



# Perawatan Paliatif

## Kebutuhan Psikososial-Spiritual untuk Pasien dan Keluarga

Ns. Bunga Permata Wenny., M.Kep. | Ns. Okky Adelirandy, S.Kep

Editor  
Bingar Hernowo



# Perawatan Paliatif

## Kebutuhan Psikososial-Spiritual untuk Pasien dan Keluarga

Perawatan paliatif merupakan perawatan yang sudah mulai meluas dikenal dan dibutuhkan. Identik sebagai perawatan yang diberikan kepada individu dengan prognosis penyakit yang panjang atau akan menghadapi akhir hayat, maka pasien maupun keluarga yang menjalani perawatan paliatif sangat rentan untuk mengalami masalah pada aspek psikososial-spiritual. Perawat sebagai salah satu tim kesehatan yang berperan penting dalam pemberian perawatan paliatif, diharapkan untuk dapat memberikan dan melihat aspek-aspek psikososial-spiritual secara komprehensif sebagai bagian utuh dari individu dan keluarga.

Untuk efektivitas intervensi psikososial-spiritual, maka diperlukan pedoman dan panduan yang dapat dijadikan acuan dan dilaksanakan oleh perawat sebagai bagian tim interprofessional dalam perawatan paliatif. Pelaksanaan intervensi tersebut juga dapat dilaksanakan tidak hanya di rumah sakit, tapi juga di dalam keluarga dan komunitas. Dengan demikian, perawat diharapkan dapat memainkan peran penting dalam perawatan paliatif.



☎ 0858 5343 1992  
✉ eurekamediaaksara@gmail.com  
📍 Jl. Banjaran RT.20 RW.10  
Bojongsari - Purbalingga 53362

ISBN 978-623-151-200-0



**PERAWATAN PALIATIF:  
KEBUTUHAN PSIKOSOSIAL-SPIRITUAL  
UNTUK PASIEN DAN KELUARGA**

Ns. Bunga Permata Wenny, M.Kep.

Ns. Okky Adelirandy, S.Kep.



**PENERBIT CV.EUREKA MEDIA AKSARA**

**PERAWATAN PALIATIF: KEBUTUHAN PSIKOSOSIAL-  
SPIRITUAL UNTUK PASIEN DAN KELUARGA**

**Penulis** : Ns. Bunga Permata Wenny, M.Kep.  
Ns. Okky Adelirandy, S.Kep.

**Editor** : Bingar Hernowo

**Penyunting** : Ari Sulistyawati

**Desain Sampul** : Ardyan Arya Hayuwaskita

**Tata Letak** : Vivi Fajar Setyaningrum, S.Pd.

**ISBN** : 978-623-151-200-0

Diterbitkan oleh: **EUREKA MEDIA AKSARA, JUNI 2023**  
**ANGGOTA IKAPI JAWA TENGAH**  
**NO. 225/JTE/2021**

**Redaksi:**

Jalan Banjaran, Desa Banjaran RT 20 RW 10 Kecamatan Bojongsari  
Kabupaten Purbalingga Telp. 0858-5343-1992

Surel : eurekamediaaksara@gmail.com

Cetakan Pertama : 2023

**All right reserved**

Hak Cipta dilindungi undang-undang

Dilarang memperbanyak atau memindahkan sebagian atau seluruh isi buku ini dalam bentuk apapun dan dengan cara apapun, termasuk memfotokopi, merekam, atau dengan teknik perekaman lainnya tanpa seizin tertulis dari penerbit.

## KATA PENGANTAR

Alhamdulillah kami panjatkan ke hadirat Allah Ta'ala, yang telah memberikan rahmat, hidayah, dan karunia-Nya sehingga buku ini dapat terwujud. Buku ini berjudul "Perawatan Paliatif: Kebutuhan Psikososial-Spiritual Pasien dan Keluarga" adalah sebuah upaya untuk memberikan gambaran mengenai kebutuhan psikososial-spiritual yang diberikan di dalam perawatan paliatif terhadap pasien dan keluarga secara komprehensif. Paliatif seringkali dikaitkan dengan kondisi dengan prognosis yang panjang atau menghadapi akhir kehidupan. Hal ini tidak hanya memiliki pengaruh yang besar terhadap kondisi fisik tetapi juga psikososial-spiritual pasien dan keluarga. Sebagai kondisi yang kompleks baik di rumah sakit, keluarga, maupun komunitas, perawat berperan besar dalam memperhatikan aspek-aspek psikososial-spiritual ini, dan melakukan kerjasama interprofessional untuk mencapai perawatan yang berkualitas dan maksimal.

Tujuan penulisan buku ini adalah memberikan pemahaman yang mendalam tentang kondisi psikososial-spiritual yang biasa muncul pada pasien paliatif, sehingga perawat diharapkan dapat memperhatikan aspek-aspek tersebut di dalam memberikan perawatan paliatif. Selain itu, buku ini juga menyajikan beberapa pedoman-pedoman dalam perawatan terkait psikososial-spiritual ini.

Penulis berharap bahwa buku ini akan menjadi sumber pengetahuan yang berharga bagi perawat, tenaga medis, pekerja sosial paliatif, kader pendamping, komunitas dan semua pihak yang terlibat dalam perawatan paliatif. Akhir kata, semoga buku ini dapat memberikan wawasan dan inspirasi kepada para pembaca untuk terus berperan aktif dalam memberikan dukungan dan perhatian terhadap aspek psikososial-spiritual pasien dan keluarga dalam perawatan paliatif.

Padang, 7 Juni 2023  
Penulis

## DAFTAR ISI

<b>KATA PENGANTAR.....</b>	<b>iii</b>
<b>DAFTAR ISI.....</b>	<b>iv</b>
<b>BAB 1 MASALAH PSIKOSOSIAL PADA PERAWATAN</b>	
<b>PALIA TIF.....</b>	<b>1</b>
A. Kelelahan.....	1
B. Depresi .....	8
C. Bunuh Diri.....	12
<b>BAB 2 INTERVENSI PSIKOSOSIAL UNTUK PASIEN DAN</b>	
<b>KELUARGA .....</b>	<b>20</b>
A. Efektivitas Intervensi Psikososial Pada Pasien	
Perawatan Paliatif Kompleks .....	20
B. Intervensi dan Interpretasi untuk Keluarga.....	25
<b>BAB 3 DUKUNGAN PERAWAT PADA KELUARGA DALAM</b>	
<b>PERAWATAN PALIA TIF .....</b>	<b>36</b>
A. Pemberian Dukungan terhadap Keluarga di Dalam	
Perawatan Paliatif.....	36
B. Panduan Dukungan Psikososial dan Dukacita	
Keluarga .....	42
C. Pedoman untuk Dukungan kepada Keluarga .....	45
<b>BAB 4 SPIRITUALITAS DALAM PERAWATAN PALIA TIF...50</b>	
A. Spiritual Perawatan Paliatif.....	50
B. Domain Perawatan Spiritual .....	53
C. Komunikasi dan Penilaian.....	54
<b>DAFTAR PUSTAKA.....</b>	<b>62</b>
<b>TENTANG PENULIS.....</b>	<b>77</b>

# BAB

# 1

## MASALAH PSIKOSOSIAL PADA PERAWATAN PALIATIF

### A. Kelelahan

#### 1. Manajemen Kelelahan di dalam Perawatan Paliatif

Walaupun hanya diakui sebagai bidang spesialisasi medis pada tahun 1987, perawatan paliatif memiliki sejarah yang jauh lebih lama dari tanggal tersebut. Evolusi ke dalam layanan yang terlihat hari ini dapat ditelusuri ke beberapa tokoh inspiratif yang tekad dan dinamismenya mendorong perubahan radikal dalam merawat orang yang sekarat. Yang paling utama adalah Dame Cicely Saunders yang sebagian besar dipuji karena menginspirasi gerakan rumah sakit modern. Namun, asal-usul perawatan paliatif dapat ditelusuri kembali jauh lebih jauh.

Kelelahan didefinisikan sebagai perasaan subjektif dari kelelahan, kelemahan umum, atau kekurangan energi (Radbruch et al., 2008). Tidak ada definisi kelelahan yang diterima secara universal. Kelelahan terkait kanker didefinisikan oleh *National Comprehensive Cancer Network* sebagai rasa tertekan, persisten, subjektif dari kelelahan fisik, emosional, dan/atau kognitif atau kelelahan yang berhubungan dengan kanker dan/atau pengobatan kanker yang tidak sebanding dengan aktivitas terkini dan mengganggu fungsi yang biasa (NCCN, 2013). Kelelahan sangat lazim dalam pengaturan perawatan paliatif. Studi tersebut menunjukkan bahwa sebanyak 60% sampai 90% pasien kanker stadium lanjut mengeluh kelelahan. Kelelahan

# BAB

# 2

## INTERVENSI PSIKOSOSIAL UNTUK PASIEN DAN KELUARGA

### A. Efektivitas Intervensi Psikososial Pada Pasien Perawatan Paliatif Kompleks

#### 1. Intervensi Psikososial

Pengentasan penderitaan sangat penting pada pasien dengan penyakit lanjut dalam situasi akhir kehidupan (WHO, 2013). Pada tahun 2013, Organisasi Kesehatan Dunia (WHO) menerbitkan sebuah resolusi yang mendesak negara-negara untuk memperkuat pemberian perawatan paliatif. The Spanish Society of Palliative Care (SECPAL, 2002, dan WHO telah menetapkan pedoman untuk mengarahkan intervensi perawatan paliatif dan memberikan pendekatan terapeutik berbasis perawatan paliatif tertentu. Prinsip-prinsip ini menekankan peran perawatan psikologis dalam menghilangkan penderitaan. Model pengobatan penderitaan pada pasien kanker saat ini mendefinisikan distress sebagai reaksi psikologis yang diharapkan dari pasien yang menghadapi kematiannya sendiri. Holland et al (2010) melaporkan di dalam penelitiannya bahwa kesusahan yang ditentukan sebagai pengalaman emosional yang tidak menyenangkan yang bersifat psikologis (kognitif, perilaku, dan emosional), sosial, dan/ atau spiritual yang dapat mengganggu kemampuan untuk mengatasi kanker secara efektif, gejala fisiknya, atau pengobatannya.



# BAB 3

## DUKUNGAN PERAWAT PADA KELUARGA DALAM PERAWATAN PALIATIF

### A. Pemberian Dukungan terhadap Keluarga di Dalam Perawatan Paliatif

#### 1. Pentingnya Dukungan untuk Keluarga

Orang-orang yang hidup dengan penyakit serius memiliki beragam masalah kualitas hidup yang seringkali paling baik ditangani oleh anggota tim perawatan paliatif. Sementara sistem medis biasanya ahli dalam mengungkap tekanan fisik seperti rasa sakit dan mual, masalah psikososial dan spiritual dapat diminimalkan atau bahkan terlewatkan sama sekali. Tentu saja, keterlibatan tim perawatan paliatif memperluas cakupan gejala yang akan disaring dan sumber penderitaan yang mungkin ditimbulkan. Bahkan tim perawatan paliatif dengan keahlian skrining seputar masalah kesehatan mental, cara mengatasi, serta makna dan tujuan mungkin tidak siap untuk menangani masalah kompleks ini dengan tepat. Untungnya, tim perawatan paliatif interdisipliner dengan sumber daya yang tepat mencakup dokter, perawat, tim pekerja sosial paliatif. Pekerja sosial paliatif adalah pekerja sosial yang dipersiapkan dengan baik dengan keahlian khusus dalam menangani masalah emosional, sosial, praktis, dan eksistensial yang terkait dengan penyakit serius. Sementara, banyak pekerja sosial berlatih dalam pengaturan perawatan kesehatan dan berkolaborasi dengan rekan perawatan paliatif di dalam dan di dalam tim, seringkali tidak ada pemahaman yang luas

# BAB

# 4

## SPIRITUALITAS DALAM PERAWATAN PALIATIF

### A. Spiritual Perawatan Paliatif

#### 1. Definisi Spiritualitas, Iman, dan Makna Hidup

Kerohanian Spiritualitas didefinisikan sebagai hubungan di luar diri seseorang. Ini didefinisikan dalam hal pandangan dan perilaku pribadi yang mengungkapkan rasa keterkaitan dengan dimensi transenden atau sesuatu yang lebih besar dari diri seseorang. Spiritualitas diekspresikan dalam pencarian individu akan makna tertinggi melalui partisipasi dalam agama dan/atau kepercayaan pada Tuhan, keluarga, naturalisme, rasionalisme humanisme, dan seni (Puchalski et al. 2009). Keyakinan-keyakinan pada kekuatan transenden yang lebih tinggi, tidak harus diidentifikasi sebagai Tuhan, dan tidak harus melalui partisipasi dalam ritual atau kepercayaan dari agama terorganisir tertentu.

Hubungan dan keterhubungan dengan kekuatan, atau yang dinggap roh ini, merupakan komponen penting dari pengalaman spiritual dan terkait dengan konsep makna. Arti (atau memiliki perasaan bahwa hidup seseorang memiliki arti) Keyakinan bahwa seseorang sedang memenuhi peran dan tujuan unik dalam kehidupan yang datang dengan tanggung jawab untuk hidup dengan potensi penuhnya sebagai manusia. Dengan melakukan itu, seseorang dapat mencapai rasa damai, kepuasan, atau bahkan transendensi melalui keterhubungan dengan sesuatu yang lebih besar dari diri sendiri (Frankl, 1992). Komponen spiritualitas "iman"

## DAFTAR PUSTAKA

- Abbey J, et al. Hopelessness at the end of life: the utility of the hopelessness scale with terminally ill cancer patients. *Br J Health Psychol.* 2005 (10): 1-11.
- Altilio T, Sumser B, Leimena ML: A commentary on compromise. *Clin Soc Work J* 2019; DOI: 10.1007/s10615-019-00702-6.
- American Psychiatric Association (APA). *Diagnostic and Statistical Manual of Mental Disorders*, 4th ed. Washington, DC: American Psychiatric Association Press; 2000.
- American Psychiatric Association. Practice guidelines for the treatment of patients with delirium. *Am J Psychiatry.* 1999; 156 (5 suppl): 1-20
- Andershed B: Relatives in end-of-life care, Part 1. A systematic review of the literature [of] the five last years, January 1999-February 2004. *J Clin. Nurs* 2006; 15 (9): 1158-11
- Anderson BA, Marasco LE, Kasl-Godley J, Kennedy SG: Social work and psychology. In: Altilio T, Otis-Green S (eds): *Oxford Textbook of Palliative Social Work*. New York: Oxford University Press, 2011, pp. 425-431.
- Ando MT, Morita T, Akechi T, et al. The efficacy of mindfulness-based meditation therapy on anxiety, depression, and spirituality in Japanese patients with cancer. *J Palliat Med* 2009; 12: 1091-1094.
- Ankuda CK, Kersting K, Guetterman TC, et al.: What matters most? A mixed methods study of critical aspects of a home-based palliative care program. *Am J Hosp Palliat Care* 2018; 35: 236-243.
- Applebaum AJ, Lichtenthal WG, Pessin H, et al.: Factors associated with attrition from a randomized controlled trial of meaning-centered group psychotherapy for patients with advanced cancer. *Psychooncology* 2012; 21: 1195-1204.

- Astudillo W, Mendinueta C, Orbegozo A: Presente y futuro de los cuidados paliativos [Internet]. [cited 2017 Apr 21]. [www.cuidadospaliativos.org/archives/biblioteca/Presente y futuro de los Cuidados Paliativos.pdf](http://www.cuidadospaliativos.org/archives/biblioteca/Presente_y_futuro_de_los_Cuidados_Paliativos.pdf) (last accessed November 27, 2017)
- Auman MJ: Bereavement support for children. *J Sch Nurs* 2007; 23: 34
- Balboni TA, Fitchett G, Handzo GF, et al.: State of the science of spirituality and palliative care research Part II: Screening, assessment, and interventions. *J Pain Symptom Manage* 2017; 54: 441-453.
- Barry LC, Kasl SV, Prigerson HG: Psychiatric disorders among bereaved persons: The role of perceived circumstances of death and preparedness for death. *Am J Geriatr Psychiatry* 2002; 10 (4): 447-457
- Beresford P, Croft S, Adshead L: 'We Don't See Her as a Social Worker': A service user case study of the importance of the social worker's relationship and humanity. *Br J Soc Work* 2008; 38: 1388-1407.
- Boettger S, Breitbart W. Phenomenology of the subtypes of delirium: Phenomenological differences between hyperactive and hypoactive delirium. *Palliat Support Care* 2011; 9: 129-135.
- Breitbart W, Rosenfeld B, Pessin H, et al.: Meaningcentered group psychotherapy: An effective intervention for improving psychological well-being in patients with advanced cancer. *J Clin Oncol* 2015; 33: 749-754.
- Breitbart W, Rosenfeld B, Gibson C, et al.: Meaning-centered group psychotherapy for patients with advanced cancer: A pilot randomized controlled trial. *Psychooncology* 2010; 19: 21-28.
- Breitbart W, Alici Y. Evidence-based treatment of delirium in patients with cancer. *J Clin Oncol.* 2012; 30: 1206-1214.

- Breitbart W, Rosenfeld B, Gibson C, Pessin H, Poppito S, Nelson C, et al. Meaning-centered group psychotherapy for patients with advanced cancer: a pilot randomized controlled trial. *Psycho-oncology* 2010 (1): 21–28.
- Breitbart W. The spiritual domain of palliative care: who should be “spiritual care professionals” *Palliat Support Care*. 2009; 7 (2): 139–141
- Breitbart W, Alici Y. Agitation and delirium at the end of life: “We couldn’t manage him.” *JAMA*. 2008; 300: 2898–2910
- Breitbart WS, Heller KS: Reframing hope: Meaning centered care for patients near the end of life. *J Palliat Care* 2003; 6: 979–988
- Breitbart W, Gibson C, Tremblay A. The delirium experience: delirium recall and delirium related distress in hospitalized patients with cancer, their spouses/caregivers, and their nurses. *Psychosomatics* 2002; 43: 183–194.
- Breitbart W, Rosenfeld B, Pessin H, et al. Depression, hopelessness, and desire for hastened death in terminally ill patients with cancer. *JAMA*. 2000; 284: 2907–2911.
- Breitbart W, Rosenfeld B, Roth A. The Memorial Delirium Assessment Scale. *J Pain Symptom Manage*. 1997; 13: 128–137.
- Cagle JG, Osteen P, Sacco P, Frey JJ: Psychosocial assessment by hospice social workers: A content review of instruments from a national sample. *J Pain Sympt Manag* 2016; 53: 40–48.
- Campbell LF, Norcross JC, Vasquez MJT, et al.: Recognition of psychotherapy effectiveness: The APA resolution. *Psychotherapy (Chic)* 2013; 50: 98–10
- Canada AL, Fitchett G: Religion/spirituality and cancer: A brief update of selected research. In: Holland JC, Breitbart WS, Butow PN, et al. (eds): *Psycho-Oncology*, 3rd ed. New York: Oxford University Press, 2015, pp. 503–508.
- Candy B, Jones L, Drake R, Leurent B, King M: Interventions for supporting informal caregivers of patients in the terminal

- phase of a disease. *Cochrane Database Syst Rev* 2011(6)
- Chochinov HM, Kristjanson LJ, Breitbart W, et al.: Effect of dignity therapy on distress and end-of-life experience in terminally ill patients: A randomized controlled trial. *Lancet Oncol* 2011; 12: 753–762.
- Chochinov HM: Dignity and the essence of medicine: The A, B, C, and D of dignity conserving care. *BMJ* 2007; 335: 184–187.
- Chochinov HM, Hack T, Hassard T, et al. Dignity therapy: a novel psychotherapeutic intervention for patients near the end of life. *J Clin Oncol* 2005; 23: 5520–5525.
- Chochinov HM, Wilson KG, Enns M, Lander S. “Are you depressed?” Screening for depression in the terminally ill. *Am J Psychiatry* 1997; 154: 674–676.
- Chochinov HMC, Wilson KG, Enns M, Mowchun N, Lander S, Levitt M, et al. Desire for death in the terminally ill. *Am J Psychiatry* 1995; 152: 1185–1191.
- Chochinov HM, Wilson KG, Enns M, Lander S. Prevalence of depression in the terminally ill: effects of diagnostic criteria and symptom threshold judgments. *Am J Psychiatry* 1994; 151: 537–540.
- Clayton CL. Barriers, boundaries, & blessings: ethical issues in physicians’ spiritual involvement with patients. *Med Humanities Rpt*, 2000; 21: 234–256.
- Cunkilton DD, Rubins VD: Psychological distress in end of-life care: A review of issues in assessment and treatment. *J Soc Work End Life Palliat Care* 2009; 5: 75–93.
- Demiris G, Oliver DRP, Courtney KL, Porock D: Use of technology as a support mechanism for caregivers of hospice patients. *J Palliat Care* 2005; 21 (4): 303–309.
- DePaolis G, Naccarato A, Cibelli F, et al.: The effectiveness of progressive muscle relaxation and interactive guided imagery as a pain-reducing intervention in advanced cancer

- patients: A multicenter randomized controlled nonpharmacological trial. *Complement Ther Clin Pract* 2019; 34: 280–287.
- Derogatis L, Feldstein M, Morrow G. A survey of psychotropic drug prescriptions in an oncology population. *Cancer* 1979; 44: 1919–1929.
- Dunn A, Littrivis E: Aligning patient preferences and patient care at the end-of-life. *Soc Gen Intern Med* 2011; 26: 681–682.
- Edmondson AC, Lei Z: Psychological safety: The history, renaissance, and future of an interpersonal construct, *Annu Rev Organ Psychol Organ Behav* 2014; 1:23–43.
- Ellis M, Vinson D, Ewigman B. Addressing spiritual concerns of patients: family physicians' attitudes and practices. *J Fam Pract* 1999; 48: 105–109.
- Fallot R, Harris M: Trauma-Informed Services: A Self Assessment and Planning Protocol. Washington, DC: Community Connections, 2009. <https://www.theannainstitute.org/TISA+PPROTOCOL.pdf> (last accessed July 8, 2019).
- Farabelli JP, Kimberly SM, Altilio T, Otis-Green S, Dale H, Dombrowski D, Kieffer R, Leff V, Schott JL, Strouth A, dan Jones CA. Top Ten Tips Palliative Care Clinicians Should Know About Psychosocial and Family Support. *Journal Of Palliative Medicine*, Volume XX, Number XX, 2019 A Mary Ann Liebert, Inc. DOI: 10.1089/jpm.2019.0506
- Frankl VE: *Man's Search for Meaning*. 1st ed. Boston: Beacon, 1992.
- Feldman G, Greeson J, Senville J: Differential effects of mindful breathing, progressive muscle relaxation, and loving-kindness meditation on decentering and negative reactions to repetitive thoughts. *Behav Res Ther* 2010;48: 1002–1011.
- Field M, Cassel C, eds. *Approaching Death: Improving Care at the End of Life*. Washington, DC: National Academy Press; 1997

- Fineberg IC: Social work perspectives on family communication and family conferences in palliative care. *Progr Palliat Care* 2010; 18: 213-220.
- Fineberg IC: Preparing professionals for family conferences in palliative care: Evaluation results of an interdisciplinary approach. *J Palliat Med* 2005; 8: 857-866.
- Fitchett G, Pierson ALH, Hoffmeyer C, Labuschagne D, Lee A, Levine S, O'Mahony S, Pugliese K, and Waite N. Development of the PC-7, a Quantifiable Assessment of Spiritual Concerns of Patients Receiving Palliative Care Near the End of Life. *Journal Of Palliative Medicine*, Volume XX, Number XX, 2019 Mary Ann Liebert, Inc. DOI: 10.1089/jpm.2019.0188
- Fitchett G: *Assessing Spiritual Needs: A Guide for Caregivers*. Lima, OH: Academic Renewal Press, 2
- Foglia MB, Lowery J, Sharple VA, et al.: A comprehensive approach to eliciting, documenting, and honoring patient wishes for care near the end-of-life: The veterans health initiative. *Jt Comm J Qual Patient Saf* 2019; 45: 47-56
- Gagnon B, Low G, Schreier G. Methylphenidate hydrochloride improves cognitive function in patients with advanced cancer and hypoactive delirium: a prospective clinical study. *J Psychiatry Neurosci*. 2005; 30: 100-107.
- Gagnon P, Charbonneau C, Allard P, Soulard C, Dumont S, Fillion L. Delirium in advanced cancer: a psychoeducational intervention for family caregivers. *J Palliat Care*. 2002; 18 (4): 253-261.
- Ganzel BL. Trauma-informed hospice and palliative care. *Gerontologist* 2016; 58: 409-419.
- Girgis A, Johnson C, Currow D, Bowman D, Waller A, Kristjanson LJ, Mitchell G, Yates P, Neil A, Kelly B, Tattersall M: *Palliative Care Needs Assessment Guidelines*. Newcastle, NSW: The Centre for Health Research & Psycho-oncology, 2006.



- Go´mez-Batiste X, Mateo-Ortega D, Lasmar´as C, et al.: Enhancing psychosocial and spiritual palliative care: Four year results of the program of comprehensive care for people with advanced illnesses and their families in Spain. *Palliat Support Care* 2017; 15: 98–109
- Grande G, Stajduhar K, Aoun S, Toye C, Funk L, Addington Hall J, Payne S, Todd C: Supporting lay carers in end of life care: Current gaps and future priorities. *Palliat Med* 2009; 23: 339–344.
- Grov EK, Dahl AA, Moum T, Fossa SD: Anxiety, depression, and quality of life in caregivers of patients with cancer in late palliative phase. *Ann Oncol* 2005; 16 (7): 1185–1191.
- Hannon B, OReilly V, Bennett K, et al.: Meeting the family: Measuring effectiveness of family meetings in a specialist inpatient palliative care unit. *Palliat Support Care* 2012; 10: 43–49.
- Harding R: Carers: Current research and developments. In: Firth P, Luff G, Oliviere D (eds). *Facing Death: Loss, Change and Bereavement in Palliative Care*, 1st ed. Maidenhead, Berkshire: Open University Press, 2005: 150–166
- Help the Hospices: Identifying carers’ needs in the palliative setting. *Help the Hospices*, 2009.
- Hem E, Loge JH, Haldorsen T, Ekeberg. 2004. Suicide risk in cancer patients from 1960 to 1999. *J Clin Oncol*; 22 (20): 4209–4216.
- Hermesen MA, Ten Have HA: Palliative care teams: Effective through moral reflection. *J Interprof Care* 2005; 19: 561–568.
- Hodas GR. *Responding to Childhood Trauma: The Promise and Practice of Trauma Informed Care*. Harrisburg, PA: Pennsylvania Office of Mental Health and Substance Abuse Services, 2006. [www.childrescuebill.org/VictimsOfAbuse/RespondingHodas.pdf](http://www.childrescuebill.org/VictimsOfAbuse/RespondingHodas.pdf) (last accessed July 8, 2019)
- Holland JC, Andersen B, Breitbart WS, et al.: Distress management: Clinical practice guidelines in oncology. *J Natl Compr Canc*

Netw 2010; 8: 448–485.

- Honea NJ, Britnall R, Given B, Sherwood P, Colao DB, Somers SC, Northouse LL. Putting evidence into practice: Nursing assessment and interventions to reduce family caregiver strain and burden. *Clin J Oncol Nurs* 2008; 12 (3): 507–516.
- Hudson P, Remedios C, Zordan R, Thomas K, Crewdson M, Hall C, Trauer T, Bolleter A, Clarke DM, Bauld C. 2012. Guidelines for the Psychosocial and Bereavement Support of Family Caregivers of Palliative Care Patients. *Journal Of Palliative Medicine*, Volume 15, Number 6, 2012 A Mary Ann Liebert, Inc. DOI: 10.1089/jpm.2011.0466
- Hudson P, Payne S: The future of family caregiving: Research, social policy and clinical practice. In: Hudson P, Payne S (eds). *Family Carers in Palliative Care: A guide for health and social care professionals*. Oxford: Oxford University Press, 2009: 277–303
- Inouye SK, Zhang Y, Jones RN, Kiely DK, Yang F, Marcantonio ER, et al. Risk factors for delirium at discharge: development and validation of a predictive model. *Arch Intern Med*. 2007; 167: 1406–1413.
- Jacobsen PB, Jim HS: Psychosocial interventions for anxiety and depression in adult cancer patients: Achievements and challenges. *CA Cancer J Clin* 2008; 58: 214–230.
- Juñger S, Payne S: Guidance on postgraduate education for psychologists involved in palliative care. *Eur J Palliat Care* 2011; 18: 238–252.
- Kathol RG, Mutgi A, Williams J, Clamon G, Noyes R. Diagnosis of major depression in cancer patients according to four sets of criteria. *Am J Psychiatry* 1990; 147: 1021–1024.
- Koenig HG, George LK, Peterson BL. Religiosity and remission of depression in medically ill older patients. *Am J Psychiatry* 1998; 155: 536–542.

- King DE, Bushwick B. Beliefs and attitudes of hospital inpatients about faith, healing, and prayer. *J Fam Pract.* 1994; 39: 349-352.
- Kissane DW, Grabsch B, Clarke DM, Smith GC, Love AW, Bloch S, et al. Supportive-expressive group therapy for women with metastatic breast cancer: survival and psychosocial outcome from a randomized controlled trial. *Psychooncology* 2007a; 16 (4): 277-286.
- Kissane DW. Letting go of the hope that psychotherapy prolongs cancer survival. *JCO* 2007b: 5689-5690
- Kissane DW, Poppito S. Death and dying. In: Blumenfield M, Strain JJ, eds. *Psychosomatic Medicine*. Philadelphia: Lippincott Williams & Wilkins; 2006: 671-694.
- Kronaizl SG: Discussing death with children: A developmental approach. *Pediatr Nurs* 2019; 45: 47-50.
- Lawlor P, Nekolaichuck C, Gagnon B, et al. Clinical utility, factor analysis and further validation of the Memorial Delirium Assessment Scale (MDAS). *Cancer* 2000; 88: 2859-2867.
- Leonard M, Raju B, Conroy M, et al. Reversibility of delirium in terminally ill patients and predictors of mortality. *Palliat Med.* 2008; 22 (7): 848-854.
- Lewis JM: Pastoral assessment in hospital ministry: A conversational approach. *Chaplaincy Today* 2002; 18: 5-13
- Lo B, Kates LW, Ruston D, et al. Responding to requests regarding prayer and religious ceremonies by patients near the end of life and their families. *J Palliative Med.* 2003; 3: 409-415.
- Longbottom S, Slaughter V: Sources of children's knowledge about death and dying. *Philos Trans Royal Soc Lond B Biol Sci* 2018; 373; DOI: 10.1098/rstb.2017.0267.
- Mate´-Me´ndez J, Gonza´lez-Barboteo J, Calsina-Berna A, et al.: The Institut Catala` d'Oncologia Model of Palliative Care: An integrated and comprehensive framework to address the

essential needs of patients with advanced cancer. *J Palliat Care* 2013; 29: 237–243

Mateo-Ortega D, Gómez-Batiste X, Mate J, Beas E, Ela S, Lasmarias C, Limonero JT. 2018. Effectiveness of Psychosocial Interventions in Complex Palliative Care Patients: A Quasi-Experimental, Prospective Multicenter Study. *Journal Of Palliative Medicine*, Volume XX, Number XX, 2018 A Mary Ann Liebert, Inc. DOI: 10.1089/jpm.2017.0355

Mateo-Ortega D, Gómez-Batiste X, Limonero JT, et al.: Efectividad de la intervención psicosocial en pacientes con enfermedad avanzada y final de vida. *Psicooncología* 2013; 10: 299–316.

Maugans TA, Wadland WC. Religion and family medicine: a survey of physicians and patients. *J Fam Pract.* 1991; 32: 210–213.

Meagher DJ, O'Hanlon D, O'Mahony E, Casey PR, Trzepacz PT. Relationship between symptoms and motoric subtype of delirium. *J Neuropsychiatry Clin Neurosci.* 2000; 12 (1): 51–56.

Monod S, Martin E, Spencer B, et al. Validation of the spiritual distress assessment tool in older hospitalized patients. *BMC Geriatr* 2012; 12: 13

Monroe B, Olivere D: Communicating with Family Carers. In: Hudson P, Payne S (eds). *Family Carers in Palliative Care: A Guide for Health and Social Care Professionals*. New York: Oxford University Press, 2009: 1–20.

Moraska AR, Sood A, Dakhil SR, et al. Phase III, randomized, double-blind, placebo-controlled study of long-acting methylphenidate for cancer-related fatigue: North Central Cancer Treatment Group NCCTG-N05C7 trial. *J Clin Oncol.* 2010; 28: 3673–3679.

Mulkerin C: The convergence of social work practice: Integrating health social work and specialized palliative care. In: Sumser B, Leimena M, Altilio T (eds): *Palliative Care: A Guide for Health Social Workers*. New York: Oxford University Press,

2019, pp. 17–30.

National Association of Social Workers: NASW Standards for Palliative and End-of-Life Care. Washington, DC: NASW, 2004. <https://bit.ly/2ChDIJO> (last accessed July 8, 2019).

National Comprehensive Cancer Network. NCCN Clinical Practice Guidelines in Oncology: Cancer Related Fatigue. V.1.2013

National Comprehensive Cancer Network: NCCN practice guidelines for the management of psychosocial distress. Oncology (Williston Park). 1999; 13 (5A): 113–147

National Consensus Project for Quality Palliative Care: Clinical Practice Guidelines for Quality Palliative Care, 4th ed. Richmond, VA: National Coalition for Hospice and Palliative Care, 2018.

National Institute for Clinical Excellence: Guidance on cancer services: Improving supportive and palliative care for adults with cancer. The manual. London: National Institute for Clinical Excellence, 2004.

Nelson CJ, Rosenfeld B, Breitbart W, et al. Spirituality, religion, and depression in the terminally ill. *Psychosomatics* 2002; 43: 213–220.

Nissim R, Freeman E, Lo C, et al. Managing Cancer and Living Meaningfully (CALM): A qualitative study of a brief individual psychotherapy for individuals with advanced cancer. *Palliat Med* [epub ahead of print October 31, 2011]

Olden M, Pessin H, Lichtenthal WG, Breitbart W, et al. 2009. Diagnosis and management of depression in palliative care. In: Chochinov H, Breitbart W, eds. *Handbook of Psychiatry in Palliative Medicine*, 2nd ed. New York: 101–112.

Otis-Green S, Thomas J, Duncan L, et al.: Advance care planning: Opportunities for clinical social work leadership. *Clinical Social Work Journal* 2019; 47; DOI: 10.1007/ s10615-019-00709-z

- Pachman DR, Barton DL, Swetz KM, Loprinzi CL. Troublesome symptoms in cancer survivors: fatigue, insomnia, neuropathy, and pain. *J Clin Oncol.* 2012; 30 (30): 3687-3696.
- Prigerson HG, Bierhals AJ, Kasl SV, Reynolds CF, 3rd, Shear MK, Newsom JT, Jacobs S: Complicated grief as a disorder distinct from bereavement-related depression and anxiety: A replication study. *Am J Psychiatry* 1996; 153 (11): 1484-1486.
- Prokopetz JJ, Lehmann LS. 2012. Redefining physicians' role in assisted dying. *N Engl J Med.*; 367 (2): 97-99.
- Puetz TW, Herring MP. Differential effects of exercise on cancer-related fatigue during and following treatment: a meta-analysis. *Am J Prev Med.* 2012; 43 (2): e1-24.
- Puchalski C, Ferrell B, Virani R, et al.: Improving the quality of spiritual care as a dimension of palliative care: The report of the Consensus Conference. *J Palliat Med* 2009; 12: 885-904.
- Puchalski CM. Spiritual issues in palliative care. In: Chochinov HMC, Breitbart W, eds. *Handbook of Psychiatry in Palliative Medicine*, 2nd ed. New York: Oxford University Press; 2009: 341-351.
- Puchalski C, Romer AL. Taking a spiritual history allows clinicians to understand patients more fully. *J Palliative Med.* 2000; 3: 129-137
- Quill TE. 2012. Physicians should "assist in suicide" when it is appropriate. *J Law Med Ethics*; 40 (1): 57-65.
- Radbruch L, Strasser F, Elsner F, et al. Fatigue in palliative care patients – an EAPC approach. *Palliat Med.* 2008; 22: 13-32
- Rousseau P. Spirituality and the dying patient. *J Clin Oncol.* 2000; 18: 2000-2002.
- Russell J: Effects of constraints and consequences on plan complexity in conversations about end-of-life care. *J Soc Work End Life Palliat Care* 2015; 11: 323-345.

- Schonfeld DJ, Demaria T: Supporting the grieving child and family. *Pediatrics* 2016; 138: 2016–2147.
- Sharkansky E. Sexual Trauma: Information for Women’s Medical Providers. [https://www.ptsd.va.gov/professional/treat/type/sexual\\_trauma\\_women.asp](https://www.ptsd.va.gov/professional/treat/type/sexual_trauma_women.asp) (last accessed July 8, 2019)
- Singer P, Martin DK, Kelner M. Quality end-of-life care: patients’ perspectives. *JAMA*. 1999; 281: 163–168.
- Sloan RP, Bagiella E, Powell T. Religion, spirituality, and medicine. *Lancet* 1999; 353: 664–667.
- Sociedad Española de Cuidados Paliativos: Guía de Cuidados Paliativos. 2002. <http://www.secpal.com/guia-cuidadospaliativos-l>
- Solomon MZ: The wisdom and necessity of focusing on family. *J Palliat Med* 2008; 11 (3): 408–409.
- Spiegel D, Bloom JR, Yalom I. Group support for patients with metastatic cancer. A randomized outcome study. *Arch Gen Psychiatry* 1981; 38: 527–533
- Spiller JA, Keen JC. Hypoactive delirium: assessing the extent of the problem for inpatient specialist palliative care. *Palliat Med*. 2006; 20 (1): 17–23.
- Stein GL, Cagle JG, Christ GH: Social work involvement in advance care planning: Findings from a large survey of social workers in hospice and palliative care settings. *J Palliat Med* 2017; 20: 253–259.
- Stoltz P, Uden G, Willman A: Support for family carers who care for an elderly person at home: A systematic literature review. *Scand J Caring Sci* 2004; 18 (2): 111–119.
- Storey P, Knight C. UNIPAC Two: alleviating psychological and spiritual pain in the terminally ill. *American Academy of Hospice and Palliative Medicine*. Dubuque, IA: Kendall/Hunt; 2001

- Substance Abuse and Mental Health Services Administration: SAMHSA's Concept of Trauma and Guidance for a Trauma-Informed Approach, 2014. <https://store.samhsa.gov/product/SAMHSA-s-Concept-of-Trauma-and-Guidance-for-a-Trauma-Informed-Approach/SMA14-4884.html> (last accessed July 8, 2019).
- Swinton M, Giacomini M, Toledo F, et al.: Experiences and expressions of spirituality at the end-of-life in the intensive care unit. *Am J Respir Crit Care Med* 2017; 195: 198–204.
- Tarakeshwar N, Vanderwerker LC, Paulk E, et al.: Religious coping is associated with quality of life of patients with advanced cancer. *J Palliat Med* 2006; 9: 646–657.
- Thekkumpurath P, Venkateswaran C, Kumar M, Bennett MI: Screening for psychological distress in palliative care: A systematic review. *J Pain Symptom Manage* 2008; 36 (5): 520–528.
- Thompson L: La ansiedad ante la muerte y el propósito en la vida en fin de vida [Internet]. Matia Fundazioa; 2013 [cited 2017 Apr 21]. [www.matiafundazioa.net/blog/unmodelo-integrativo-del-abordaje-psicologico-en-cuidadospaliativos](http://www.matiafundazioa.net/blog/unmodelo-integrativo-del-abordaje-psicologico-en-cuidadospaliativos)
- UK Department of Health: End of Life Care Strategy: Quality Markers and Measures for End of Life Care. London: Department of Health, 2009: 52.
- Van der Lee ML, van der Bom JG, Swarte NB, Heintz AP, de Graeff A, van den Bout J. Euthanasia and depression: a prospective cohort study among terminally ill cancer patients. *J Clin Oncol* 2005 Sep 20; 23 (27): 6607–6612. Epub August 22, 2005.
- Wachholtz AB, Fitch CE, Makowski S, Tija J: A comprehensive approach to the patient at end-of-life: Assessment of multidimensional suffering. *South Med J* 2016; 109: 200–206
- Wang CW, Chan CLW, Chow AYM: Social workers' involvement in advance care planning: A systematic narrative review. *BMC Palliat Care* 2017; 17: 5.



- Wilson K, Lander M, Chochinov HM. Diagnosis and management of depression in palliative care. In: Chochinov H, Breitbart W, eds. *Handbook of Psychiatry in Palliative Medicine*. New York: Oxford University Press, 2009: 39–68.
- Wilson KG, Chochinov HM, McPherson CJ, Skirko MG, Allard P, Chary S, et al. 2007b. Desire for euthanasia or physician-assisted suicide in palliative cancer care. *Health Psychol*; 26 (3): 314–323.
- Worden JW: *Grief Counseling and Grief Therapy*, 5th ed. New York: Springer Publishing Company, 2018, pp. 18–32 and 138–148.
- World Health Organization: *Strengthening of palliative care as a component of integrated treatment throughout the life course*. Report by de Secretariat. December 2013
- World Health Organisation. *National cancer control programmes: Policies and managerial guidelines*, 2nd ed. Geneva: WHO, 2002.
- Zwahlen D, Hagenbuch N, Jenewein J, Carley MI, Buchi S: Adopting a family approach to theory and practice: Measuring distress in cancer patient-partner dyads with the distress thermometer. *Psychooncology*. 2010.
- Zwahlen D, Hagenbuch N, Carley MI, Recklitis CJ, Buchni S: Screening cancer patients' families with the distress thermometer (DT): A validation study. *Psychooncology* 2008; 17 (10): 959–966.

## TENTANG PENULIS

### **Ns. Bunga Permata Wenny, M.Kep.**

Penulis merupakan seorang pengajar pada bagian Departemen Keperawatan Jiwa dan Komunitas pada Fakultas Keperawatan Universitas Andalas, dengan spesifikasi pada Keperawatan Jiwa. Lulusan Sarjana, profesi dan Magister dari Fakultas Keperawatan Universitas Andalas. Bekerja pada Fakultas Keperawatan Sejak Tahun 2014 hingga saat ini.

### **Ns. Okky Adelirandy, S.Kep**

Penulis merupakan salah satu asisten di Fakultas Keperawatan Universitas Andalas. Lulus sebagai sarjana keperawatan di Universitas Padjadjaran, yang kemudian juga melanjutkan program studi profesi nersnya di Universitas tersebut. Hingga saat ini telah bekerja selama hampir 8 tahun di Fakultas Keperawatan Universitas Andalas.