Since January 2020 Elsevier has created a COVID-19 resource centre with free information in English and Mandarin on the novel coronavirus COVID-19. The COVID-19 resource centre is hosted on Elsevier Connect, the company's public news and information website.

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Positive patient-clinician relationships enriched care experiences and, when perceived as human-centric, were seen as higher quality. Care transitions led to goal discordance when presented with logistical barriers, relationship rebuilding, inadequate information transfer, and coordination issues.

**Conclusion.** Bereaved family caregivers consistently rated care as goal concordant while also identifying areas of disappointing and low-quality care at the end of life.

**Implications for Research, Policy, or Practice.** Communication, relationships and humanistic care, and care transitions are all modifiable targets for quality improvement and deserve reform to enhance care quality for patients with advanced cancer and their families at the end of life.

**Layers of Loss: Defining a Taxonomy to Better Understand Huntington’s Disease Caregivers’ Spiritual Suffering, Grief and Coping Strategies**

Buddy Marterre, MD MDiv, Wake Forest Baptist Health. Francis Walker, MD, Wake Forest School of Medicine. Debbi Fox-Davis, MBA, HD Reach. Bethany Leidl, MD Student, Wake Forest School of Medicine.

**Outcomes.**

1. Illustrate the gravity and significant themes of Huntington’s disease (HD) caregiver spiritual distress, grief and loss, and coping strategies, and how they relate to one another
2. Outline a strategy to integrate with interdisciplinary neurology-based teams to foster more compassionate engagement and psycho-socio-spiritual support for family caregivers of patients with HD

**Background and Objective.** Huntington’s disease (HD), an incurable, multigenerational, autosomal dominant disorder, creates unique challenges and myriad spiritually related stressors in those affected and their familial caregivers. Spiritual distress has not previously been systematically studied among HD caregivers. We aimed to comprehensively define the elements of HD caregiver spiritual pain.

**Study Identification.** A PRISMA-ScR scoping literature review initially identified 465 articles. Original research studies, including quantitative and qualitative studies, were included. Review articles, studies validating tools, and single case reports were excluded.

**Data Extraction and Synthesis.** Data from included research articles were organized thematically via inductive and open coding. A grounded, deductive approach delineated a demarcated taxonomy of key themes. Four reviewers, using a modified Delphi approach, ascertained which themes were clearly demonstrated by research participants in each study.

**Results.** 36 of 465 articles met review criteria; none were published in the palliative care literature. Data extraction and coding produced an overarching framework to understand HD caregiver spiritual suffering, grief and loss, and coping mechanisms. Investigations focused primarily on intrapersonal (self-image) spiritual distress and existential angst, only rarely looking deeper into divine or transpersonal suffering, disrupted religious relationships, or meaning distress. HD caregivers experience profound grief and loss, expressed as disenfranchised grief or ambiguous loss of their loved one, loss of family structure, loss of social connectedness, and practical and personal losses. The majority of studies reported maladaptive HD caregiver coping strategies, characterized by dysfunctional escape schemes; in contrast, transcendent or creative strategies were often unexplored.

**Conclusions and Implications for Practice, Policy, and Research.** HD caregivers experience prolonged and complicated grief and many other forms of spiritual suffering as they progressively lose their loved one—as well as their own lives as they have known them. The comprehensive taxonomy that we defined will be used to create an improved spiritual pain and coping assessment tool that will be piloted and validated in the HD community, so that palliative care experts may one day integrate into neurology-based interdisciplinary teams to better support HD caregivers and families.

“I Had Never Felt More Alone in My Life as I Did Those Eight Days.” Impact of COVID-19 Visitation Restrictions on Patients and Caregivers

Sandra Stevens, MD, Maine Medical Center. Jaime Bickford, DO, St. Peter’s Healthcare. Anny Fenton, PhD, Dana Farber Cancer Institute. Rebecca Hutchinson, MD MPH, Maine Medical Center.

**Outcomes.**

1. Determine the impact of visitation restriction on caregivers and patients
2. Describe ways to improve communication and caregiver involvement to families during times of caregiver separation

**Original Research Background.** The impact of restricting hospital visitation during the COVID-19 pandemic on patients and caregivers has not been described.

**Research Objectives.** We explored how hospital visitation restrictions affected the health and experience of hospitalized patients and their caregivers.
Methods. We conducted a multimethod cohort study, matching adult patients (N = 100) hospitalized before the pandemic with 100 patients hospitalized after the pandemic. Matching was based on age, gender, and primary diagnosis. Based on chart abstractions, we conducted t tests estimating whether patient outcomes and medical teams’ communication with caregiver varied by status of visitor restrictions. We then conducted and analyzed semistructured interviews with a subset of patients hospitalized under visitor restrictions and their caregivers (N = 13) to understand the impact of visitation restrictions on patient and caregiver experience.

Results. Our chart abstraction revealed that caregivers of patients hospitalized during visitation restriction were more likely to receive no contact from medical teams (36.1% vs 16.5%; P < 0.001) and less likely to receive discharge counseling compared to those hospitalized before visitation restriction (36.5% vs 51.6%; P = 0.04). There were no significant differences in emergency department visits, rehospitalization, or death. Our qualitative analysis revealed that caregivers and patients experienced negative emotional consequences of the separation, such as anxiety, confusion, fear, and conflict with the medical team. Caregivers struggled with a lack of information about their loved ones’ overall psychological state. Although video visits were helpful, many caregivers either were not offered this option or did not have the technological literacy necessary to benefit.

Conclusion. Visitation restrictions during COVID were associated with lack of communication with caregivers but no significant differences in hospitalizations or ER visits. Interviews indicate that patients’ and caregivers’ unmet information needs due to lack of communication caused negative emotional consequences.

Implications for Research, Policy, or Practice. Future research should explore how to mediate the negative emotional sequelae of caregiver physical separation.

Cancer Hospice Caregivers’ Self-Care Behaviors: The Role of Mental Health, Burden, and Perceptions of Competency
Djin Tay, PhD RN, University of Utah. Eli Iacob, PhD, University of Utah. Maija Reblin, PhD, University of Vermont. Kristin Cloyes, PhD MN RN, University of Utah College of Nursing. Miranda Jones, BS, Anna Beck, MD, Huntsman Cancer Institute/University of Utah. Kathi Mooney, PhD RN FAAN, University of Utah. Lee Ellington, PhD, University of Utah.

Outcomes.
1. Identify 2 or 3 self-care behaviors that hospice family caregivers commonly underengage in
2. Recognize 3 or 4 hospice family caregiver characteristics associated with lower odds of self-care behaviors

Original Research Background. Hospice family caregivers (HFCs) provide intensive physical and emotional support of patients at the end of life, sometimes to the detriment of their own self-care.

Research Objectives. The purpose of this secondary data analysis is to examine sociodemographic and caregiving factors associated with HFC self-care.

Methods. HFCs of patients with cancer were purposively recruited from hospices in 4 US states. The relationships between sociodemographics (eg, race and ethnicity, age, gender), caregiver factors (Medical Outcomes Survey—Social Support, Zarit Burden Inventory, Caregiving Competency Scale, PROMIS—Mental Health), and caregivers’ self-care behaviors were examined via logistic regression models.

Results. Participants (N = 102) were mostly female (n = 74, 72.55%), White (n = 80, 78.43%), and spousal caregivers (n = 53, 51.96%). Almost half reported not having enough time to slow down and rest when they got sick (48.91%), get enough rest in general (47.96%), and exercise (46.94%). Although effect sizes were small, HFCs reporting better mental health were less likely to miss a doctor’s appointment in the past 6 months (aOR 0.89, 95% CI 0.81 to 0.98) and more likely to get enough rest in general (aOR = 1.15, 95% CI 1.05 to 1.26) or slow down when they get sick (aOR 1.22, 95% CI 1.08 to 1.38). HFCs reporting greater caregiving burden were more likely to miss a doctor’s appointment in the last 6 months (aOR 1.08, 95% CI 1.00 to 1.17), and those perceiving greater caregiving competence were less likely to slow down when sick (aOR 0.68, 95% CI 0.49 to 0.94). Male gender, age, race or ethnicity, co-residence with patients, and social support were not associated with use of the examined self-care behaviors.

Conclusion. This study indicates that almost half of HFCs did not engage in one or more self-care behaviors and provides a preliminary understanding of factors, particularly the inverse relationship of caregiver competency, that may contribute to self-care.

Implications for Research, Policy, or Practice. Regular communication and education about self-care are needed, even if HFCs report high self-efficacy in caregiving.

Narcan or Can’t? Opioid Overdose Education for Patients with Cancer Pain
Debora Afezolli, MD, Icahn School of Medicine at Mount Sinai. Vanessa DiMaria Austin, AGPCNP-BC, Mount Sinai Hospital. David Flemig, MD, Icahn School