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**PC-FACS (Fast Article Critical Summaries for Clinicians in Palliative Care)** provides hospice and palliative care clinicians with concise summaries of the most important findings from more than 100 medical and scientific journals. If you have colleagues who would benefit from receiving PCFACS, please encourage them to join the AAHPM at aahpm.org.

Comments from readers are welcomed at pcfacs@aahpm.org.

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Mello MM, Persad G, White DB. Respecting disability rights—toward improved crisis standards of care. *N Engl J Med.* 2020;383(5):e26. https://doi.org/10.1056/NEJMp2011997.

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**Rave Reviews**

**Summaries With Commentaries**

**Electrophysiological Evidence of Preserved Hearing at the End of Life**

*Background.* There is a belief that in the last hours before death, some patients remain aware of their external environment despite being unable to signal their awareness. Are unresponsive patients aware of loved ones’ words? 

*Design and Participants.* This study investigated whether hearing is one of the last senses to lose function as humans die, presenting EEG evidence from unresponsive, actively dying hospice patients.

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Individual event-related brain responses (mismatch negativity [MMN], P3a, and P3b) to deviations in auditory/tone patterns were reported for conscious, young, healthy control participants and for hospice patients when conscious and when unresponsive. Whereas MMN (and perhaps P3a) is considered an automatic response to auditory irregularities, P3b is associated with conscious detection of oddball targets or target stimuli that occur infrequently or irregularly in a series. Analyses included a cluster-based permutations test.

Results. Patients were age 28–88 years (mean=68), 44% female, terminally ill (usually diagnosed with cancer), and medicated (typically with opioids). Eight were recorded when they were responsive, five when unresponsive, and four were recorded once when responsive and again when unresponsive. Controls (n=17; age mean=21 years) were 59% female. Like controls, all responsive patients evidenced MMN and/or P3a to tone changes; 50% evidenced P3b to tone changes. Latencies of both P3a and P3b to local tone changes were generally longer among responsive patients vs. controls.

Twenty-five percent of responsive patients evidenced P3b and none evidenced P3a to pattern changes. Like controls and responsive patients, all unresponsive patients evidenced MMN and/or P3a to tone changes. No unresponsive patients evidenced P3b to tone changes. One unresponsive patient evidenced a weak P3a to pattern changes, and two evidenced stronger P3b to pattern changes (all P<.05).

Commentary. There is limited evidence showing that dying patients are cognitively aware of what they are hearing. This study evaluated electrophysiological responses to tone and pattern changes as opposed to other methods of assessing consciousness, including behavioral responses to physical stimulation or verbal commands that may be confounded in dying patients as a result of physiology or the use of opioids. This study, limited by its small sample size, shows hospice patients present some EEG evidence of response to auditory/tone patterns, suggesting that hearing remains preserved. In terminally ill patients with cancer and delirium that resolves with treatment, the majority recollected the delirium experience. These studies support the common practice by healthcare providers of encouraging friends and family to continue speaking to their dying loved one who may retain some degree of consciousness, which can be potentially therapeutic for both patients and family members.

Bottom Line. Electrophysiological evidence that hearing was preserved was present in actively dying hospice patients.

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Respecting Disability Rights—Toward Improved Crisis Standards of Care

Background. To enable hospitals to respond to COVID-19, the US Department of Health and Human Services (HHS) waived multiple federal regulatory requirements. How can our legal system’s commitment to prohibiting discrimination remain steadfast in times of emergency?

Design and Participants. This paper discussed how policymakers and hospitals (anticipating COVID-19 surges) can honor commitments to antidiscrimination while stewarding scarce resources. In March/April, disability rights (DRs) advocacy groups and persons with disabilities filed complaints with the HHS Office of Civil Rights (OCR) alleging that several US states’ guidelines illegally discriminate against persons with disabilities (eg, basing triage decisions on quality-of-life judgments or excluding patients with specific conditions). Furthermore, because it is negatively affected by some disabilities and by social circumstances (eg, poverty and healthcare access), long-term life expectancy should not influence triage decisions. Considering near-term prognosis in allocation decisions (eg, assigning lower priority to patients who are expected to die <1 year from an end-stage condition) is acceptable. In April, OCR approved Pennsylvania triage guidelines considering near-term prognosis.

Results. The authors propose guideposts for respecting DRs: First, do not use categorical exclusions, especially ones based on disability or diagnosis. Second, do not use perceived quality of life. Third, use hospital survival and near-term prognosis but not long-term life expectancy. Fourth, when patients who use ventilators in their daily lives (eg, home ventilation) present to acute care, their ventilators should not be reallocated to other patients. Fifth, designate triage officers as decision makers and train them to respect DRs (information available to triage officers could exclude all patient characteristics not
Commentary. COVID-19 has changed a lot of things about how we care for patients. Though prognosis is a central part of what hospice and palliative medicine providers do, it is easy to mingle our perceptions of quality of life and value. This article powerfully reminds us that when stewarding scarce resources in a pandemic, our job is to evaluate people’s short-term mortality rather than their disability or our view of their quality of life. Given multiple lawsuits and protests by disability groups to overturn states’ guidance on who has value during the pandemic, this article is a reminder that quality of life most matters to the person living it.

Bottom line. According to this piece, allocation of scarce resources should depend on objective criteria that focus on the likelihood of short-time survival, not our perception of the life they live.

Reviewers. Greg Phelps, MD MPH FAAHPM, University of Texas Health Science Center, Memphis, TN, and Alleo Health System, Chattanooga, TN

Source. Mello MM, Persad G, White DB. Respecting disability rights—toward improved crisis standards of care. N Engl J Med. 2020;383(5):e26. https://doi.org/10.1056/NEJMp2011997.

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Racial and Ethnic Disparities in Serious Psychological Distress Among Those with Alzheimer’s Disease and Related Dementias

Background. Because of the disease burden of Alzheimer’s disease and other related dementias (ADRD) and the projected prevalence increase as the American population ages and enters Medicare eligibility, the significance of ADRD in the healthcare context cannot be overstated.1 Does serious psychological distress (SPD) contribute to the burden of ADRD among African Americans (AAs) disproportionately to whites?

Design and Participants. This study examined the existence of SPD and calculated the predicted probability of ADRD (among whites, AAs, and Hispanics age ≥65 years), and decomposed the differences among ADRD populations. Nationally representative Medical Expenditure Panel Survey data (2007–2015) were used to estimate the association between ADRD and race, ethnicity, and SPD. Blinder-Oaxaca decomposition estimated to what extent greater SPD among Hispanics and AAs (vs. whites) was associated with higher ADRD rates, χ2, multivariable logistic regression, and the Andersen behavioral model were used.

Results. Compared with whites, AAs and Hispanics had higher SPD rates (non-ADRD cohort) and AAs were less likely to have a depression/anxiety diagnosis (ADRD cohort). After controlling for demographics/socioeconomics and coexisting medical conditions, SPD presence was still associated with greater ADRD likelihood. Individuals with a diagnosis of depression/anxiety also were likelier to have ADRD. Results did not show an association between ADRD and education, family income, or insurance. The likelihoods of having ADRD for AAs, Hispanics, and whites were 7.1%, 5.7%, and 4.5%. Higher rates of having SPD among AAs explained 15% of white-Black difference and 40% of the white-Hispanic difference in ADRD rates, respectively. SPD rates among AAs, Hispanics, and whites were 24%, 27%, and 17% (all P<.05).

Commentary. Structural racism contributes to health disparities via numerous pathways. Diverse racial and ethnic people have “repeated experience with social or economic adversity and political marginalization,” which create biological “weathering,” defined as the emergence of morbidity and mortality at younger ages or accelerated aging.2 The weathering hypothesis has been substantiated by studies that link racial discrimination to markers of physiologic aging, such as telomere length.3 Structural and interpersonal racism also increase SPD.4 This study suggests that increased prevalence of SPD in racially and ethnically diverse communities may contribute to higher rates of ADRD, providing more evidence for the causal pathway of weathering. This cross-sectional study is limited in elucidating the causal relationship between SPD and ADRD given the bidirectional nature of this relationship and the possibility that SPD may represent a prodromal syndrome of ADRD.

Bottom Line. Longitudinal studies are required to establish the causal relationship between the greater
prevalence of SPD in diverse populations and racial and ethnic disparities in the prevalence of ADRD.

**Reviewer.** Elizabeth Chuang, MD MPH FAAHPM, Albert Einstein College of Medicine, Bronx, NY

**Source.** Novak P, Chu J, Ali MM, Chen J. Racial and ethnic disparities in serious psychological distress among those with Alzheimer’s disease and related dementias. *Am J Geriatr Psychiatry*. 2020;28(4):478–490. https://doi.org/10.1016/j.jagp.2019.08.010.

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**Recovery from Severe Disability that Develops Progressively Versus Catastrophically: Incidence, Risk Factors, and Intervening Events**

**Background.** Severe disability (SD) in older persons may develop progressively through an intermediary stage of mild disability or abruptly (catastrophically). What factors are associated with reduced recovery after SD?

**Design and Participants.** This single-site prospective longitudinal study (1998–2016) among nondisabled community-living persons age ≥70 years evaluated risk factors and intervening illnesses and injuries (ie, events) associated with reduced recovery after episodes of progressive and catastrophic SD. Candidate risk factors were assessed every 18 months. Functional status and exposure to intervening events leading to hospitalization, emergency department visit, or restricted activity were assessed each month. SD was defined as the need for personal assistance with ≥3 of four essential activities of daily living. Recovery was defined as return to independent function (no disability) ≤6 months after developing SD. Multivariable analyses, Poisson modeling, and logistic regression were used.

**Results.** Four hundred thirty-one episodes were evaluated: 116 progressive (115 participants, 54% age ≥85 years, 66% female, 92% white, 52% living alone, and 34% educated <12 years) and 315 catastrophic (270 participants, 46%, 64%, 88%, 49%, and 32%). Recovery occurred among 35% (95% CI=26%–48%) and 62% (54%–71%) of the progressive and catastrophic SD episodes, respectively, with median=2 (IQR=1–3) and 1 (1–3) months to recovery, respectively. In multivariable analyses, lives alone, frailty, and hospitalization were each independently associated with reduced recovery from progressive disability (aHR=0.31 [95% CI=0.15–0.64], 0.23 [0.12–0.45], and 0.27 [0.08–0.95], respectively), whereas low functional self-efficacy, restricted activity, and hospitalization were each independently associated with reduced recovery from catastrophic disability (aHR=0.56 [0.40–0.81], 0.55 [0.35–0.85], and 0.45 [0.31–0.66], respectively).

**Commentary.** Assisting patients and families in planning for probable outcomes following the onset of disability is a key function of palliative care practitioners. Not much has been written about recovery from catastrophic vs. progressive disability. This article provides some insights that can help palliative care practitioners give more accurate prognostic information to older patients with onset of disability and their families. For most practitioners, the bottom lines to remember are 1) recovery is likely after catastrophic, but not progressive, disability; 2) an intervening hospitalization or restriction of activity reduces the likelihood of recovery in both subtypes of disability; and 3) the risk factors for poor recovery are different for catastrophic and progressive disability.

**Bottom Line.** Palliative care practitioners should be aware that recovery is likely for older adults with catastrophic disability and unlikely for older adults with progressive disability, and that intervening illness or injury worsens outcomes in both subtypes of disability.

**Reviewer.** C. Bree Johnston, MD MPH FACP, University of Arizona College of Medicine and Banner University Medical Center, Tucson, AZ

**Source.** Gill TM, Gahbauer EA, Leo-Summers L, Murphy TE. Recovery from severe disability that develops progressively versus catastrophically: incidence, risk factors, and intervening events [published online ahead of print June 3, 2020]. *J Am Geriatr Soc.* https://doi.org/10.1111/jgs.16567.

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**Is Inpatient Hospice Care Clinically Effective? Using Phase of Illness to Evaluate Care Outcomes for Patients Admitted to a Specialist Palliative Care Unit in Ireland**

**Background.** Clinical effectiveness is defined as the application of the best knowledge (from research, clinical experience, and patient preferences), to achieve optimum processes and care outcomes.

What is the daily effect of specialist palliative care unit (SPCU) admission on patient and family/caregiver outcomes?

**Design and Participants.** This study evaluated care effectiveness in an Ireland SPCU, including an analysis of the temporal relationship among unit admission, patients’ phase of illness, and different aspects of patient and family distress. This was a consecutive case series with prospectively collected data of consecutive admissions (2014–2015). Patients received a comprehensive assessment and management plan to address their physical symptoms, psychosocial/spiritual distress, and family/caregiver distress by a multidisciplinary specialist palliative care team. Case mix was evaluated using the Phase of Illness and the Palliative Care Problem Severity Score (PCPSS). Functional status was documented using the Palliative Performance Scale. Descriptive statistics and Chi-square analysis were used.

**Results.** Three hundred forty-two (85%) patients had complete data recorded on day 1. There were linear correlations between days postadmission and improvements in pain (Cramer’s V=0.131), other symptoms (V=0.206), psychological/spiritual distress (V=0.101), and family/caregiver distress (V=0.124). Forty-three percent were in an unstable phase on admission, 61% and 71% of whom converted to a stable phase within 48 and 72 hours (linear temporal-phase association) (χ²=19.64; df=1). Patients in the unstable, deteriorating, and terminal phases were likelier to have higher pain, “other symptom,” psychological/spiritual distress, and family/caregiver distress scores. During the first 4 days and first 14 days, stable phase was associated with higher performance scores (Cramer’s V=0.526; all P<0.001).

**Commentary.** Demonstrating value to stakeholders is a perennial effort for palliative specialists. It is well established that palliative care improves patient and family satisfaction as well as reduces cost.1–3 However, traditional metrics to quantify outcomes rely on patient or proxy symptom reports or system level processes—length of stay, time to consult, etc. Neither approach provides comprehensive assessments of quality and value. This phase of illness model demonstrates a strong association between level of acuity and symptom distress for patients and caregivers in Ireland while establishing SPCU clinical effectiveness. This improves upon our traditional diagnosis-related group outcomes for inpatient palliative care, which focus on financial gaps without accounting for quality.4 Interestingly, no association between psychospiritual problems and phase was noted in a US cohort.5 This disparity needs further exploration before widespread adoption.

**Bottom Line.** Admission to a SPCU stabilizes illness for many patients, offering direct evidence of clinical quality.

**Reviewers.** Shweta Sundarajan, MD, and Kyle Neale, DO, Cleveland Clinic, OH

**Source.** Lucey M, O’Reilly M, Currow D, et al. Is inpatient hospice care clinically effective? Using phase of illness to evaluate care outcomes for patients admitted to a specialist palliative care unit in Ireland. *J Palliat Med.* 2020;23(4):535–541. https://doi.org/10.1089/jpm.2019.0295.

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Association of Mental Health Treatment with Outcomes for US Veterans Diagnosed with Non–Small Cell Lung Cancer

Background. Studies evaluating the effects of pre-existing mental health disorders (MHDs) on patients diagnosed with lung cancer universally find mental illness to be associated with increased mortality.1–4 Do mental health treatment programs (MHTPs) improve cancer-related outcomes among patients with pre-existing MHDs?

Design and Participants. This retrospective population-based cohort study evaluated the association of participation in MHTPs, housing support programs, or employment support programs with stage at cancer diagnosis, receipt of stage-appropriate treatment, and mortality among patients with a pre-existing MHD. Veterans in the Veterans Affairs Central Cancer Registry who had newly diagnosed non–small cell lung cancer (NSCLC) from 2000–2011 were included. Data were analyzed 2017–2020. MHDs included schizophrenia, bipolar disorder, depressive disorder, anxiety disorder, posttraumatic stress disorder, and substance use disorder (SUD). Analyses included t-tests, $\chi^2$, and Cox proportional hazards regression models.

Results. Veterans (N=55,315) were age mean=68 (SD=9.8) years, 98% male, 79% white, and 45% married. Of those, 18,229 had a pre-existing MHD (depression 44%, anxiety 35%, and SUD 31%), among whom rates of all-cause mortality (aHR=1.03; 95% CI=1.01–1.06; $P=0.08$) and lung cancer–specific mortality (aHR=1.03; 1.01–1.06; $P=.02$) were higher and among whom participation in MHTPs (57% participated in $\geq$1 MHTP) was associated with a lower likelihood of being diagnosed in a late stage (OR=0.62; 95% CI=0.58–0.66; $P<.001$), a greater likelihood of receiving stage-appropriate treatment (OR=1.55; 1.26–1.89; $P<.001$), lower all-cause mortality (aHR=0.74; 0.72–0.77; $P<.001$), and lower lung cancer–specific mortality (aHR=0.77; 0.74–0.80; $P<.001$). Likewise, participation in housing and employment support programs was associated with similar improvements in all above-described outcomes.

Commentary. This large population-based study is the first to examine the impact of interventions targeting mental health and social needs on cancer-related outcomes. Findings provide strong support that participation in MHTPs, housing support programs, and employment support programs is associated with earlier-stage diagnosis and better outcomes, including reduced mortality, in patients with NSCLC and pre-existing MHDs. Study limitations include lack of documentation of MHD severity or the extent of program utilization and the predominantly male sample. Generalization to healthcare settings outside of the Veteran Health Administration (VHA) also is unknown. The authors note the importance of integrated health systems such as the VHA for coordinating care for complex patients.

Bottom Line. Access and engagement in mental health, housing, and employment services may improve outcomes in patients with lung cancer and pre-existing mental health disorders.

Reviewer. Laura Porter, PhD, Duke University School of Medicine, Durham, NC

Source. Berchuck JE, Meyer CS, Zhang N, et al. Association of mental health treatment with outcomes for US veterans diagnosed with non–small cell lung cancer. JAMA Oncol. 2020;6(7):1–8. https://doi.org/10.1001/jamaoncol.2020.1466.

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Methylphenidate as Needed for Fatigue in Patients with Advanced Cancer: A Prospective Double-Blind Placebo-Controlled Study

Background. Cancer-related fatigue (CRF) is a highly prevalent symptom in patients with advanced cancer and has a strong negative impact
on patients’ daily life.1–4 Can methylphenidate relieve CRF?

**Design and Participants.** This Danish paired-design study (where the patient was their own control) evaluated the efficacy of methylphenidate as needed for the management of fatigue in patients with advanced cancer. Patients with a tiredness score ≥50 (0–100 visual analogue scale [VAS]) were included. Patients were given 10 placebo and 10 methylphenidate tablets numbered 1–20 packed in blocks of four with two active and two placebo tablets. Patients taking ≥3 tablets were regarded evaluable. Primary effect parameters were mean VAS differences for tiredness after 2 and 5 hours. The Wilcoxon signed rank test was used.

**Results.** With 28 evaluable patients, the study had a power of 0.90 to detect a mean difference of 15 between active and placebo. Evaluable patients (28 of 38 enrolled) were age mean=69 years and 71% female. Regarding tiredness, mean decreases for methylphenidate after 2 and 5 hours were 20 and 17 (8 and 5 for placebo). Comparing mean differences, the decrease for methylphenidate was greater than for placebo after 2 hours ($P=0.004$) and 5 hours ($P=0.001$). Regarding secondary parameters, methylphenidate (vs. placebo) was more effective after 2 hours for drowsiness and activity ($P<0.001$ and $P=0.008$). Five hours after patients took the tablets, methylphenidate (vs. placebo) was more effective for drowsiness ($P=0.018$). For methylphenidate, no increases were found in any other Edmonton Symptom Assessment System or VAS symptoms (concerning concentration problems vs. placebo).

**Commentary.** Cancer-related fatigue has a strong negative impact on patients’ daily lives and overall quality of life. This small study demonstrated that methylphenidate was significantly more effective at relieving fatigue than placebo after 2 and 5 hours from administration. Patients who took methylphenidate also reported a difference in drowsiness and clinical activity, indicating the possibility of broader clinical relevance for this medication beyond just improving fatigue. Important limitations of this study included exclusion of patients undergoing radiotherapy or chemotherapy, exclusion of patients with brain metastases, and a completely inpatient study population. Studies in outpatient settings with comparable designs have not shown a benefit in reported fatigue when compared to placebo.5 Longer studies are needed to determine whether the benefits in fatigue demonstrated here persist or whether tolerance or adverse effects develop over time.

**Bottom Line.** Methylphenidate may have a short-term benefit for hospitalized patients with cancer suffering from severe fatigue.

**Reviewer.** Sara F. Martin, MD, Vanderbilt University Medical Center, Nashville, TN

**Source.** Pedersen L, Lund L, Petersen MA, Sjogren P, Groenvold M. Methylphenidate as needed for fatigue in patients with advanced cancer. A prospective, double-blind, placebo-controlled study [published online ahead of print May 26, 2020]. *J Pain Symptom Manage.* https://doi.org/10.1016/j.jpainsymman.2020.05.023.

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**Rave Reviews**

Weaver MS, October T, Feudtner C, Hinds PS. ‘Good-parent beliefs’: research, concept, and clinical practice. *Pediatrics.* 2020;145(6):e20194018. https://doi.org/10.1542/peds.2019-4018.

Many parents of seriously ill children make decisions not based on what is objectively in their child’s “best interest,” but rather based on what they feel a “good parent” would decide in that situation. This review provides an outstanding summary of existing research and best practices for supporting parents in achieving this goal.

Sreedhar SS, Kraft C, Friebert S. Primary palliative care: skills for all clinicians [published online ahead
of print June 29, 2020]. Curr Probl Pediatr Adolesc Health Care. https://doi.org/10.1016/j.cppeds.2020.100814.

Given the workforce shortage in pediatric palliative care, it is crucial that nonspecialists be equipped to provide primary palliative care. This article is a valuable resource, especially for learners who are seeking to identify core skills.

Marcus KL, Santos G, Ciapponi A, et al. Impact of specialized pediatric palliative care: a systematic review. J Pain Symptom Manage. 2020;59(2):339–364.e10. https://doi.org/10.1016/j.jpainsymman.2019.08.005.

From an institutional standpoint, “doing the right thing” is often not enough to justify support for pediatric palliative care programs. This review highlights the areas where pediatric palliative care has been shown to provide benefit, as well as areas that require additional research.

PC-FACS Feedback

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