A Pilot Study of a Comprehensive Financial Navigation Program in Patients With Cancer and Caregivers

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ABSTRACT

Background: Few studies have engaged patients and caregivers in interventions to alleviate financial hardship. We collaborated with Consumer Education and Training Services (CENTS), Patient Advocate Foundation (PAF), and Family Reach (FR) to assess the feasibility of enrolling patient-caregiver dyads in a program that provides financial counseling, insurance navigation, and assistance with medical and cost of living expenses. **Methods:** Patients with solid tumors aged ≥ 18 years and their primary caregiver received a financial education video, monthly contact with a CENTS counselor and PAF case manager for 6 months, and referral to FR for help with unpaid cost of living bills (eg, transportation or housing). Patient financial hardship and caregiver burden were measured using the Comprehensive Score for Financial Toxicity–Patient-Reported Outcomes (COST-PRO) and Caregiver Strain Index (CSI) measures, respectively, at baseline and follow-up. **Results:** Thirty patients (median age, 59.5 years; 40% commercially insured) and 18 caregivers (67% spouses) consented (78% dyad participation rate). Many participants faced cancer-related financial hardships prior to enrollment, such as work change or loss (45% of patients; 39% of caregivers) and debt (64% of patients); 39% of caregivers reported high levels of financial burden at enrollment. Subjects received \$11,000 in assistance (mean, \$772 per household); 66% of subjects with income $\leq$ \$50,000 received cost-of-living assistance. COST-PRO and CSI scores did not change significantly. **Conclusions:** Patient-caregiver dyads were willing to participate in a financial navigation program that addresses various financial issues, particularly cost of living expenses in lower income participants. Future work should address financial concerns at diagnosis and determine whether doing so improves patient and caregiver outcomes.

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Background

Financial toxicity is a well-documented consequence of cancer diagnosis that encompasses a range of material, psychological, and behavioral hardships, including debt, bankruptcy, financial worry, and treatment nonadherence.^{1–6} Although younger individuals from low-income households are at highest risk, studies suggest that all patients, regardless of insurance type or socioeconomic status, are vulnerable to adverse financial consequences after cancer diagnosis.

Informal cancer caregivers often share in this experience of financial hardship, particularly spouse caregivers, whose assets, income, and expenses are often inextricably linked with those of the patient. Caregivers often face work changes, loss of income, and increased out-of-pocket spending, all of which can affect their well-being and ability to perform caregiving duties.^{7–10}

We previously reported our experience pilot-testing an oncology financial navigation program in patients with cancer with early-stage solid tumors.¹¹ We found that it was feasible to enroll patients in this program and provide concrete assistance with budgeting, employment concerns, cost-of-living issues (eg, transportation, meals), insurance coverage, and medical expenses. We also found that 33% of enrolled subjects experienced a decrease in anxiety about cost of care after the program. However, our previous study and other recent studies of financial counseling and navigation interventions did not specifically include informal caregivers (eg, spouses, adult children, friends) as study participants.^{11–13} With growing evidence that cancer-related financial hardship adversely affects patients and their informal caregivers and contributes to disparities in health outcomes, there is an urgent need for interventions that address the individual and shared financial concerns of both patients with cancer and their caregivers. Recent research demonstrates the importance of addressing patient and caregiver needs at the individual and dyad level; however, the feasibility of dyad engagement with a financial navigation program has not been reported.^{14,15} Building

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on our prior work, we have expanded our oncology financial navigation program to include caregivers and patients with advanced-stage cancer, and have partnered with another organization that provides direct funding to families for nonmedical bills.

This article reports on the feasibility of enrolling patient–caregiver dyads in a comprehensive oncology financial navigation program and describes the assistance provided by our partnering organizations. Program gaps and opportunities for future study are also discussed.

Methods

Study Design

We conducted a single-institution prospective cohort study to assess the feasibility of enrolling patient–caregiver dyads to an oncology financial navigation program. We describe the demographic and financial characteristics of enrolled subjects, the assistance provided to participants by our navigation partners, participants' overall satisfaction with the program, and gaps in available assistance. All study procedures and materials were approved by the Fred Hutchinson Cancer Research Center Institutional Review Board.

Study Population

Patients were recruited from the Seattle Cancer Care Alliance (SCCA), a metropolitan academic cancer center in Seattle, Washington. English-speaking patients aged ≥ 18 years with any-stage solid tumor diagnosis actively receiving or within 6 months of prior receipt of systemic therapy (hormonal, chemotherapy, biologic or immune checkpoint inhibitor therapy, and/or radiation) at SCCA were considered eligible. To maximize participation and follow-up, patients were excluded if they were considered by their oncologist to have a life expectancy of < 6 months. Patients were asked to identify a caregiver, defined as a family member or friend who provides unpaid emotional, logistic, medical, and/or financial support to the patient during cancer treatment. Although patients could participate without a caregiver, all identified caregivers aged ≥ 18 years were invited to participate in the program along with the patient as part of a patient–caregiver dyad.

Financial Counseling and Navigation Partners

As described in our prior study, we previously partnered with 2 organizations that specialize in providing financial education and navigation services to individuals from various backgrounds. Consumer Education and Training Services (CENTS; www.centsprogram.org) is a nonprofit organization that focuses on improving financial literacy and providing financial counseling and budget management

training to residents of the greater Seattle area. Patient Advocate Foundation (PAF; www.patientadvocate.org/) is a national organization that assists patients with a range of issues, including access to health insurance coverage, medication access assistance, coverage denials, transportation and meals, debt relief, and disability applications. In the current study, we included a third partner, Family Reach (FR; <https://familyreach.org>), specifically to complement the role of PAF in providing additional assistance with cost-of-living expenses that subjects in our previous study had reported. FR is a national nonprofit organization dedicated to alleviating the financial burdens of cancer by providing small grants to cover household nonmedical expenses, such as rent, utilities, and mortgage payments.

Approach and Intervention

Eligible patients were identified by their treating oncology providers prospectively from their clinic templates or in real-time during a clinic visit. Oncology providers were not specifically asked to identify patients and caregivers with stated financial need; however, many did refer patients and caregivers who had reported a financial concern during a clinic visit. Research staff met with and obtained consent from patients and caregivers after clinic visits or during infusion sessions. Consent from caregivers who were not present at the initial patient consent visit was obtained by telephone or at a subsequent clinic visit by the study coordinator. All patients and caregivers who provided consent were separately emailed a link to an online financial education course developed by CENTS in collaboration with our team and described in detail previously.¹¹ A CENTS financial coach arranged an initial meeting with the patient or patient–caregiver dyad to generate a prospective budget or financial strategy informed by reviewing patients' and caregivers' assets and liabilities and patients' health plan details (eg, annual out-of-pocket maximums, deductibles, copayments or coinsurance for medical services) provided by the billing specialists at SCCA. PAF case managers contacted participants by telephone to determine their financial or logistical needs and then attempted to secure assistance where possible. The CENTS financial coaches and PAF case managers contacted the participants once per month for the following 6 months, or more often if needed; in addition, CENTS coaches and PAF case managers could communicate if needed regarding specific cases to divide tasks or clarify participants' financial circumstances. Patients with nonmedical financial needs were referred by either CENTS counselors or PAF case managers to FR social workers for payments toward specific nonmedical bills.

Study Instruments, Measurements, and Analytic Approach

Three surveys were administered to participants (at baseline, 3 months, and 6 months postenrollment) during the study period, adapted from previously tested and validated surveys.^{4,11}

The baseline patient survey, administered at consent, assessed demographic characteristics not available in the medical record (education level, marital status, race), annual income, and employment status prediagnosis and postdiagnosis. Both baseline and follow-up patient surveys assessed financial or employment changes in the preceding 3 months (accrual of debt, selling/refinancing home, decline in income, new loans, loss of work or decrease in work hours), and cost-related nonadherence (skipping doses of medication or refusing treatment due to cost concerns). In addition, general financial hardship was measured using the 11-item Comprehensive Score for Financial Toxicity (COST)-Functional Assessment of Chronic Illness Therapy (FACIT), with lower scores (range, 0–44) indicating greater financial hardship.^{16,17} In the follow-up surveys, patients were asked to rate their satisfaction with the financial education video, CENTS financial coaches, PAF navigators, and the overall program on a 5-point Likert scale (1 = strongly disagree, 5 = strongly agree). Caregiver baseline and follow-up surveys assessed demographic characteristics, including sex, employment status, and relationship to patient; impact of caregiving on employment and finances; single-item measuring financial burden related to loved one's cancer diagnosis (5-point Likert scale; 1 = strongly disagree, 5 = strongly agree), and overall caregiver burden using the 13-item Modified Caregiver Strain Index that includes 2 items focusing on work adjustments and financial strain (higher scores = higher burden; each item scored on a 3-point scale: 0 = no, 1 = sometimes, 2 = on a regular basis).¹⁸ In addition, CENTS financial coaches, PAF case managers, and FR social workers documented number of hours spent interacting with participants, recommendations and interventions made to and for participants, and financial assistance procured through charitable entities.

To address our aim of assessing feasibility of enrolling caregivers as part of a patient-caregiver dyad, we reported the proportion of identified caregivers who participated together with the patient as part of a dyad (agreement rate). We used descriptive statistics to summarize the financial and employment impacts of cancer diagnosis on patients and caregivers. For patients who completed follow-up surveys, we compared mean COST-FACIT scores at baseline and follow-up using a 2-sample *z* test. Mean Modified Caregiver Strain Index

(MCSI) scores were calculated for all caregivers at baseline and for the group that completed follow-up surveys.

Results

Between January and July 2018, 54 potentially eligible patients were identified, of whom 30 consented and were enrolled in the study; 23 (77%) identified a primary caregiver. Of these caregivers, 18 participated as part of a patient-caregiver dyad, yielding a 78% agreement rate (Figure 1). All enrolled subjects had some form of health insurance, with 8 (27%) having either Medicaid or charity care. As expected with this adult patient population, most caregivers were spouses (67%) and shared household finances with the patient (56%). At baseline, most enrolled patients (55%) reported an annual household income of ≤\$25,000; caregivers generally reported higher annual household income than patients at baseline, with 63% reporting annual incomes of >\$50,000. For cases in which caregivers reported living off of a combined household income with the patient (*n*=10), both parties separately reported the same annual household income 80% of the time, suggesting that most subjects were indeed reporting combined household income. Patient and caregiver characteristics are summarized in Tables 1 and 2.

Median time from diagnosis to baseline survey was 435 days. As such, many patients and caregivers reported cancer-related employment and financial challenges in the baseline survey. For example, although 69% of patients were employed prior to diagnosis, only 24% reported maintaining employment after diagnosis. A similar trend was seen with caregivers; 50% were employed prior to the patient's diagnosis, whereas only 28% remained employed after. More than three-quarters (78%) of working caregivers changed their work routines (ie, using their own sick leave or vacation time, cutting back on hours or quitting, taking unpaid leave or Family and Medical Leave Act, or working additional hours or jobs to earn money) as a result of their caregiving role. Most patients (64%) reported being in debt and 44% reported a decline in income due to cancer diagnosis. Refusing treatment or skipping medication doses due to financial concerns was rare (2%) in this cohort. Nearly 40% of caregivers reported that cancer was a financial burden to them, and 56% reported that their level of financial worry increased after the patient's cancer diagnosis.

Most participants engaged with CENTS counselors, PAF case managers, and FR social workers (if referred). However, only 33% of patients and 44% of caregivers completed a follow-up survey. Furthermore, a greater proportion of married versus nonmarried patients (44% vs 27%; *P*=.36) and those with a participating caregiver

Figure 1. Patient and caregiver participation.

Abbreviations: CENTS, Consumer Education and Training Services; FNP, Financial Navigation Program; PAF, Patient Advocate Foundation.

^aPercent of eligible patients and caregivers that both agree to participate as dyads.

(56% vs 9%; $P=.01$) completed follow-up surveys. Neither of the 2 caregivers with a patient who died during the study completed a follow-up survey after the patient's death. The low follow-up response rate for both patients and caregivers limited our ability to draw rigorous conclusions about self-reported financial strain before and after the program. Nonetheless, among patients who completed both baseline and follow-up surveys, COST-FACIT score was not significantly lower at follow-up compared with baseline (20.95 baseline vs 18.04 follow-up; $P=.63$), suggesting relative stability in financial status; whether COST-FACIT scores would have declined significantly in the absence of financial counseling and navigation is not known. Caregivers had a slight but not statistically significant overall improvement in caregiver burden after the program, as indicated by a decline in the modified CSI score (6.56 baseline vs 4.71 follow-up; $P=.33$). CENTS counselors and PAF case managers were rated highly (4 or 5 on a 5-point Likert scale) by patients (63% for both) and caregivers (43% CENTS and 50% PAF). By contrast, most participants indicated that they had trouble focusing on the financial education video or felt overwhelmed by its content.

CENTS, PAF, and FR were able to provide practical assistance to participants for a variety of financial issues,

categorized into one of the following: cost of living, insurance navigation, medical costs, employment, legal counsel, financial counseling, and other. Table 3 summarizes all assistance and counseling provided during the study, as reported by both participants and our partner organizations. Among subjects with annual income <\$25,000, cost of living (eg, transportation, housing) was the predominant issue requiring assistance. These same individuals were also less likely to establish contact with CENTS counselors, and when they did, CENTS counselors reported that financial counseling was less effective due to minimal assets and significant additional challenges such as homelessness. Six patients or patient-caregiver dyads were referred to FR by CENTS and PAF based on need identified during their assessments. Participants referred to FR were generally disadvantaged; 80% of patients referred had an annual income <\$15,000 and 80% had Medicaid insurance. As expected, PAF helped more often with cost-of-living issues, whereas CENTS focused on its core educational and financial counseling functions. All subjects receiving cost-of-living assistance from PAF and FR reported an annual income of ≤\$50,000 (and most had incomes <\$25,000 annually). PAF was able to secure \$6,950 on behalf of study subjects (\$772, on average, per household

Table 1. Baseline Patient Characteristics (N=30)

Characteristic	n (%)
Sex	
Male	16 (53%)
Female	14 (47%)
Race	
White	16 (53%)
Black	4 (13%)
Asian	3 (10%)
Hispanic/Latino	2 (7%)
Other/Unknown	5 (17%)
Annual income, USD (n=29)	
\$0–\$25,000	16 (55%)
\$25,001–\$50,000	2 (7%)
\$50,001–\$75,000	6 (21%)
\$75,001–\$100,000	1 (3%)
>\$100,000	4 (14%)
Employment prediagnosis (n=29)	
Employed	20 (69%)
Retired	6 (21%)
Unemployed, disabled, LOA	3 (10%)
Employment postdiagnosis (n=29)	
Employed	7 (24%)
Retired	9 (31%)
Unemployed, disabled, LOA	13 (45%)
Financial impacts of cancer diagnosis	
Debt, USD	18 (60%)
≤\$25,000	12 (66%)
>\$25,000	6 (33%)
Income decline	12 (40%)
≤20%	5 (42%)
>20%	6 (50%)
New loans	7 (24%)
Sold or refinanced home	1 (3%)
Cost-related nonadherence	2 (7%)
Median age (range), y	59.5 (31–75)
Median days from diagnosis	435
Education (n=23)	
≤High school/GED	11 (48%)
Bachelor's degree	10 (43%)
Graduate degree	2 (9%)
Marital status	
Married/Partnered	18 (62%)
Single	2 (7%)
Divorced/Widowed	9 (31%)

(continued)

Table 1. Baseline Patient Characteristics (N=30) (cont.)

Characteristic	n (%)
Insurance type	
Commercial	12 (40%)
Medicare	10 (33%)
Medicaid	7 (23%)
Charity care	1 (3%)
Cancer stage	
I or II	1 (3%)
III	5 (17%)
IV	24 (80%)
Mean COST score (range)	17.78 (0–41)

Abbreviations: COST, Comprehensive Score for Financial Toxicity; LOA, leave of absence.

receiving assistance), whereas FR provided \$4,133 (\$647 per household) for nonmedical expenses.

Discussion

We implemented a financial navigation program to address some of the financial and logistical challenges not often identified as aspects of the cancer experience. We discovered that it was feasible to enroll both patients and patient–caregiver dyads across a range of insurance types and income levels to this program. A substantial proportion of patients and caregivers reported high levels of financial burden and anxiety due to cancer diagnosis. A large proportion of caregivers made work sacrifices or changes to their employment because of their caregiving role, a finding that aligns with other studies. Caregivers and patients independently reported high satisfaction with the program, suggesting that the benefits can be experienced collectively and individually. The type of assistance provided differed by income level; lower-income individuals needed help with basic cost-of-living expenses such as transportation and housing, whereas higher-income participants had more issues related to employment, medical cost coverage, and insurance navigation. Study subjects received >\$11,000 in financial assistance from our partner organizations for cost-of-living and medical expenses. A dollar value was not assigned to the more intangible assistance such as financial counseling, education, insurance navigation, and moral support. Finally, we noted that patients' self-reported financial hardship and caregiver burden did not significantly decline during the program, although we cannot specifically attribute this stability to the program.

Caregivers are important patient partners in navigating the financial aspects of cancer care. Many spouse caregivers often take on the role of managing household finances when patients are ill, and may have more energy

Table 2. Baseline Caregiver Characteristics (N=18)

Characteristic	n (%)
Sex	
Male	5 (28%)
Female	13 (72%)
Race	
White	13 (76%)
Black	1 (6%)
Asian	2 (12%)
Hispanic/Latino	0 (0%)
Other/Unknown	2 (6%)
Annual income, USD (n=16)	
\$0–\$25,000	2 (13%)
\$25,001–\$50,000	4 (25%)
\$50,001–\$75,000	4 (25%)
\$75,001–\$100,000	2 (13%)
>\$100,000	4 (25%)
Employment prediagnosis	
Employed	9 (50%)
Retired	3 (17%)
Unemployed, disabled, LOA	5 (28%)
Student	1 (6%)
Employment postdiagnosis	
Employed	5 (28%)
Retired	6 (33%)
Unemployed, disabled, LOA	6 (33%)
Student	1 (6%)
Financial impacts of cancer diagnosis (n=17)	
Used savings/retirement	6 (35%)
Cut spending on leisure, health, food, or other necessities	9 (53%)
Relationship to patient	
Spouse	12 (67%)
Sibling	4 (22%)
Child	2 (11%)
Shares finances with patient	10 (56%)
Work change or loss because of caregiving	7 (39%)
Financial worry because of cancer	
Decreased	0 (0%)
No effect	8 (44%)
Increased	10 (56%)
Caregiver financial burden ^a	
1–3	11 (61%)
4–5	7 (39%)

(continued)

Table 2. Baseline Caregiver Characteristics (N=18) (cont.)

Characteristic	n (%)
Caregiver strain index, mean	6.6
Financial strain (score ≥1) ^b	8 (44%)
Work change (score ≥1) ^b	6 (33%)

Abbreviation: LOA, leave of absence

^aMeasured on a 5-point Likert scale.^bScores of ≥1 indicate self-reported strain in these domains.

and focus to receive assistance and recommendations from financial navigators. We saw a higher dropout rate in our previous pilot study, often due to patients' medical issues and feeling overwhelmed; by including caregivers in the current study, we were able to overcome some of these recruitment and retention challenges. In an advanced cancer population, caregivers also often deal with significant financial fallout after patient death. Future studies should focus on easing the financial burden and financial confusion during the postbereavement period.

In the context of these findings, several limitations should be acknowledged. First, this pilot study was conducted at a single institution that serves a largely White, urban, and insured patient population. Our findings therefore may not be generalizable to a socio-economically and racially diverse population. Second, we did not dictate the type and scope of assistance that CENTS, PAF, and FR could provide participants in this study. Rather, we left room for tailored, personalized need-based assessments and interventions, allowing the specialists to use their knowledge base and expertise to "do what they do best." Lack of a specific script or mandated workflow may raise questions about scalability to other cancer centers and clinics. However, because the financial coaches and case managers are not embedded as paid employees within a clinic, many centers throughout the country could conceivably create similar partnerships between the patients they serve and community-based organizations such as CENTS, PAF, and FR. Third, at the time of enrollment, many patients were well into their diagnosis and treatment (median time from diagnosis, 435 days), raising concerns about recall bias for questions about the prediagnosis period. We therefore avoided specific questions about detailed financial circumstances and instead focused on prediagnosis employment status and income, which would be less prone to recall bias. Moreover, our decision not to limit enrollment to newly diagnosed patients was informed by feedback from patients in our previous studies who reported feeling overwhelmed and unable to focus on this program so early in their care. Despite the decision to liberalize the enrollment window for the current study, we believe that intervening proactively from the time of

Table 3. Type and Amount of Assistance Provided by CENTS, PAF, and FR to Patients and Patient–Caregiver Dyads

Type	Patient Income Range				
	≤\$15,000 (n=7)	\$15,001–\$25,000 (n=9)	\$25,001–\$50,000 (n=2)	\$50,001–\$100,000 (n=7)	>\$100,000 (n=4)
Cost of living	4 (57%) • Housing referral (CENTS) • Transportation referral (CENTS) • Secured housing assistance (PAF) • Rent assistance (PAF) • Utility payment assistance (PAF) • Free/Charity transportation (PAF) • \$838 rent payment (FR) • \$1,595 rent payment (FR) • \$500 for outstanding home bills (FR) • \$200 gas, for travel to medical appointments (FR)	7 (78%) • \$100 transportation assistance (PAF) • Rental payment waiver (PAF) • Free/Charity transportation (PAF)	1 (50%) • \$100 transportation assistance (PAF)	0 (0%)	0 (0%)
Insurance navigation	0 (0%)	2 (22%) • General benefits, coverage (PAF) • Applied for premium assistance (PAF) • COBRA eligibility, coverage (PAF)	1 (50%) • Medicaid information (CENTS) • ACA information (PAF)	3 (43%) • Medicare supplement enrollment (PAF) • Future insurance charges and out-of-network coverage (PAF) • Long-term care benefit information (PAF) • ACA information (PAF) • Verification of benefits (PAF)	1 (25%) • Medicare Part B information (PAF) • COBRA information (PAF)
Medical costs	1 (14%) • Enrolled in pharma indigent drug program (PAF)	3 (33%) • Negotiated payment discount/plan for medical service (PAF) • Free drug, could not afford medication cost share (PAF)	1 (50%) • \$100 for direct medical equipment cost share (PAF)	2 (28%) • Negotiated discount to payment plan for hospital/facility cost share (PAF) • Secured \$4,000 for medication cost share (PAF)	0 (0%)
Employment	1 (14%) • Disability application process (PAF)	0 (0%)	1 (50%) • Counsel regarding potential employer retaliation because of patient's illness (CENTS)	2 (28%) • Employment rights information (PAF) • Disability application process (PAF)	2 (50%) • Working part-time while on disability (CENTS) • Disability application process (PAF) • Employment rights information (PAF)
Financial counseling	1 (14%) • Pro bono referral for filing overdue tax returns (CENTS)	3 (33%) • Budget plan (CENTS)	2 (100%) • Budget plan (CENTS)	3 (43%) • Budget plan (CENTS)	2 (50%) • Budget plan (CENTS)
Legal counsel	1 (14%) • Legal referral for court-ordered parenting plan (CENTS)	0 (0%)	0 (0%)	1 (14%) • Pro bono services to write will (CENTS)	0 (0%)
Other	2 (28%) • Listening, support (CENTS)	2 (22%) • Listening, support (CENTS) • Referred for grief counseling (PAF)	0 (0%)	3 (43%) • Listening, support (CENTS) • Referred for assistance with clinical trial options (PAF) • \$1,000 for prepaid funeral services (FR)	0 (0%)

Abbreviations: ACA, Affordable Care Act; CENTS, Consumer Education and Training Services; COBRA, Consolidated Omnibus Budget Reconciliation Act; FR, Family Reach; PAF, Patient Advocate Foundation.

diagnosis has the greatest potential to mitigate financial toxicity. Future studies should focus on implementing financial navigation early in the care continuum. Finally, as in similar studies of financial navigation in patients with cancer, the survey response rate was relatively low.¹² We attribute this low response rate to the fact that most patients had stage IV cancer and they and their caregivers were dealing with significant medical issues.

Conclusions

We believe our findings set the stage for future studies engaging patients and caregivers in addressing financial burden in cancer care. More research is necessary to understand the peridiagnosis period (6 months before and after diagnosis) to understanding the appropriate timing for financial navigation interventions. We believe that proactive financial navigation serves one of ASCO's

major efforts to address the growing problem of financial toxicity, equipping patients and their families with tools they can use as they face one of the many daunting aspects of cancer care.

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