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*Effect of Disney Movies on QoL**Hospital Clowns Effect on Symptoms**Therapeutic Agents for Neuropathic Pain**Racial Disparities in Quality EOL Care**Ventilation in Older Adults**Home Health Agencies and Hospice**Symptom Suffering in Children with Cancer**Social Technology Use for Patient in Pain**Effect of Methylphenidate on Apathy**Effect of Viewing Disney Movies During Chemotherapy on Self-Reported Quality of Life Among Patients with Gynecologic Cancer*

**Background:** “Now, think of the happiest things. It's the same as having wings.”<sup>1</sup> Is watching Disney movies during chemotherapy associated with improved quality of life?

**Design and Participants:** This trial (2017–2018) at a cancer referral center in Vienna, Austria, evaluated the association of watching Disney movies during chemotherapy with emotional and social functioning and fatigue status. A consecutive sample of women with gynecologic cancers and six planned cycles of chemotherapy with either carboplatin and paclitaxel or carboplatin and pegylated liposomal doxorubicin were recruited. Participants were either shown Disney movies or not during chemotherapy cycles. Before and after every cycle, participants completed European

Organization for Research and Treatment of Cancer (EORTC) questionnaires. Primary outcomes were quality-of-life change, as defined by the EORTC Core-30 questionnaire, and fatigue, as defined by the EORTC Quality-of-Life Questionnaire Fatigue, during chemotherapy cycles. Welch-Satterthwaite's t-test, Fisher's exact test, and regression models were used.

**Results:** Participants were 25 women in the Disney group (age mean = 59 years [SD = 12]) and 25 controls (62 years [8]). Disney patients felt less tense and worried less than controls according to their responses to questions about emotional functioning (mean score = 87 [SD = 14] vs. 66 [27]; maximum test,  $P = 0.02$ ). Furthermore, watching Disney was associated with less encroachment on family life and social activities, as evaluated by the social functioning questions (mean score = 86 [SD = 23] vs. 64 [34]; maximum test,  $P = 0.01$ ). Moreover, this intervention led to fewer fatigue symptoms (mean score = 86 [SD = 14] vs. 66 [23]; maximum test,  $P = 0.01$ ). Perceived global health status was not associated with watching Disney (mean score = 76 [SD = 18] vs. 61 [25]; maximum test,  $P = 0.16$ ).

**Commentary:** The need to address complex physical, psychosocial, and spiritual distress while minimizing side effects has led to creative treatment solutions for patients with cancer. This study found that patients with gynecologic cancers who watched Disney movies during chemotherapy had significantly improved emotional and social functioning as well as less fatigue. Only the classics worked—with a Goldilocks length of about 90 minutes (not too long, not too short) and the happy-ever-after endings we all love. Extending this study to other types of cancer (and maybe even DreamWorks movies?!) could confirm generalizability. Although we wish we had magic wands to make disease and sadness disappear, a little help from a fairy godmother may be more than just a fairy tale.

**Bottom Line:** Though binge-watching Disney movies may not give our patients magical superpowers, there's a chance they just may burst into spontaneous song (caution: this may attract small animals who insist on completing household chores).

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*Reviewer:* Ambereen K. Mehta, Fairy Godmother Expert, MD MPH, Johns Hopkins Bayview Medical Center, Baltimore, MD

*Reference:*

1. Cahn S, Fain S. You Can Fly! [Peter Pan]. United States: Walt Disney Productions; 1953.

*Source:* Pils S, Ott J, Reinthaller A, Steiner E, Springer S, Ristl R. Effect of viewing Disney movies during chemotherapy on self-reported quality of life among patients with gynecologic cancer—a randomized clinical trial. *JAMA Netw Open*. 2020;3(5):e204568. doi:10.1001/jamanetworkopen.2020.4568

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**Effectiveness of Hospital Clowns for Symptom Management in Pediatrics**

*Background:* In pediatric settings, hospital clowns (HCs) use “in-tents” play, laughter, and imagination to stimulate a positive emotional state and environment that promotes interaction between parents and children.<sup>1–5</sup> Does evidence indicate improved symptom management and psychological well-being in pediatric inpatients receiving HC visits?

*Design and Participants:* This review evaluated the effectiveness of HCs for several symptom clusters in children and adolescents in various hospital settings. Databases were searched for trials (1947–2020) using the following eligibility criteria: children and adolescents who were admitted to hospital for acute conditions or chronic disorders, studies comparing HCs vs. standard care, and studies evaluating the effect of HCs on symptom management as a primary outcome. Two investigators independently assessed trial quality using the Jadad scale, the revised Cochrane risk-of-bias tool for randomized trials (RoB 2), and the Risk of Bias in Nonrandomized Studies of Interventions (ROBINS-I) tool for non-randomized controlled trials.

*Results:* Twenty-four studies (N = 1,612) were included (13 randomized controlled trials [RCTs]). Anxiety was the most frequently analyzed symptom (n = 13), followed by pain (n = 9), psychological and emotional responses and perceived well-being (n = 4), stress (n = 4), cancer-related fatigue (n = 3), and crying (n = 2). Five studies used biomarkers, mainly cortisol, to assess stress or fatigue outcome. Eleven RCTs were rated as showing some concerns, and two were rated high risk of bias. Six non-RCTs were rated moderate risk of bias. Studies showed that children and adolescents who were in the presence of HCs, with/without a parent, reported less anxiety during a range of medical procedures and improved psychological adjustment (P

< 0.05). Three studies that evaluated chronic conditions showed reduction in stress, fatigue, pain, and distress (P < 0.05).

*Commentary:* Hanging with clowns, like munching cilantro, divides people into two camps: some LOVE the experience and others see it as akin to having their mouth washed out with soap. This systematic review of the benefits of clowns in pediatric care, an academic inquest felt Pennywise by funders, found that those who think clowns don’t help kids can best be described as Bozos. Whether telling jokes, holding hands, or encouraging children to smell their flower (a funny “jester” to be sure), clowns decrease anxiety and improve well-being for kids on the ward and during anesthesia induction. Further studies are needed to understand whether the quadrupling of errors committed by terrified medical providers is worth *It*.

*Bottom Line:* Though you should add clowns to your pediatric repertoire, do not add them to your guacamole, lest your Dad tell you that “it tastes funny. . .bah, ding, boom.”

*Reviewer:* Christopher A. “Big Shoes to Fill” Jones, MD MBA HMDc FAAHPM, Duke-doo-doo-duh-doo-doo-doo-doo-do University Health System, Durham, NC

*References:*

1. BnF Gallica. Le Petit Journal, every issue from 1863 to 1940. <https://gallica.bnf.fr/ark:/12148/cb32895690j/date>
2. Spitzer P. Essay: Hospital clowns—modern-day court jesters at work. *Lancet*. 2006;368:S34–S35. doi:10.1016/S0140-673669919-4
3. Dionigi A, Goldberg A. Highly sensitive persons, caregiving strategies and humour: The case of Italian and Israeli medical clowns. *Eur J Humour Res*. 2019;7:1–15. doi:10.7592/EJHR2019.7.4.dionigi
4. Manyande A, Cyna AM, Yip P, Chooi C, Middleton P. Nonpharmacological interventions for assisting the induction of anaesthesia in children. *Cochrane Database Syst Rev*. 2015:CD006447. doi:10.1002/14651858.CD006447.pub3
5. Vagnoli L, Dionigi A. Clowns in support of the care process: A literature review. *Rivista Italiana di Studi sull’Umore*. 2019;2:7–22.

*Source:* Lopes-Júnior LC, Bomfim E, Olson K, et al. Effectiveness of hospital clowns for symptom management in paediatrics: Systematic review of randomised and non-randomised controlled trials. *BMJ*. 2020;371:m4290. doi:10.1136/bmj.m4290

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**Does the data tell us that humor can cure all ailments?**

**Our PC FACS April Fool's summaries aim to prove that laughter may still be the best medicine.**

**While the articles above were selected to make you giggle, the cutting edge HAPC research below is no joke.**

**Implications in Neuropathic Pain When the  $\sigma$ 1-Receptor and the HINT1 Protein Control  $\alpha$ 2 $\delta$ 1 Bind to Glutamate NMDA-Receptors**

*Background:* Nerve injury increases the association of  $\alpha$ 2 $\delta$ 1 proteins with NMDA-receptors, promoting neuropathic pain (NP).<sup>1</sup> How do  $\sigma$ 1-receptors ( $\sigma$ 1Rs) and HINT1 proteins affect  $\alpha$ 2 $\delta$ 1-NMDA-receptor complex formation?

*Design and Participants:* This study investigated  $\sigma$ 1Rs and HINT1 (which promote and dampen NMDA-receptor-mediated NP, respectively) in  $\alpha$ 2 $\delta$ 1-NMDA-receptor complex formation within the periaqueductal gray (implicated in pain modulation) using  $\sigma$ 1R- and HINT1-knockout mice with sciatic nerve chronic constriction injury (CCI). Gabapentinoids (used to target  $\alpha$ 2 $\delta$ 1 and alleviate NP) and SIRA ( $\sigma$ 1R antagonist) were injected into the lateral ventricles. Mechanical paw-withdrawal thresholds were performed as well as immunoprecipitation and Western blots of central nervous system (CNS) structures. Analysis used ANOVA.

*Results:* Immunoprecipitation and Western blotting determined that nerve damage recruited  $\sigma$ 1Rs, which coupled  $\alpha$ 2 $\delta$ 1 to the NR1 subunit of the NMDA-receptor, enhancing NMDA-receptor activity and neuropathy as measured via paw-withdrawal thresholds.  $\sigma$ 1R-NR1 dimer formation depended on calcium, and SIRA could dissociate them. Contrarily, neuropathy-related  $\delta$ 1- $\sigma$ 1R-NR1 trimers remained stable in low calcium, and they were less sensitive to SIRA. HINT1-to-NR1 binding did not require calcium and limited  $\sigma$ 1Rs' access to NMDA-receptors. In addition, once the  $\delta$ 1- $\sigma$ 1R-NR1 trimer formed, HINT1 removed the  $\delta$ 1 peptide and restored the potential of antagonists to disrupt the  $\sigma$ 1R-NR1 interaction. Thus,  $\sigma$ 1Rs and HINT1 controlled the access of  $\alpha$ 2 $\delta$ 1 to NMDA-receptors and, consequently, NP severity. In  $\sigma$ 1R-knockouts, CCI did not promote NMDA-receptor- $\alpha$ 2 $\delta$ 1 formation, whereas  $\sigma$ 1R-NMDA-receptor- $\alpha$ 2 $\delta$ 1 complexes increased in HINT1-knockout mice and after CCI. Notably, SIRA, but not gabapentinoids, alleviated NP in these mice. In conclusion, metabolism of  $\alpha$ 2 $\delta$ 1 proteins during neuropathy may account for the failure of patients to respond to gabapentinoids.

*Commentary:* The  $\alpha$ 2 $\delta$ 1-NMDA-receptor complex is important in pain perception. Gabapentinoids are known to target the  $\alpha$ 2 $\delta$ 1 molecule, and prior studies of the spinal cord indicate they decrease the ability of  $\alpha$ 2 $\delta$ 1 to regulate  $\alpha$ 2 $\delta$ 1-NMDA-receptor synaptic

expression and trafficking. In this thorough, well-designed study, the authors explored the role of  $\alpha$ 2 $\delta$ 1 in the CNS and confirmed the ability of  $\sigma$ 1R and HINT1 to regulate  $\alpha$ 2 $\delta$ 1 and, in turn, the NMDA-receptor complex. Inhibition  $\sigma$ 1Rs appeared to be more effective in decreasing pain than targeting  $\alpha$ 2 $\delta$ 1 with gabapentinoids. Study limitations include the use of mouse models, potential role of other CNS pain centers, relatively short period of CCI pain, and need to better understand the role of glycosylation in  $\alpha$ 2 $\delta$  activities.

*Bottom Line:* Elucidation of the role of  $\sigma$ 1R, HINT1, and  $\alpha$ 2 $\delta$ 1 in NMDA-receptor complex function can guide development of new therapeutic agents for neuropathic pain.

*Reviewer:* Kenneth Cornetta, MD, Indiana University School of Medicine, Indianapolis, IN

*Reference:*

1. Chen J, Li L, Chen S-R, et al. The alpha2delta-1-NMDA receptor complex is critically involved in neuropathic pain development and gabapentin therapeutic actions. *Cell Rep.* 2018;22:2307–2321. doi:10.1016/j.celrep.2018.02.021

*Source:* Rodríguez-Muñoz M, Cortés-Montero E, Onetti Y, Sánchez-Blázquez P, Garzón-Niño J. The  $\sigma$ 1 receptor and the HINT1 protein control  $\alpha$ 2 $\delta$ 1 binding to glutamate NMDA receptors: Implications in neuropathic pain. *Biomolecules.* 2021;11(11):1681. doi:10.3390/biom11111681

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**Association of Nursing Home Organizational Culture and Staff Perspectives With Variability in Advanced Dementia Care**

*Background:* Nursing home (NH) residents with advanced dementia (AD) commonly experience potentially burdensome interventions (eg, tube feeding, hospitalizations).<sup>1–4</sup> How do NH organizational factors and staff perceptions affect AD care intensity?

*Design and Participants:* This study assessed factors associated with facility and regional variation in care intensity for NH residents with AD. In the Assessment of Disparities and Variation for Alzheimer Disease Nursing Home Care at End of Life (ADVANCE) qualitative study, nationwide Medicare Minimum Data Set information from 2016–2017 identified hospital referral regions with high ( $n = 2$ ) and low ( $n = 2$ ) care intensity for patients with AD based on hospital transfer and tube-feeding rates; 14 high-intensity and low-intensity care NHs were recruited. Framework analyses explored factors and perceptions in these domains: physical

environment, care processes, decision-making processes, and implicit and explicit values.

**Results:** Overall, 169 staff were interviewed (91% women, aged mean = 48 years [SD = 4.7], 32% Black). Tube-feeding rates ranged from 0% in five low-intensity facilities to 44% in 1 high-intensity facility, and hospital transfer rates ranged from 0 transfers/resident-year in two low-intensity facilities to 1.6 in one high-intensity facility. The proportion of Black residents ranged from 2.9% in one low-intensity facility to 72% in high-intensity, and the proportion of Medicaid recipients ranged from 45% in 1 low-intensity facility to 81% in one high-intensity. Factors distinguishing lowest-intensity vs. highest-intensity facilities included having a more pleasant physical environment (e.g., good repair and nonmalodorous), standardized advance care planning, greater staff engagement in shared decision making, and staff implicit values unfavorable to tube-feeding. Staff in all NHs assumed proxies for Black residents were reluctant to engage in advance care planning and favored more aggressive care. Except in the lowest-intensity NHs, many staff believed tube feeding prolonged life and had other benefits.

**Commentary:** This is a must-read study that represents a significant advance in end-of-life health equity research. The National Institute on Minority Health and Health Disparities framework for health disparities research encourages researchers to expand our scope beyond individual and cultural factors to better understand structural, interpersonal, and societal determinants of disparities.<sup>5</sup> This study clearly demonstrates the manifestations of structural racism in environmental factors such as malodorous spaces and disrepair. The physical neglect of the facilities serving Black patients in this study was stark and would not engender the trust that is a prerequisite for quality end-of-life care discussions. Despite the fact that the majority of Black people would prefer comfort-oriented end-of-life care,<sup>6</sup> NH staff demonstrated stereotypical beliefs about proxies for Black residents, which may explain why Black families rate quality of communication about end-of-life care more poorly than white families.<sup>7</sup>

**Bottom Line:** Structural and interpersonal racism must be addressed to reduce racial disparities in quality of end-of-life care.

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

#### References:

1. Mitchell SL, Shaffer ML, Cohen S, Hanson LC, Habtemariam D, Volandes AE. An advance care planning video decision support tool for nursing home residents with advanced dementia: A cluster randomized clinical trial. *JAMA Intern Med.* 2018;178:961–969. doi:10.1001/jamainternmed.2018.1506

2. Sampson EL, Candy B, Jones L. Enteral tube feeding for older people with advanced dementia. *Cochrane Database Syst Rev.* 2009;2009:CD007209. doi:10.1002/14651858.CD007209.pub2
3. Mitchell SL, Teno JM, Roy J, Kabumoto G, Mor V. Clinical and organizational factors associated with feeding tube use among nursing home residents with advanced cognitive impairment. *JAMA.* 2003;290:73–80. doi:10.1001/jama.290.1.41
4. Teno JM, Gozalo PL, Mitchell SL, et al. Does feeding tube insertion and its timing improve survival? *J Am Geriatr Soc.* 2012;60:1918–1921. doi:10.1111/j.1532-5415.2012.04148.x
5. Alvidrez J, Castille D, Laude-Sharp M, Rosario A, Tabor D. The National Institute on Minority Health and Health Disparities Research Framework. *Am J Public Health.* 2019;109(S1):S16–s20. doi:10.2105/ajph.2018.304883
6. Barnato AE, Anthony DL, Skinner J, Gallagher PM, Fisher ES. Racial and ethnic differences in preferences for end-of-life treatment. *J Gen Intern Med.* 2009;24:695–701. doi:10.1007/s11606-009-0952-6
7. Welch LC, Teno JM, Mor V. End-of-life care in black and white: Race matters for medical care of dying patients and their families. *J Am Geriatr Soc.* 2005;53:1145–1153. doi:10.1111/j.1532-5415.2005.53357.x

**Source:** Palan Lopez R, Hendricksen M, McCarthy EP, et al. Association of nursing home organizational culture and staff perspectives with variability in advanced dementia care: The ADVANCE study. *JAMA Intern Med.* 2022;182:313–323. doi:10.1001/jamainternmed.2021.7921

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#### **Survival and Costs with Medical Ventilation in Dementia Patients Admitted with Pneumonia and Respiratory Failure**

**Background:** Invasive mechanical ventilation (IMV) use in people with dementia has increased in Canada, Spain, and the United States.<sup>1–3</sup> How does IMV affect outcomes and healthcare costs among patients with dementia?

**Design and Participants:** This study characterized survival and healthcare expenditures among a retrospective cohort of people (aged ≥66 years) with advanced dementia and nursing home stays who were hospitalized with pneumonia or septicemia with pneumonia requiring either IMV or noninvasive ventilation (NIV) in 2015–2017. People were included if they had a Minimum Data Set (MDS) assessment 1–120 days

prehospitalization indicating advanced dementia with more than four impairments in activities of daily living (ADLs). Propensity-matched analysis was performed using MDS clinical information, Chronic Condition Warehouse chronic disease indicators, and prior utilization measures. The main outcomes were survival and healthcare costs  $\leq 1$  year post-discharge. Descriptive statistics were used.

**Results:** Among the 27,483 hospitalizations, 7.1% received NIV, 12% IMV, and 1.1% both; 96% of IMV-only treated cases matched. People with NIV were older (83 vs. 82 years), were less likely to be Black (22% vs. 30%), were less likely to have used IMV in the previous 90 days (6.7% vs. 9.9%), and had lower presence of shock at admission (29% vs. 45%). NIV-matched cases had a higher 30-day mortality rate vs. IMV cases (59% vs. 52%,  $P < 0.001$ ; adjusted odds ratio [AOR] 0.71 [95% CI = 0.59–0.84]), but this survival benefit did not persist, as one-year mortality was slightly higher among IMV vs. NIV (87% vs. 86%,  $P > 0.05$ ; AOR = 0.93 [0.74–1.17]). One-year healthcare costs postmatching were higher among those treated with IMV vs. NIV (mean = \$57,122 [95% CI = \$56,652–\$57,591] vs. \$33,696 [\$33,249–\$34,144],  $P < 0.001$ ).

**Commentary:** This study covers a cohort of seriously ill nursing home older adults suffering from advanced dementia with additional serious comorbid illnesses. In the event of respiratory failure requiring ventilation support (either IMV or NIV), this study showed high mortality rate at 30 days and at one year. Even though the survival benefit is better in the IMV group at 30 days, it comes with an additional adjusted mean expenditure of \$23,423 per patient in the year after the illness, and the benefit did not persist at one year. This data would be helpful as clinicians engage serious illness conversation with surrogates. Some surrogates may wish to know that their loved one has 50% likelihood of death within one month of hospitalization despite ventilation support.

**Bottom Line:** It is important to initiate early discussions on the role and goal of hospitalization for older adults suffering from advanced dementia at risk for pneumonia.

**Reviewer:** Sik Kim Ang, MD AGSF FAAHPM FACP, Permanente Medicine, Washington Permanente Medical Group, Seattle, WA

#### References:

1. Teno JM, Gozalo P, Khandelwal N, et al. Association of increasing use of mechanical ventilation among nursing home residents with advanced dementia and intensive care unit beds. *JAMA Intern Med.* 2016;176:1809–1816. doi:10.1001/jamainternmed.2016.5964
2. Borjaille CZ, Hill AD, Pinto R, Fowler RA, Scales DC, Wunsch H. Rates of mechanical ventilation for patients with dementia in Ontario: A population-based cohort study. *Anesth Analg.* 2019;129:e122–e125. doi:10.1213/ane.0000000000004003
3. Bouza C, Martínez-Alés G, López-Cuadrado T. Effect of dementia on the incidence, short-term outcomes, and resource utilization of invasive mechanical ventilation in the elderly: A nationwide population-based study. *Crit Care.* 2019;23:291. doi:10.1186/s13054-019-2580-9

**Source:** Teno JM, Sullivan DR, Bunker J, Gozalo P. Survival and health care costs with IMV vs. NIV in dementia patients admitted with pneumonia and respiratory failure [published online ahead of print 10 February 2022]. *Ann Am Thorac Soc.* doi:10.1513/AnnalsATS.202110-1161OC

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#### *The Role of Agencies in Transitions from Home Health to Hospice*

**Background:** Home health agencies (HHAs) are often affiliated with hospice agencies and commonly care for patients with serious illness under Medicare.<sup>1–2</sup> Do patients cared for by HHAs affiliated with hospice agencies experience differential hospice use?

**Design and Participants:** This nationally representative cohort study of decedents in the 2002–2017 Medicare Current Beneficiary Survey assessed if beneficiaries who received home health in the last year of life were more likely to enroll in hospice if they were served by HHAs affiliated with a hospice. The primary independent variable was HHA hospice affiliation. The primary dependent variable was hospice enrollment; secondary dependent variables were hospice live discharge and length of stay. Bivariate logistic regression and multivariable models were used.

**Results:** Decedents ( $n = 1,431$ ) were aged mean = 82 years (SD = 10), 45% female, and 78% white. The 27% of decedents cared for by HHAs affiliated (vs. unaffiliated) with a hospice had higher education (17% vs. 11% college educated,  $P = 0.02$ ) and wealth (60% vs. 52%  $\geq$ \$25,000/year,  $P = 0.01$ ) and were more likely to live in the Midwest and Northeast (66% vs. 33%,  $P < 0.001$ ). In adjusted models, decedent of HHAs affiliated with a hospice had greater odds of enrolling in hospice vs. those cared for by HHAs not affiliated with a hospice, corresponding to a hospice enrollment rate of 51% (95% CI = 45%–57%) for those cared for by HHAs affiliated with hospices vs. 40% (36%–44%) for HHAs not affiliated ( $P = 0.004$ ). There were no differences in hospice length of stay or

live discharge rate by hospice affiliation. The only factors as strongly associated with hospice enrollment were dementia (odds ratio 1.68, 95% CI = 1.25–2.24) and cancer (1.59, 1.24–2.05) diagnoses ( $P < 0.01$ ).

*Commentary:* This study compared hospice enrollment rates between hospices affiliated with HHAs and independent hospice agencies. It is not surprising that the results showed that those agencies affiliated with hospices had a significantly higher rate of patients enrolled in home hospice care. There were no other significant differences between the two groups including length of stay in hospice. This result is most likely secondary to the prior relationship that has been built with the patient, family, and HHA and increased knowledge of the hospice Medicare benefit. This is an important finding in that increased exposure, education, and knowledge of the hospice Medicare rate lead to higher utilization of home hospice care with subsequent higher satisfaction rates with end-of-life care.

*Bottom Line:* Patients who receive home healthcare from agencies affiliated with a hospice are more likely to utilize the hospice benefit.

*Reviewer:* Alan R. Roth, DO FAAFP FAAHPM, Jamaica Hospital Medical Center, Jamaica, NY

#### References:

1. Teno JM, Bunker J, Gozalo P. Applying Sutton's Law to alternative payment models for the seriously ill. *Health Affairs*. [https:// www.healthaffairs.org/doi/10.1377/hblog20190823.145514/full/](https://www.healthaffairs.org/doi/10.1377/hblog20190823.145514/full/). Published August 27, 2019. Accessed March 31, 2022.
2. Park-Lee EY, Decker FH. Comparison of home health and hospice care agencies by organizational characteristics and services provided: United States, 2007. *Natl Health Stat Report*. 2010;9:1–23.

*Source:* Ankuda CK, Moreno J, Teno JM, Aldridge MD. Transitions from home health to hospice: The role of agency affiliation [published online ahead of print 29 December 2021]. *J Palliat Med*. doi:10.1089/jpm.2021.0390

Access this article on [PubMed](#).

#### Normalization of Symptoms in Advanced Child Cancer

*Background:* Children with cancer continue to experience significant symptom suffering.<sup>1–3</sup> Is pediatric cancer-related suffering overly tolerated?

*Design and Participants:* This qualitative, multiple-case study identified barriers to effective symptom management (SM) in patients with pediatric advanced cancer. A purposive sample of children aged  $\geq 2$  years with advanced cancer, their parents, and primary and

pediatric palliative care (PPC) clinicians were enrolled. Children and parents reported symptoms weekly for four months using the Memorial Symptom Assessment Scale (MSAS) administered via the Pediatric Quality-of-Life and Evaluation of Symptoms Technology Response to the Pediatric Oncology Symptom Experience (PediQUEST Response). When symptom distress episodes (SDEs) were reported (MSAS symptom score  $\geq 33$ ), SM processes were studied using interviews of family members and clinicians and chart abstractions. Analysis used grounded theory.

*Results:* Patients ( $n = 23$ ) were aged median = 13 years (IQR = 7–15), 60% female, and 78% white; 70% had solid tumors. Parents (78% mothers) were aged median = 46 years. Clinicians ( $n = 38$ ) were 82% female, 47% MDs, 21% nurses, and 16% psychologists or psychiatrists. Children reported 308 SDEs in 193 surveys, and parents reported 529 SDEs in 165 surveys. Eighty-five and 88 interviews were conducted with families and clinicians, respectively. A prominent theme emerged: symptom-related suffering was normalized (appraised as unavoidable). Patients, parents, and all clinicians, including PPC specialists, got accustomed to high symptom burden and lacked expectations that distress could be alleviated. Some assumed that symptoms were proof treatment was working and, therefore, expected and worth it. Symptom assessment and monitoring was limited, and it was usually tied to clinical encounters, not distress episodes. Oncology clinicians never documented the use of standardized symptom assessment tools. Families had a high threshold for seeking symptom support, and they were reluctant to use pharmacological approaches to SM.

*Commentary:* In this qualitative case study of parents of children with advanced cancer and their clinicians, parents and clinicians both normalized symptoms and suffering in children with advanced cancer, leading to poor symptom control. Communication and expectations are critical. Families need to know that clinicians have the tools (pharmacologic and nonpharmacologic) to help. Therefore, clinicians must not only discuss potential side effects but also discuss potential solutions. Notably, although clinicians have the tools to alleviate symptoms, complete avoidance or relief is not always possible. Clear communication around when symptom avoidance or relief may not be possible is essential. In this study, normalization prevented adequate symptom control for children with cancer; however, normalization of symptoms may be beneficial for children with other complex chronic conditions, allowing them to function despite chronic symptom burdens. Clinicians need to consider when normalization is beneficial and when it is harmful and appropriately counsel families.

*Bottom Line:* Parent and clinician normalization of symptoms prevented appropriate symptom

management; clear communication around symptom expectations is critical.

*Reviewer:* Charles C. Paine, MD, Children's of Mississippi, Jackson, MS

#### References:

1. Heath JA, Clarke NE, Donath SM, McCarthy M, Anderson VA, Wolfe J. Symptoms and suffering at the end of life in children with cancer: An Australian perspective. *Med J Aust.* 2010;192:71–75. doi:10.5694/j.1326-5377.2010.tb03420.x
2. Levine DR, Mandrell BN, Sykes A, et al. Patients' and parents' needs, attitudes, and perceptions about early palliative care integration in pediatric oncology. *JAMA Oncol.* 2017;3:1214–1220. doi:10.1001/jamaoncol.2017.0368
3. Simon JDHP, Van Loon FRAA, Van Amstel J, et al. Pain at home during childhood cancer treatment: Severity, prevalence, analgesic use, and interference with daily life. *Pediatr Blood Cancer.* 2020;67:e28699. doi:10.1002/pbc.28699

*Source:* Requena ML, Avery M, Feraco AM, Uzal LG, Wolfe J, Dussel V. Normalization of symptoms in advanced child cancer: The PediQUEST-Response case study. *J Pain Symptom Manage.* 2022;63(4):548–562. doi:10.1016/j.jpainsymman.2021.12.009

Access this article on [PubMed](#).

### **The Relationship Between Pain and Psychological Distress and the Use of Social Technology**

*Background:* The COVID-19 pandemic and resulting shelter-in-place orders profoundly changed the everyday social environment.<sup>1–2</sup> Was chronic pain status associated with psychological distress early in the pandemic, and did social technology (ST) moderate this relationship?

*Design and Participants:* This study, using cross-sectional data from the 2020 Health and Retirement Study COVID-19 Project, explored associations between pain, psychological distress, and ST during the pandemic among US adults aged  $\geq 54$  years. The authors analyzed whether individuals with pain disproportionately suffered from loneliness, depression, and anxiety vs. their pain-free counterparts and whether ST use moderated the associations between pain and these outcomes. Descriptive statistics and regression modeling were used.

*Results:* Participants (N = 1,014) (61% pain-free, 11% mild, 22% moderate, 6% severe) were aged mean = 67 years (SD = 7.3), 52% female, 81% white, 68% married, and 36% college educated. Individuals with moderate and severe pain (vs. pain-free) reported

more depression—the higher the pain, the higher the average number of depressive symptoms; more frequent ST was associated with fewer depressive symptoms (B = -0.12,  $P = 0.03$ ). More frequent ST predicted a lower number of depressive symptoms among pain-free individuals but a greater number among those with pain. People with severe pain (vs. pain-free) reported higher anxiety (B = 0.26,  $P < 0.05$ ); ST was not associated with reduced anxiety; however, individuals with moderate pain showed steeper anxiety reductions than other groups as they increased ST, but it did not meet standard thresholds for statistical significance. Individuals with any pain level (vs. pain-free) reported marginally higher loneliness ( $P < 0.10$ ); more frequent ST predicted less loneliness (B = -0.08,  $P < 0.05$ ); ST benefits were of similar magnitude across all pain groups.

*Commentary:* COVID resulted in isolation for everyone, but especially for older, medically vulnerable adults. One option to mitigate this isolation was ST use. This study investigated psychological symptoms in patients with and without pain and how ST use affected these symptoms. Overall, ST use was associated with lower depressive symptoms. However, in patients with moderate-severe pain, who, as expected, had higher depressive symptoms, more pain was associated with more frequent ST use. In comparison, pain-free patients who had frequent ST use also had fewer depressive symptoms. Investigators hypothesized this may have been due to increased strain with screen time, a replacement of in-person interaction by ST, and ST effects on sleep quality.

*Bottom Line:* Overall, ST use correlates with fewer depressive symptoms; however, in older patients with significant pain, it may instead be associated with higher levels of depression.

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#### References:

1. Holmes EA, O'Connor RC, Perry VH, et al. Multi-disciplinary research priorities for the COVID-19 pandemic: A call for action for mental health science. *Lancet Psychiatry.* 2020;7(6):547–560. doi:10.1016/S2215-036630168-1
2. Van Bavel JJ, Baicker K, Boggio PS, et al. Using social and behavioural science to support COVID-19 pandemic response. *Nat Hum Behav.* 2020;4:460–471. doi:10.1038/s41562-020-0884-z

*Source:* Yang Y, Grol-Prokopczyk H, Reid MC, Pillemer K. The relationship between pain and psychological distress during the COVID-19 pandemic: Is social technology use protective? *Pain Med.* 2022;23(2):280–287. doi:10.1093/pm/pnab262

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### **Effect of Methylphenidate on Apathy in Patients With Alzheimer Disease**

**Background:** Apathy affects up to 71% of people with dementia and results in excess disability.<sup>1–3</sup> Does methylphenidate decrease apathy in individuals with Alzheimer disease (AD)?

**Design and Participants:** This multicenter, randomized, placebo-controlled trial (2016–2020) in nine US clinics and one Canadian dementia care clinic measured whether methylphenidate (10 mg, twice daily) decreases the severity of apathy in individuals with AD, mild to moderate cognitive impairment, and frequent/severe apathy as measured by the Neuropsychiatric Inventory (NPI). Outcomes included baseline to 6 months NPI change or improved rating on the AD Cooperative Study Clinical Global Impression of Change (ADCS-CGIC). Other outcomes were safety, cognition change, and quality of life. Proportional odds logistic regression and linear mixed-effects modeling were used.

**Results:** Participants (99 methylphenidate and 101 placebo) were aged median = 76 years (IQR = 71–81), 66% male, 90% white, and 86% married; 55% graduated college. A larger NPI decrease was found in those receiving methylphenidate vs. placebo (mean difference = -1.25; 95% CI = -2.03 to -0.47;  $P = 0.002$ ). The largest NPI decrease was observed in the first 100 days with a significant hazard ratio for the proportion of participants with no apathy symptoms receiving methylphenidate vs. placebo (hazard ratio = 2.16; 1.19–3.91;  $P = 0.01$ ). At 6 months, the odds ratio of having an improved rating on the ADCS-CGIC for methylphenidate vs. placebo was 1.90 (0.95–3.84;  $P = 0.07$ ). The difference in mean baseline to 6 months change estimated using a longitudinal model was 1.43 (1.00–2.04;  $P = 0.048$ ). Cognitive measures and quality of life were insignificantly different between groups. Of the 17 serious adverse events that occurred, none were methylphenidate related. No between-group safety differences were noted.

**Commentary:** Apathy is a common symptom in patients with AD and is associated with increased caregiver distress and mortality risk. In this study, while there was a greater reduction in NPI apathy score in

the intervention group, the decrease was largest in the first 100 days and was not maintained to that level of reduction at six months. Of note, there was increased NPI aberrant motor behavior in the methylphenidate group compared with placebo; however, the result was not statistically significant. Furthermore, lack of statistically significant difference in caregiver distress and no treatment difference in quality of life or activities of daily living (ADLs) limits the potential overall clinical benefit. Study participants were also mostly white (90%) and male (66%), limiting the generalizability of these results.

**Bottom Line:** Methylphenidate may modestly and temporarily reduce apathy in patients with AD. Its overall clinical benefit is further limited by lack of effect on quality of life or ADLs.

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#### *References:*

1. Brodaty H, Altendorf A, Withall A, Sachdev P. Do people become more apathetic as they grow older? A longitudinal study in healthy individuals. *Int Psychogeriatr*. 2010;22:426–436. doi:10.1017/S1041610209991335
2. Benoit M, Robert P. [Depression and apathy in Alzheimer's disease]. *Presse Med*. 2003;32(24 Suppl):S14–S18.
3. Steinberg M, Shao H, Zandi P, et al. Point and 5-year period prevalence of neuropsychiatric symptoms in dementia: the Cache County Study. *Int J Geriatr Psychiatry*. 2008;23:170–177. doi:10.1002/gps.1858

**Source:** Mintzer J, Lanctôt KL, Scherer RW, et al. Effect of methylphenidate on apathy in patients with Alzheimer disease: The ADMET 2 randomized clinical trial. *JAMA Neurol*. 2021;78(11):1324–1332. doi:10.1001/jamaneurol.2021.3356

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