 outlines cross-cultural considerations of QoL assessment such as cultural validity and considerations when translating measures or using them with diverse populations and contexts. A number of subsequent chapters outline which topics QoL data can be used for and inform such as mortality aspects (Chap. 13), healthcare cost-effectiveness (Chap. 14), patient satisfaction with care in the context of patient-reported experience measures (Chap. 15), decision-making in health care (Chap. 20) and drug development (Chap. 21). Chapter 16 focuses on a specific symptom (fatigue) that warrants greater focus from researchers and clinicians, and Chaps. 17 and 18, respectively, outline the use of QoL data for specific populations (adolescents and young adults) and as a proxy

measure for patients. Chapter 19 outlines the evidence on studies with psychosocial interventions with QoL as an outcome and how mental health can be related to QoL.

The fourth part of the handbook, *Case Studies of Using Quality of Life Tools for Specific Cancer Types*, presents some case studies on QoL aspects of specific cancer populations: breast cancer (Chap. 22), brain cancer (Chap. 23), colorectal cancer (Chap. 24), endometrial cancer (Chap. 25) and melanoma (Chap. 26). These chapters offer more in-depth information on patients with different tumour sites and how their QoL can be affected, as well as the specific tools that can be used for these populations.

The Handbook of Quality of Life in Cancer makes a unique contribution to knowledge by collating contemporary evidence and perspectives with practical guidance. It is also designed to be useful for a diverse readership and offers food for thought for new directions for research and clinical practice towards improving QoL for cancer patients.

London, UK Angelos P. Kassianos

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About the Contributors

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Amélie Anota, PhD is a senior statistician at the Cancer Care Center Léon Bérard in France. She is expert in the longitudinal analysis of quality of life data in oncology. After obtaining a PhD in biostatistics in 2014 at the University of Franche-Comté, France, she realised a one-year research fellowship in the Health Outcomes Research Unit of the GIMEMA Fondazione in Rome, Italy. She previously worked at the University Hospital of Besançon and is also statistician for the French National Platform of Quality of Life and Cancer.

Iris Bartula, DCP is a clinical and research psychologist. She is a senior lecturer at the University of Sydney and leads supportive care and survivorship research at Melanoma Institute Australia. Both her clinical work and research efforts focus on improving quality of life and emotional wellbeing of melanoma patients. She has particular interest in the development, validation and implementation of psychometric measurements and psychosocial interventions. She is a strong advocate for consideration and integration of psychosocial support into a routine medical practice.

Melanie Bell, PhD, MS is professor in the Department of Epidemiology and Biostatistics at the Mel and Enid Zuckerman College of Public Health at the University of Arizona. Her research focus is statistical methods for handling missing data in randomised trials, and the design and analysis of studies using patient-reported outcomes. She has published extensively both in methodological issues in the design and analysis of patient-reported outcomes, as well as collaboratively for trials that use patient-reported outcomes.

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Jason Bredle, MFA is the director of licensing operations for FACIT.org and coordinates the translation and linguistic validation of the FACIT measurement system with FACITtrans in the United States. His contributions to linguistics and health outcomes have appeared in *Quality of Life Research*, *International Journal of Infectious Diseases*, *Journal of Palliative Medicine*, *Value in Health Regional Issues*, and *Pulmonary Therapy*, and have been presented at international forums in the United States, Canada, France and the Netherlands, among other places.

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Mbathio Dieng, PhD is a recognised expert in health economics, epidemiology and cancer quality of life research. She is currently a postdoctoral research fellow at the NHMRC Clinical Trials Centre, a specialised centre of the University of Sydney that has more than 25 years of expertise conducting randomised trials including landmark studies in cancer. Dr. Dieng has strong experience in within-trial and modelled economic evaluation applied to cancer, and her current research interests cover the areas of diagnostic tests, quality of life, benefits and harms of patient follow-up and monitoring, randomised control trials incorporating patient preferences, and the specific economic methods underpinning these.

Linda Dirven, PhD is an epidemiologist at the Leiden University Medical Center and Haaglanden Medical Center in the Netherlands. She became the chair of the EORTC Brain Tumour Group Quality of Life Committee in 2018. She is currently associate editor of *Neuro-Oncology*. The main focus of her research is clinical outcome measures in neuro-oncology, such as health-related quality of life, functioning in daily life, neurocognition, epilepsy and end-of-life care.

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Abbreviations

ACT	Acceptance and Commitment Therapy
ADL	Activities of Daily Living
AJCC	American Joint Committee on Cancer
ALL	Acute Lymphoblastic Leukaemia
ANOVA	Analysis of Variance
AQOL	Assessment of Quality of Life
AS	Active Surveillance
ATA	American Telemedicine Association
AUC	Area Under the Curve
AYAs	Adolescents and Young Adults
BCT	Breast-Conserving Therapy
BLA	Biological License Application
BP	Brief Psychotherapy
CAHPS	Consumer Assessment of Healthcare Providers and Systems
CAM	Complementary and Alternative Medicine
CASC	Comprehensive Assessment of Satisfaction with Care
CAT	Computerised Adaptive Testing
CAYA-T	Cancer Assessment for Young Adults-Testicular
CBT	Cognitive Behavioural Therapy
CCA	Cross-Cultural Adaptation
CDC	Centers for Disease Control and Prevention
CDF	Cumulative Distribution Function
CFA	Confirmatory Factor Analysis
CFI	Comparative Fit Index
CIs	Confidence Intervals
ClinROs	Clinician-Reported Outcomes
CNS	Central Nervous System
COAs	Clinical Outcome Assessments
COC	Consensus on Cancer
COS	Core Outcome Sets
COSMIN	COnsensus-based Standards for the selection of health Measurement INstruments
CRC	Colorectal Cancer
CRCI	Cancer-Related Cognitive Impairment
CrF	Cancer-Related Fatigue
CT	Chemotherapy / Cognitive Therapy / Computed Tomography

CUA	Cost-Utility Analysis
DFS	Disease-Free Survival
DIF	Differential Item Functioning
EC	Endometrial Cancer
eCDF	Empirical Cumulative Distribution Function
ECOG	Eastern Cooperative Oncology Group
EFA	Exploratory Factor Analysis
EHR	Electronic Health Records
EMA	European Medicines Agency
EORTC CAT	European Organisation for Research and Treatment of Cancer Computerised Adaptive Testing
EORTC QLQ	European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire
EORTC QOL	European Organisation for Research and Treatment of Cancer Quality of Life
EORTC	European Organisation for Research and Treatment of Cancer
EPIC	Expanded Prostate Cancer Index Composite
ePROs	Electronic Patient-Reported Outcomes
ES	Effect Size
ESMO	European Society for Medical Oncology
FACIT	Functional Assessment of Chronic Illness Therapy
FACIT-SP	Functional Assessment of Chronic Illness Therapy-Spiritual Wellbeing
FACT	Functional Assessment of Cancer Therapy
FACT-Cog	Functional Assessment of Cancer Therapy-Cognitive Function
FACT-G	Functional Assessment of Cancer Therapy-General
FACT-GP	Functional Assessment of Cancer Therapy-General Population
FACT-M	Functional Assessment of Cancer Therapy-Melanoma
FACT-PWB	Functional Assessment of Cancer Therapy-Physical Wellbeing
FCR	Fear of Cancer Recurrence
FDA	Food and Drug Administration
FIGO	International Federation of Gynaecology and Obstetrics
FKSI	FACT Kidney Symptom Index
FLIC	Functional Living Index-Cancer
FPQLI	Ferrans & Powers Quality of Life Index
GDI	Good Death Inventory
GDP	Gross Domestic Product
GEE	Generalised Estimating Equation
HADS	Hospital Anxiety and Depression Scale
HBM	Health Belief Model
HCC	Hepatocellular Carcinoma
HCPs	Healthcare Professionals (or Providers)
HL	Hodgkin Lymphoma
HNPCC	Hereditary Nonpolyposis Colorectal Cancer

HPA	Hypothalamic Pituitary Adrenal (axis)
HRQoL	Health-Related Quality of Life
HRSA	Health Resources and Services Administration
HS	Perceived Health Status
HSCT	Hematopoietic Stem Cell Transplantation
HUI	Health Utility Index
IARC	International Agency for Research on Cancer
ICC	Intraclass Correlation Coefficient
ICD-11	International Statistical Classification of Diseases and Related Health Problems
ICER	Incremental Cost Effectiveness Ratio
ICI	Isolated Limb Infusion
ILP	Isolated Limb Perfusion
IOM	Institute of Medicine
IPOS	Integrated Palliative Care Outcome Scale
IPSS	International Prognostic Scoring System
IRT	Item Response Theory
ISOQOL	International Society for Quality of Life Research
ISPOR	International Society for Health Economics and Outcomes Research
IVR	Interactive Voice Response
JLA	James Lind Alliance
KPS	Karnofsky Performance Status
LAF	Lance Armstrong Foundation
LAYA-SRQL	Late Adolescence and Young Adulthood Survivorship-Related Quality of Life measure
LCI	Likely Change Index
LD	Local Dependence
LND	Lymph Node Dissection
LOA	Limits of Agreement
LoL	Longevity of Life
LS	Least Squares
MAR	Missing At Random
MAUCa	Multi-Attribute Utility in Cancer
MAUIs	Multi-Attribute Utility Instruments
MBCT	Mindfulness-Based Cognitive Therapy
MBSR	Mindfulness-Based Stress Reduction
MCAR	Missing Completely at Random
MCS	Mental Component Summary score
MCT	Meaningful Change Thresholds
MDASI	MD Anderson Symptom Inventory
MEK	Mitogen-activated protein kinase
MI	Multiple Imputation
MIDs	Minimal Important Difference
MMRMs	Mixed Models for Repeated Measures
MNAR	Missing Not at Random
MQOL	McGill Quality of Life
MSAS	Memorial Symptom Assessment Scale

MTC	Mastectomy
NATs	Negative Automatic Thoughts
NCCN	National Comprehensive Cancer Network
NCI	National Cancer Institute
NHL	Non-Hodgkin Lymphoma
NHS	National Health Service
NHSS	National Health Services Survey
NICE	National Institute for Health and Care Excellence
NIH	National Institutes of Health
NIS	National Insurance Services
NPC	Nasopharyngeal Carcinoma
ObsROs	Observer-Reported Outcomes
OECD	Organisation for Economic Co-operation and Development
ORR	Overall Response Rate
PASS	Power Analysis and Sample Size
PC	Prostate Cancer
PCM	Partial Credit Model
PCOC	Palliative Care Outcomes Collaboration
PediQUEST	Pediatric Quality of Life and Evaluation of Symptoms Technology
Peds FACT-Br	Pediatric Functional Assessment of Cancer Therapy – Brain
PedsQL	Pediatric Quality of Life Inventory
PerfOS	Performance Outcomes
PET	Positron Emission Tomography
PFS	Progression-Free Survival
PGIC	Patient Global Impression of Change
PhD	Doctorate of Philosophy
PHQ	Patient Health Questionnaire
PMH/PSQ	Princess Margaret Hospital Patient Satisfaction Questionnaire
PREMs	Patient-Reported Experience Measures
PRO-CTCAE	Patient-Reported Outcome – Common Terminology Criteria for Adverse Events
PROMIS	Patient-Reported Outcome Measures Information System
PROMs	Patient-Reported Outcome Measures
PRO-PMs	Patient-Reported Outcomes – Performance Measures
PROs	Patient-Reported Outcomes
PROTEUS	Patient-Reported Outcome Tools: Engaging Users and Stakeholders
QALY	Quality-Adjusted Life Years
QLG	Quality of Life Group
QLIC-ON	Quality of Life in Childhood Oncology
QLU-CIOD	Quality of Life Utility Measure-Core 10 Dimensions
QODD	Quality of Death and Dying
QOF	Quality and Outcomes Framework
QoL	Quality of Life
QOLCC	Quality of Life in Childhood Cancer

QOLIE	Quality of Life in Epilepsy Inventory
RCI	Reliable Change Index
RCT	Randomised Controlled Trial
REML	Restricted Maximum Likelihood
RI	Radiation-Induced Brain Injury
RIME	Relaxation, Mental Images and Spirituality
RMSEA	Root Mean Square Error of Approximation
ROC	Receiver Operating Characteristic Curve
RP	Radical Prostatectomy
RPM	Remote Patient Monitoring
RSM	Rating Scale Model
RT	Radiotherapy
RWD	Real World Data
RWE	Real World Evidence
SDC	Smallest Detectable Change
SEER	Surveillance, Epidemiology and End Results
SEM	Standard Error of Measurement
SES	Standardised Effect Size
SET	Supportive-Expressive Group Therapy
SF-12	Short Form 12
SF-36	Short Form 36
SG	Sun Ginseng
SGO	Society of Gynecologic Oncology
SISAQOL	Setting International Standards in Analyzing Patient-Reported Outcomes and Quality of Life Endpoints
SLNB	Sentinel Lymph Node Biopsy
SML	Social Media Listening
SMR	Social Media Review
SRM	Standardised Response Mean
SRMR	Standardised Root Mean Square (residual)
SRPB	Spirituality, Religion and Personal Beliefs
TAH	Total Abdominal Hysterectomy
TCIs	Threshold for Clinical Importance
TNF	Tumour Necrosis Factor (receptor)
UK	United Kingdom
US	United States
VBT	Vaginal Brachytherapy
WCSQ	Worthing Chemotherapy Satisfaction Questionnaire
WHO	World Health Organization
WHOQOL	World Health Organization Quality of Life

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