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GENERAL INFORMATION

Title of Dataset:

Comparing knowledge and perceptions of palliative care among neuro-oncology patients, caregivers, and providers to a representative U.S. sample

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*Date of data collection (20200801 - 20201101)

*Geographic location of data collection (if applicable): Durham, NC, USA

DATA & FILE OVERVIEW

File list (filenames, directory structure (for zipped files) and brief description of all data files):

One file is included:

Overall GAPP Data deidentified.xls - This file contains the data, with variable names and integrated formatted, that were collected from study participants at Duke. To deidentify the dataset, responses to the following variables were deleted:

- How old were you when you were diagnosed (for patient)
- Please tell us how old you are now (for patient and caregiver)
- Number of years since completion of training (for providers)

The survey contains questions for patients, caregivers, and providers. Some data fields within this file are intentionally blank as the question was not posed to that particular participant group. Any other data field

that appears to be "missing" is a result of the patient providing an incomplete response when responding to the survey online.

Data from a representative U.S. Sample are not provided here as HINTS 5, Cycle 2 data from 3504 respondents are available from the NCI (<https://hints.cancer.gov/data/download-data.aspx>) in SAS databases.

METHODOLOGICAL INFORMATION

Description of methods used for collection/generation of data:

An electronic survey was distributed to PBT patients, caregivers, and medical providers, that included questions regarding PC from the Health Information National Trends Survey (HINTS). Survey responses were analyzed; comparisons were made between the three groups as well as the general population.

This IRB-exempt study involved an online anonymous questionnaire, utilizing questions from the HINTS survey, that could be completed in under 5 minutes during a routine clinic visit (Supplemental Material 1). Participants included in the study were 1) self-identified established patients receiving care for their PBT, 2) self-identified caregivers of established patients receiving care for their PBT, and 3) medical providers from the treating clinical teams.

Recruitment strategies included signage in clinic as well as verbal prompts from clinic staff (check-in desk, medical assistants (MAs), nurses, advanced practice providers (APPs), and physicians). Participants accessed the survey with a QR code or customized URL in clinic or by email for medical providers. Posters were displayed in multiple locations, including patient waiting areas, the nurse's station, individual patient rooms, and clinic work rooms.

For all respondents (patients, caregivers, medical providers), the REDCap survey was accessed by a single QR code or shortened URL. The QR code was generated by using the following website: <https://www.qr-code-generator.com>. We used a customized URL - e.g., bit.ly/DukeBTC that participants could access through any browser on their mobile device. Study data were collected and managed using REDCap electronic data capture tools.

To avoid the risk of people incorrectly identifying themselves, the online survey had a confirmatory question before an individual could proceed. For example, "Are you a patient with a brain tumor receiving medical care at The Preston Robert Tisch Brain Tumor Center in clinic 3-1?" If the response was NO, they could not proceed. To prevent duplicate responses, we also asked, "Have you completed this survey before?" If the answer was YES, they could not proceed. To ensure participant privacy, no protected health information from any of the three study groups was collected, and identifiable personal information was not gathered.

Participation was voluntary for patients ≥ 18 years old, receiving care from one of our healthcare providers, irrespective of their primary brain tumor type. Caregivers ≥ 18 years old were also eligible to participate, provided they identified themselves as caregivers to one of the established patients. Additionally, medical providers with titles such as MD, DO, PA, NP, and RN, who regularly treated patients with PBTs as part of their practice, were included.

A validated instrument of 9 questions was used, with the first 6 questions addressing knowledge of PC, and the last 3 questions addressing perceptions about PC. Since this was an IRB-exempt, quality improvement project, we did not create unique identifiers to link patients with their caregiver's responses. Hence, patients, caregivers, and providers were treated as three independent groups in analyses.

HINTS 5, Cycle 2 data from 3504 respondents are available from the NCI (<https://hints.cancer.gov/data/download-data.aspx>) in SAS datasets. These data have been more recently updated. However, we used the dataset analogous to the time frame for our survey.

The percentage of patients, caregivers, providers, and members of a national sample who indicated that they had heard about palliative care was computed. An exact chi-square test compared groups (patients, caregivers, providers, and a national sample) with respect to the percentage of patients who had heard about palliative care. Among those participants who had heard about palliative care, frequency distributions within participant groups were generated for each survey question. We compared patient, caregiver, and clinician responses to the outcomes observed within the national sample.

The appendix of the manuscript includes the survey used. This has been made into a separate .pdf for reference.

USE and ACCESS INFORMATION

Data License: CC0 <http://creativecommons.org/publicdomain/zero/1.0/>

Other Rights Information: NA

To cite the data:

Johnson, M. O., Kim, J., Dalton, J. C., Cort, N., Herndon, II, J. E., Affronti, M. L., Peters, K. B., Jones, C. A. (2024). Data from: Comparing knowledge and perceptions of palliative care among neuro-oncology patients, caregivers, and providers to a representative U.S. sample. Duke Research Data Repository. <https://doi.org/10.7924/r40s0030b>.