

VOLUME 18 NUMBER 2 APRIL, 2020

# Palliative & Supportive Care

CAMBRIDGE  
UNIVERSITY PRESS

# Palliative & Supportive Care

## Editor-in-Chief

William Breitbart, M.D.  
Memorial Sloan Kettering Cancer Center  
Department of Psychiatry & Behavioral Sciences  
641 Lexington Avenue, 7th Floor  
New York, NY 10022  
Phone: (646) 888-0020  
Fax: (212) 888-2356  
E-mail: breitbart@mskcc.org

## Managing Editor

Theresa Carpenter, B.S.  
Memorial Sloan Kettering Cancer Center  
Department of Psychiatry & Behavioral Sciences  
641 Lexington Avenue, 7th Floor  
New York, NY 10022  
Phone: (646) 888-0056  
Fax: (212) 888-2356  
E-mail: carpentt@mskcc.org

## Associate Editors

Allison Applebaum, Ph.D., *Memorial Sloan Kettering Cancer Center, USA*  
Gian Domenico Borasio, M.D., *Centre Hospitalier Universitaire Vaudois (CHUV), Switzerland*  
Harvey Chochinov, M.D., *University of Manitoba, Canada*  
Juhee Cho, Ph.D., *SAIHST, Sungkyunkwan University, South Korea*

Gil Goldezwieg, Ph.D., *The Academic College of Tel Aviv-Yaffo, Tel Aviv, Israel*  
Mayumi Ishida, CP, Ph.D., *Saitama Medical University International Medical Center, Japan*  
Matthew Loscalzo, M.D., *City of Hope – Department of Supportive Care Medicine / Sheri & Les Biller Patient and Family Resource Center, USA*

## Editorial Board

Tatsuo Akechi, M.D., *Nagoya City University, Japan*  
Yesne Alici, M.D., *Memorial Sloan Kettering Cancer Center, USA*  
Eduardo Bruera, MD *Anderson Cancer Center, USA*  
Phyllis Butow, Ph.D., *University of Sydney, Australia*  
Maria E. Carlsson, *Uppsala University, Sweden*  
Nathan I. Chorney, *Shaare Zedek Medical Center, Israel*  
Nessa Coyle, *Memorial Sloan Kettering Cancer Center, USA*  
Albert Diefenbacher, *Evangelische Krankenhaus Königin Elisabeth Herzberge, Germany*  
Sylvie Dolbeault, *Institut Curie, France*  
Martin Fegg, M.D., *University of Munich, Germany*  
Richard Fielding, Ph.D., *University of Hong Kong, Hong Kong*  
Linda Ganzini, *Oregon Health & Science University, USA*  
Francisco Gil, M.D., *Catalan Institute of Oncology, Spain*

Paul Glare, M.D., *University of Sydney, Australia*  
Xavier Gómez-Batiste, M.D., Ph.D., *Catalan Institute of Oncology, Spain*  
Luigi Grassi, M.D., *University of Ferrara, Italy*  
Stein Kaasa, *Norwegian University of Science and Technology, Norway*  
Brian Kelly, *The University of Newcastle, Australia*  
David Kissane, M.D., *Monash University, Australia*  
Mark Lazenby, RN, *Yale University, USA*  
Virginia Lee, RN, Ph.D., *McGill University, Canada*  
Madeline Li, M.D., *University of Toronto, Canada*  
Wendy Lichtenthal, Ph.D., *Memorial Sloan Kettering Cancer Center, USA*  
Anja Mehnart, Ph.D., *University of Leipzig, Germany*  
Lisa Miller, *9 Tralee Road, Floreat, Western Australia*  
Tatsuya Morita, M.D., *Seirei Mikatabara General Hospital, Japan*  
Patricia Parker, Ph.D., *Memorial Sloan Kettering Cancer Center, USA*  
Holly Prigerson, Ph.D., *Cornell University, USA*

Christina Pulchalski, M.D., *George Washington University, USA*  
Michel Reich, *Centre Oscar Lambret, France*  
Carla Ripamonti, M.D., *Istituto di Tumori, Italy*  
Barry Rosenfeld, Ph.D., *Fordham University, USA*  
Tone Rustoen, RN, Ph.D., *Oslo University College, Norway*  
Frederic Stiefel, M.D., *University of Lausanne, Switzerland*  
Lilli Tang, M.D., *Central South University, China*  
Luzia Travado, Ph.D., *Champalimaud Clinical and Research Center, Portugal*  
James Tulskey, M.D., *Dana-Farber Cancer Institute, USA*  
Yosuke Uchitomi, M.D., *National Cancer Center, Japan*  
Alan Valentine, M.D., *University of Texas, USA*  
Maggie Watson, Ph.D., *The Royal Marsden Hospital, UK*  
Lori Weiner, Ph.D., *National Cancer Institute, USA*

## Emeritus

Lea Baider, *Sharett Institute of Oncology, Israel*  
Susan Block, *Dana-Farber Cancer Institute, USA*  
Irene Higginson, *King's College London, UK*  
Paul Jacobsen, Ph.D., *National Cancer Institute, USA*

Professor Uwe Koch, *University Hospital at Hamburg-Eppendorf, Germany*  
Neil MacDonald, *McGill University, Canada*

**Palliative & Supportive Care** (ISSN: 1478-9515) is a bimonthly international journal of palliative medicine that focuses on the psychiatric, psychosocial, spiritual, existential, ethical, and philosophical aspects of palliative care. The journal's aim is to serve as an educational resource for practitioners from a wide array of disciplines engaged in the delivery of care to those with life threatening illnesses along the entire continuum of care from diagnosis to the end of life.

© **Cambridge University Press, 2020**. All rights reserved. No part of this publication may be reproduced, in any form or by any means, electronic, photocopying, or otherwise, without permission in writing from Cambridge University Press. For further information see <http://us.cambridge.org/formation/rights/> or <http://www.cambridge.org/uk/information/rights/>. Authorization to photocopy items for internal or personal use, or the internal or personal use of specific clients, is granted by Cambridge University Press, provided that the appropriate fee is paid directly to Copyright Clearance Center, 222 Rosewood Drive, Danvers, MA 01923, USA (Telephone: (508) 750-8400), stating the ISSN (1478-9515/15 \$20.00), the volume, and the first and last page numbers of each article copied. The copyright owner's consent does not include copying for general distribution, promotion, new works, or resale. Ad sales: contact M. J. Mrvica Associates, 2 West Taunton Avenue, Berlin, NJ 08009; Phone: 856-768-9360; Fax: 856-753-0064; E-mail: [mjmrvica@mrvica.com](mailto:mjmrvica@mrvica.com).

**2020 Subscription Rates:** **Palliative & Supportive Care** is published in February, April, June, August, October, and December by Cambridge University Press, One Liberty Plaza, New York, NY 10006, USA / Cambridge University Press, University Printing House, Shaftesbury Road, Cambridge CB2 8BS, UK. Institutions electronic only: US \$647.00 in the USA, Canada, and Mexico; UK £374.00 + VAT elsewhere. Individuals electronic only: US \$368.00 in the USA, Canada, and Mexico; UK £203.00 + VAT elsewhere. Subscribers in the USA, Canada, and Mexico should send their orders, with payment in US dollars or the equivalent value in Canadian dollars to: Cambridge University Press, Journals Customer Services Department, One Liberty Plaza, New York, NY 10006, USA. Orders may be phoned direct (toll free): (800) 872-7423. E-mail: [subscriptions\\_newyork@cambridge.org](mailto:subscriptions_newyork@cambridge.org). Subscribers elsewhere should send their orders with payment in sterling to: Journals Customer Services Department Cambridge University Press, University Printing House, Shaftesbury Road, Cambridge, CB2 8BS, United Kingdom. Telephone: +44 (0) 1223 326070. E-mail: [journals@cambridge.org](mailto:journals@cambridge.org).

**Abstracted and indexed in the following:** CINAHL database; Cumulative Index to Nursing and Allied Health Literature; MEDLINE

**Change of address:** Allow six weeks for all changes to become effective. All communication should include both old and new addresses (with postal codes) and should be accompanied by a mailing label from a recent issue.

**Editorial Office:** William Breitbart, Editor-in-Chief, Memorial Sloan Kettering Cancer Center, Department of Psychiatry and Behavioral Sciences, 641 Lexington Avenue, New York, NY 10022, USA. Telephone: (646) 888-0020. Fax: (212) 888-2356. E-mail: [breitbart@mskcc.org](mailto:breitbart@mskcc.org).

**Office of Publication:** Cambridge University Press, One Liberty Plaza, New York, NY 10006, USA: Telephone: (212) 337-5000. Fax: (212) 337-5959.

Printed in the United States of America on acid-free paper.

## CONTENTS

### Editorial

- WILLIAM BREITBART 128 In Memoriam: Marguerite S. Lederberg, M.D. (1937–2020)

### Original Articles

- JOANNE BROOKER, JOHN JULIAN, JEREMY MILLAR, H. MILES PRINCE, MELITA KENEALY, KIRSTEN HERBERT, ANNETTE GRAHAM, ROBIN SMITH, DAVID KISSANE, KAREN TAYLOR, MARK FRYDENBERG, IAN PORTER, JANE FLETCHER, IAN HAINES AND SUE BURNEY 130 A feasibility and acceptability study of an adaptation of the Mindful Self-Compassion program for adult cancer patients
- HANNEKE POORT, JAMIE M. JACOBS, WILLIAM F. PIRL, JENNIFER S. TEMEL AND JOSEPH A. GREER 141 Fatigue in patients on oral targeted or chemotherapy for cancer and associations with anxiety, depression, and quality of life
- SOENKE BOETTGER, RAFAEL MEYER, ANDRÉ RICHTER, ALAIN RUDIGER, MARIA SCHUBERT, JOSEF JENEWEIN AND DAVID GARCIA NUÑEZ 148 Delirium in the intensive care setting dependent on the Richmond Agitation and Sedation Scale (RASS): Inattention and visuo-spatial impairment as potential screening domains
- MEAGHANN S. WEAVER, JACOB ROBINSON AND CHRISTOPHER WICHMAN 158 Aromatherapy improves nausea, pain, and mood for patients receiving pediatric palliative care symptom-based consults: A pilot design trial
- CHIN YEE CHEONG, NGOC HUONG LIEN HA, LAURENCE LEAN CHIN TAN AND JAMES A. LOW 164 Attitudes towards the dying and death anxiety in acute care nurses – can a workshop make any difference? A mixed-methods evaluation
- VANESSA L. BEESLEY, ALEKSANDRA STANEVA, CAROLINE NEHILL, VIVIENNE MILCH, FELICITY HUGHES AND PENELOPE M. WEBB 170 Patterns of, and barriers to supportive care needs assessment and provision for Australian women with gynecological cancer and their caregivers: a mixed-methods study of clinical practice
- M. GRAÇA PEREIRA, MARGARIDA VILAÇA, MARTA PEREIRA, ROSÁRIO BACALHAU, SARA MONTEIRO, BRUNA FERNANDES, SARA FARIA AND GABRIELA FERREIRA 178 Validation of the caregiver oncology quality of life questionnaire in Portuguese caregivers of myeloma patients
- WILLIAM EDUARDO PIROLA, BIANCA SAKAMOTO RIBEIRO PAIVA, CLEYTON ZANARDO DE OLIVEIRA, GIANCARLO LUCCHETTI, ALESSANDRA LAMAS GRANERO LUCCHETTI, DAVID KISSANE AND CARLOS EDUARDO PAIVA 186 Validation of the Brazilian version of the Shame and Stigma Scale (SSS-Br) for patients with head and neck cancers
- CHRISTIANE KREYER, JOHANNES BÜKKI AND SABINE PLESCHBERGER 193 Development of a German version of the Carer Support Needs Assessment Tool (CSNAT): The process of translation and cultural adaptation
- MIGUEL JULIÃO, BÁRBARA ANTUNES, ANA SANTOS, MARIA ANA SOBRAL, SARA ALBUQUERQUE, FILIPA FARELEIRA, DANIELA RUNA, PAULO FARIA DE SOUSA, PETRA CHAVES, CÉLIA GONÇALVES, DUARTE SOARES AND HARVEY MAX CHOCHINOV 199 Adapting the Portuguese dignity question framework for adolescents: ages 10–18
- ELISSA KOLVA, LILIAN HOFFECKER AND EMILY COX-MARTIN 206 Suicidal ideation in patients with cancer: A systematic review of prevalence, risk factors, intervention and assessment
- CAROL Y. OCHOA, NATASHA BUCHANAN LUNSFORD AND JUDITH LEE SMITH 220 Impact of informal cancer caregiving across the cancer experience: A systematic literature review of quality of life

### Review Articles

## Case Report

HIDEKI ONISHI, TAKASHI OKABE, NOZOMU UCHIDA,  
SUGURU SHIROTAKE, MAKI TODO, MASAFUMI OYAMA  
AND MAYUMI ISHIDA 241

Thiamine deficiency in a patient with recurrent renal cell carcinoma who developed weight loss with normal appetite and loss of energy soon after nivolumab treatment

## Essay/Personal Reflection

ALDIS HARALDS PETRICEKS 244

Hospice and the giant: A volunteer's story

HENRY BAIR 246

The lost art of letter writing

EMILY ADAM 248

The Tulip - A Personal Reflection from a Hospice Doctor

## Poetry

IJEOMA JULIE ECHE 249

Patience

## Letter to the Editor

SUSANA MIGUEL AND SILVIA CALDEIRA 250

A commentary on: Pirola et al. (2019) "Validation of the Brazilian version of the Shame and Stigma Scale (SSS-Br) for patients with head and neck cancers"