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## Pilot Feasibility Study of an Oncology Financial Navigation Program in Brain Cancer Patients

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### Description of the problem.

Patients with brain cancer are at risk for developing financial toxicity, which is defined as a combination of subjective financial concerns (e.g., anxiety), objective financial consequences of health issues and treatments (e.g., decreased income, medical debt), and patients' coping behaviors<sup>1</sup>. The direct costs of care are considerably high in these patients (monthly direct medical cost of approximately \$8,478<sup>2</sup>), and decreased household income is common and reported by at least half of the patients as a result of cancer treatment<sup>3</sup>. Financial toxicity has been shown to be linked with several clinically relevant patient outcomes, including health-related quality of life (HRQOL)<sup>4</sup>, symptom burden<sup>5</sup>, care adherence<sup>6</sup>, and survival<sup>7</sup>. Extreme financial distress after cancer diagnosis (manifested by declaring personal bankruptcy) has been reported to be a risk factor for mortality<sup>7</sup>. Given delay or non-receipt of an indicated imaging tests is a potential outcome of financial toxicity,

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it is critical for radiologists to understand the financial impact of treatment, which includes surveillance imaging, among patients with this condition.

Providing patients with resources to proactively manage the costs of their cancer care may help to reduce financial toxicity<sup>8</sup> and ultimately improve treatment and imaging adherence. Financial navigation can be offered at any stage of patients' care from surgery to oncology to radiology encounters. However, financial navigation, must be provided in a manner that is acceptable, accessible, less cumbersome, thereby not affecting the flow of clinical care<sup>8</sup>. In order to better understand how to equip patients and their families with tools that have the potential to reduce financial toxicity, there is an urgent need to study interventions at the patient, clinic, payer, and policy level. In the current study, we aimed to assess the feasibility of providing a financial navigation program alongside treatment in brain cancer patients.

## What we did

Procedures for obtaining informed consent and protecting participants were approved and monitored by the Emory Institutional Review Board. The study was Health Insurance Probability and Accountability Act (HIPAA) compliant.

In this prospective single-arm pilot longitudinal observational study, we recruited adult patients with newly diagnosed brain cancer visiting outpatient oncology clinics, identified through prospective review of clinic schedule. Inclusion criteria were age 18 or older, with a new diagnosis of either primary malignant brain cancer (pathology proven) or brain metastasis (diagnosed on brain MRI), and receipt or plan to receive any of surgery, chemotherapy or radiation therapy. New diagnosis was defined as within the first 2 months of diagnosis. Patients who were not able to read or speak English at the time of their appointment were excluded.

Informed consent from eligible patients were obtained in person in the waiting room prior to their oncology clinic visits by a study coordinator. Those who consented were invited to complete a 15-minute paper survey at baseline. Follow-up surveys were completed at 3, 6 and 9 months after enrollment either during follow-up clinic visits (paper survey) or on the phone, if a patient did not have scheduled clinic visit or did not show up to the visit. The surveys included questions to assess financial toxicity, financial coping mechanisms and care-nonadherence due to cost of care. Financial toxicity was measured using the validated Comprehensive Score for financial Toxicity (COST) questionnaire<sup>9</sup>, which includes 11 questions reflecting five latent dominant themes of affect, coping, family, financial and resources<sup>9</sup>, and results in a score ranging between 0 to 44. The lower the score, the worse the financial toxicity<sup>9</sup>. Financial coping mechanisms were measured with questions on decreased spending on food, clothing or leisure<sup>10</sup>, and financial hardship such as withdrawing money from savings accounts or borrowing money<sup>11</sup>. Care non-adherence was defined as any self-reported patient-initiated inappropriate cessation of prescribed medication or late- or partial-filling of prescriptions. Caregivers were allowed to help patients answer the survey questions.

Patients who completed the baseline survey were asked to participate in a centralized oncology financial navigation program. The financial navigation program was offered through the Patient Advocate Foundation (PAF)<sup>12</sup>, a national case-management organization that assists patients with a range of issues, including access to health insurance coverage, debt relief, cost of living and disability applications. Upon consent, a member of PAF initiated the contact with patient and determined patients' financial or care concerns or needs and attempts were made to secure assistance whenever possible. Subsequently, PAF case managers contacted the participants once per month for 6 months at minimum. In addition, participants could contact their case manager if additional financial issues arose. For each patient, we documented the number of contacts made with the participants (regardless if patient or PAF initiated the contact); all recommendations or interventions made by PAF; and any financial assistance procured through charitable entities on behalf of the patients.

For each patient, mean financial toxicity score (COST) at baseline was reported with standard deviation (SD) and range. Changes in COST from baseline to each time point were compared using paired t-test. Patient characteristics and care non-adherence were summarized with frequencies and percentages or means and SDs, where appropriate. Feasibility for financial navigation program was measured as program participation, type and amount of services provided. For program participation, we calculated proportion of patients who consented and completed at least one contact appointment with a PAF case manager during the 6 months program. We described the type and amount of assistance that were provided to the participants.

## Outcomes and Limitations

During the study recruitment period (October 2017-December 2018), 102 eligible patients were identified, of whom 12 patients consented to participate in the study (Figure 1). Reasons for nonparticipation were "not interested in this research", "want to focus on my treatment" and "too overwhelmed with my disease and treatment that do not have time or energy to participate in this research". Respondents were more likely to be younger on average (45.5 years vs 59.0 years;  $P=.004$ ) compared with non-respondents. Further, respondents were more likely to be uninsured (16.7% vs. 8.1%) or have Medicaid (16.7% vs. 13.9%) and less likely to have Medicare (16.7% vs. 42.3%) ( $P=0.04$ ). Gender, race, and marital status did not reach statistical significance at the .05 level between respondents vs. non-respondents.

Among respondents, 83% (n=10) completed the entire baseline questionnaire; remaining 17% (n=2) completed 95% of the baseline questionnaire. A total of 66% of respondents (n=8) had primary malignant brain cancer; while 34% (n=4) had secondary brain cancer from colon (n=2), lung (n=1) or breast (n=1) primary cancers. Baseline characteristics of the study population is shown in table 1.

At baseline, patients' mean COST score was 9.4 (SD, 9.0), ranging from 0 to 23. This was lower than reported COST scores in the literature for patients with solid tumors (mean of 23)<sup>9</sup>, indicating brain cancer patients are likely at higher risk of financial toxicity compared to other tumors. All 12 patients reported decreased spending on basic needs (e.g., food and

clothing) or leisure activities due to cost of their treatment. A total of 75% (n=9) of patients reported care non-adherence due to cost of treatment. Financial hardship was reported by 58% (n=7) of patients including borrowing money (n=4) or using saving account to pay for treatment (n=5).

Before contact with PAF, 92% (n=11) of patients used some sort of financial support including, using a financial advocate/navigator (n=6), meeting with a social worker (n=10), help with understanding how to pay for care (n=1), and what insurance covers (n=2), free medication samples or help paying for medications (n=2).

A total of 92% (n=11) of consented patients completed at least one contact appointment with a PAF case manager and were considered participants. Participants had an average of 69 contacts [median of 126; interquartile range, 96–142.5] with a PAF case manager over the 6-month study period. The main concerns discussed with PAF staff included debt crisis/cost of living (e.g., inability to afford transportation, food, utility, rent, mortgage), disability (e.g., disability qualification or application assistance), employment (e.g., questions on employment rights such as family and medical leave act [FMLA]), insurance (e.g., general benefit/coverage question, inability to afford care requiring cost-share, inability to afford Marketplace premium), medical decision making (e.g., assistance with clinical trials options), psychosocial support (e.g., counseling for caregivers). Table 2 demonstrates the total number of issues discussed with PAF case managers and percentage of these issues resolved during the 6 months contact with PAF. An issue was considered resolved if the case manager was able to address the specific patient concern/issue, either through education, direct assistance or location of external resource(s). Overall, there were 45 total issues discussed with PAF for 12 patients. Ninety-three percent (n=42) were resolved during the 6 months post enrollment. Total amount of debt relief provided through PAF case management work during the study period was \$15,110.

There was no significant difference in the COST score of 5 patients who had follow-up scores at 3 months when compared to baseline (mean score of 8.8 at baseline vs. 8.0 at 3 months;  $p = 0.89$ ), although the sample size is likely too small to detect a significant difference. Supplemental Figure 1 shows a plot of changes in individual patients COST score over time.

We encountered significant limitations. We found that recruitment and follow-up for our pilot study was challenging for several reasons. First, the high rate of mortality<sup>13</sup>, patients' rapid cognitive decline<sup>14</sup> and high caregiver dependency<sup>15</sup> served as a barrier to recruiting patients and following-up during the time. We recruited patients within the first two months of diagnosis, when many patients were coping with physical and psychosocial issues associated with a new cancer diagnosis. Further, many patients had not yet received their hospital bill. Participation in a financial burden study may have been of a less priority for them, with many patients mentioning a preference for focusing on their cancer treatment or participate in a treatment clinical trial. Finally, contact initiation and consistency with PAF was challenging, as some patients did not respond phone calls or messages. Others forgot what PAF was as an organization. Despite these limitations, our findings support the feasibility of centrally provided oncology financial navigation programs once patients

express interest in such programs. These results can be used to design future interventions to address whether use of financial navigation program can reduce financial burden resulting from cancer care. For future studies, involvement of all team members (e.g. oncologist, radiologist, social worker, financial counselor) in patient recruitment, addition of patient incentives, use of several methods for recruitment may help improving response rate. Further, routine patient-physician communication about out-of-pocket expenses, may result in better engagement of patients in shared decision-making<sup>16</sup> as well as increasing awareness of importance of research studies focusing on financial burden. In addition, we can enhance study participation by helping patients understand that their responses to follow-up surveys are critical in improving clinical outcomes and care adherence.

Challenges of navigating imaging centers for brain cancer patients is variable across institutions and states. Although our pilot study reports the results from one institution, understanding the difficulties these patients face is important. As radiologists are expected to be part of integrated patient care, radiology practices are encouraged to develop processes to identify patients at risk for financial toxicity and imaging non-adherence and refer these patients to existing financial support services within the hospital system. This will help to streamline care and potentially off set many of the missed appointments, care non-adherence and unnecessary costs. Further, our results emphasize the important role of radiologists in recommending evidence-based and cost-effective imaging modality when it comes to cancer diagnosis and follow-up.

## Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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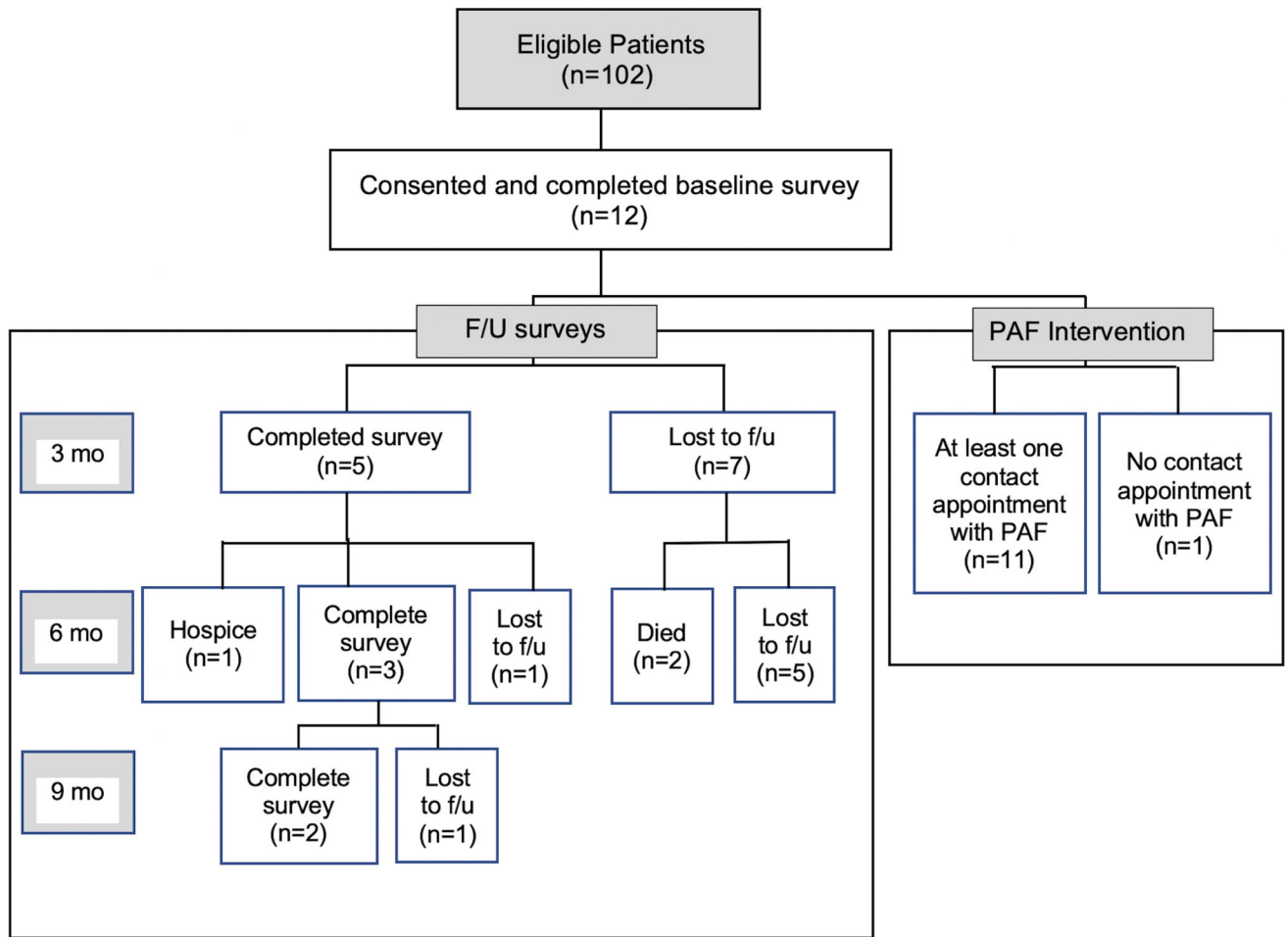
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**Figure 1.**  
Study Flowchart.

**Table 1.**

Baseline characteristics of study population.

Mean age, yr (SD)	45.5 (12.7)
Gender, % (n)	
Female	58.3% (7)
Male	41.7% (5)
Race, % (n)	
White	58.3% (7)
African American	41.7% (5)
Ethnicity, % (n)	
Not Hispanic, Spanish or Latino	90.9% (10)
Hispanic, Spanish or Latino	9.1% (1)
Highest level of education, % (n)	
High school graduate or less	27.3% (3)
More than high school graduate	73.7% (8)
Marital Status, % (n)	
Single/never married	33.3% (4)
Married or living with a partner	50% (6)
Separated, divorced, widowed	16.7% (2)
Employment Status, % (n)	
Full-time or part-time	41.7% (5)
Unemployed, disabled, retired	58.3% (7)
Annual household income, % (n)	
Less than \$60k	50% (6)
\$60k or more	50% (6)
Health insurance, % (n)	
Medicare	16.7% (2)
Medicaid	16.7% (2)
Private	33.2% (4)
Other types (e.g., marketplace, military)	16.7% (2)
No insurance	16.7% (2)
Mean monthly premium, \$ (SD)	174 (136)



**Table 2.**  
**Number of issues discussed with PAF case managers and resolved.**

Please note that numbers are not at patient-level. A patient may have more than one-time issue in each category.

	# discussed with PAF	# resolved
Debt crisis/Cost of living	11	11
Disability issues	10	9
Employment issues	1	1
Insurance issues	18	16
Medical decision-making issues	1	1
Psychosocial support request	5	5

An issue was considered resolved if the case manager was able to address the specific patient concern/issue, either through education, direct assistance or location of external resource(s).

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