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The National Hospice and Palliative Care Organization 2020 Needs Survey: Results of a Behavioral Health Addendum

Daniel Shalev, MD[1,2], **Stephanie Cheung, MD**[3], **Brigitta Spaeth-Rublee, MS**[4], **Jon Levenson, MD**[3], **Lori Bishop, MHA BSN RN**[5], **Harold Pincus, MD**[3,4]

[1]:Weill Cornell Medicine, Department of Medicine, Division of Geriatrics and Palliative Care

[2]:Weill Cornell Medicine, Department of Psychiatry

[3]:Columbia University, Department of Psychiatry

[4]:New York State Psychiatric Institute

[5]:National Hospice and Palliative Care Organization

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Palliative care improves quality of life of patients with serious illness and caregivers through symptom management and psychosocial support. Older adults represent a growing population of patients with palliative care needs. Patients living with serious illness have high rates of behavioral health (BH) comorbidity which have an adverse effect on outcomes.[1] However, mental health integration into palliative care is inchoate.

The National Hospice and Palliative Care Organization (NHPCO) is a professional organization representing hospice and palliative care programs. In June of 2020, the NHPCO emailed a Palliative Care Needs Survey to 2200 hospice and/or palliative care programs nationally. In recognition of the importance of BH integration into palliative care services, an optional subsection on BH was added to the survey based on a framework of BH-serious illness care integration.[1] The BH addendum included questions about features supporting BH provision, barriers to BH integration, clinical guidelines for BH problems, formal relationships with external referral sources for BH needs, and workforce development/staff training aimed at meeting BH needs (see supplement 1).

325/2200 programs responded to the main survey. Respondents provided care to 89,609 patients in 2019. Programs provided care across a range of settings. Services provided

Corresponding author: Harold Alan Pincus, M.D., Professor and Vice Chair, Department of Psychiatry, Co-Director, Irving Institute for Clinical and Translational Research, Vagelos College of Physicians and Surgeons, Columbia University, New York State Psychiatric Institute, 1051 Riverside Drive, Unit 09, New York, NY 10032, Phone: 646.774.5400, Harold.Pincus@nyspi.columbia.edu.

Author Contributions:

DS, SC, BSR, JL, LB, and HP all created to the behavioral health needs assessment survey and planned the experiment. LB coordinated with the National Hospice and Palliative Care Organization and integrated the BH addendum into the survey, as well as conducting initial data extraction and analysis. SC conducted additional data analysis and interpretation. DS and SC wrote the manuscript with editorial input and in discussion with other authors. BSR, HP, JL and LB contributed to editing and revision of the manuscript.

by programs include symptom management (52%), advance care planning (52%), and care coordination (49%). Approximately 54% of programs identified offering at least one psychosocial service such as counseling. Programs identified staff training (38%) and webinars (59%) as areas that NHPCO could support.

38 respondents (12%) proceeded to the BH addendum. BH addendum respondents served 16481 patients in 22 states. Most programs (89%) had embedded social workers and pastoral care (76%), though few had other embedded BH personnel. 32% of programs reported established linkages to BH referral sources.

Most of those respondents participating in the BH survey noted a desire to provide embedded BH services (63%) and a majority (53%) cited a desire for an embedded psychiatrist or psychologist. Programs overwhelmingly believed that additional funding (84%) and staff training (76%) were essential to building BH capacity. Staff training was highest in existential/spiritual issues (47%), cognitive impairment (45%), and grief/bereavement (45%) and lowest for serious mental illness (24%). Programs commonly reported having guidelines for anxiety (50%), depression (50%), grief/bereavement (50%), cognitive impairment (dementia/delirium) (47%) but not serious mental illness (18%).

The NHPCO palliative care needs survey represents a real-world cross-section of clinical programs providing palliative care. These results lay a path for involvement of geriatric psychiatrists to contribute to BH workforce development in palliative care. It is noteworthy that many identified needs including training in neurocognitive disorders and bereavement are areas of expertise for geriatric psychiatrists. The need to support programs addressing disparities for older adults with SMI and serious medical illness is particularly striking and something that geriatric psychiatrists are well positioned to help address.

Strengths of this manuscript include a nationally representative, diverse sample of clinical programs providing care to many patients. However, generalizability is limited by the low response rate perhaps due to poor streamlining between the overall and BH portions of the survey.

Conflicts of Interest and Source of Funding

Harold Pincus reports payments from Bind Health Plan, AbleTo, Cerebral, Magellan Health Studio and the National Council on Community Wellness in his role as member of the advisory committee of the entities listed; he also received funding from the Gordon and Betty Moore Foundation. Brigitta Spaeth-Rublee received funding from the Gordon and Betty Moore Foundation. Dan Shalev received funding from the Gordon and Betty Moore Foundation. Stephanie Cheung does not report any conflicts of interest. Jon Levenson reports royalty from UpToDate for coauthoring chapters on psycho oncology for UpToDate. Lori Bishop is employed by NHPCO and also serves on the National Advisory Board of CSU Shiley Haynes Institute for Palliative Care and NASEM SI Roundtable, both on behalf of NHPCO.

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