

**1.1 BACKGROUND/SIGNIFICANCE** One in three Americans suffers a financial burden as a result of medical care (1). The Kaiser Family Foundation report “The Burden of Medical Debt” found that two-thirds of insured patients use up all or most of their savings to pay for healthcare (2). One-third of patients use long-term savings (e.g., retirement, college or other savings accounts) to pay for current healthcare costs. The situation is worsening, as increasingly, insured patients face rising drug costs, coinsurance payments and deductibles (3).

Although these financial burdens are experienced by patients with a wide variety of chronic illnesses, they are greatest for oncology patients, regardless of cancer type or insurance status (4, 5, 6). Patients may delay, or even forego, life-prolonging treatments when faced with a choice between their cancer care and basic needs such as food and shelter. In one recent study, cancer patients were nearly three times more likely to declare bankruptcy than people without cancer, and cancer patients who filed for bankruptcy due to medical debt were 79% more likely to die than cancer patients who did not file for bankruptcy (7). Other groups have reported associations between what has recently been called “**financial toxicity**” (FT) and cancer-related mortality (8,9).

Having health insurance does not necessarily protect against cancer-related FT as many insured cancer patients experience some degree of underinsurance, defined as a lack of adequate health care coverage. De Souza, et al reported that 42% of insured cancer patients reported ‘significant’ or ‘catastrophic’ financial burden (10) and a large majority of cancer patients had applied for copayment assistance for medications. Cancer patients with higher co-pays are 70% more likely to discontinue their medications and 42% more likely to be non-adherent to their medication regimen, compared with cancer patients who have lower co-pays (5).

Consequently, there is a pressing need for the development of FT interventions for cancer patients who need them most (10,11,12). These high-risk patients and their caregivers need financial counseling and assistance managing medical bills, transportation, and non-medical issues. They also need hands-on guidance with applications for financial assistance programs (5,7).

Our team’s 2016 survey of 78 North Carolina-based oncology patient navigators found that NC navigators thought 75% of their patients experienced some degree of FT related to their cancer while only 45% of navigators felt that most of their patients were able to get any financial assistance. Common barriers to obtaining financial assistance included **lack of resources** (50%), **lack of knowledge about resources** (46%), and **complex/duplicative paperwork** (20%) (13).

Within the UNC Health Care System (HCS), twelve recent in-depth interviews with North Carolina Cancer Hospital (NCCH) providers (including financial counselors, social workers, and nurse navigators) identified **the need for more coordinated efforts to help patients identify financial resources available within and outside of the NC HCS** (e.g. UNC Charity Care, Pharmacy Assistance, Medicaid, Social Security and Disability). NCCH providers also cited the **administrative burden of multiple applications, lack of staff time** to help patients with applications, and **application delays** as the most common system barriers.

The approach detailed in this proposal addresses the growing need at the NCCH for early identification of financial distress. Importantly, **the NCCH recently identified the development of a comprehensive financial navigation program as one of its FY 2018 goals**. In addition to responding to this identified goal, the results of this project will inform the financial navigation process throughout the UNC HCS. We will deliver patient-centered financial education and support through a novel, alternatively staffed, financial navigation clinic structure.

**1.2 PROJECT GOALS AND OUTCOME METRICS** The overarching goal of this project is to decrease the burden of FT among uninsured and underinsured cancer patients treated at the NCCH by identifying patients with high levels of financial distress and connecting them with available financial resources without having to hire additional permanent employees. Our strategy is to establish a novel, cost-effective, patient-centered financial navigation clinic that will be fully integrated within existing care coordination services.

**Goal 1.** To develop a financial distress screening strategy for the patient population(s) experiencing the greatest financial burden by eliciting patient feedback on existing financial distress screening instruments.

**Goal 2.** To design, implement, and evaluate a new financial navigation clinic for 50 NCCH patients who screen positive for high levels of financial distress.

**Table 1.0 Goals and Corresponding Outcome Metrics**

<b>Project Goal</b>	<b>Associated Outcome Metrics</b>
Goal 1. Develop financial distress screening strategy	Financial distress screening tool; number of patients screened; screening outcomes
Goal 2. Implement and evaluate new financial navigation clinic	Amount of financial assistance provided/patient; number of successful (accepted) financial assistance applications; type of applications submitted; type of resources patient was eligible for; number of programs patient is referred to (including in-house programs and referrals to community partners); number of applications submitted; pre- and post-intervention financial distress screening results; patient satisfaction; number of patients who attend new financial clinic appointments; and the number of financial clinic appointments/patient.

**1.3 PROJECT DESCRIPTION, APPROACH, METHODS** Cancer-related FT is a recently appreciated problem and, to our knowledge, there are no data-driven and systematically administered FT navigation programs available for NC cancer patients. This study is innovative in its approach in that it will: (1) identify patients at high risk for FT among uninsured and underinsured patients; (2) elucidate and refine the operational/logistical processes needed to implement financial distress screening at NCCH; and (3) improve coordination of care for uninsured and underinsured cancer patients by addressing FT as barrier to high quality cancer care.

The team will target two high volume clinics in the NCCH, the Hem/Onc clinic (also known as the multidisciplinary clinic) and the breast cancer clinic. These clinics not only have a high patient volume, they see both female and male patients and patients from a broad range of social-economic backgrounds. The multidisciplinary and breast clinics have , 14 providers and 9 providers respectively and their clinic days (Wednesdays and Thursdays) align with the availability of the social work interns availability to meet with patients for financial distress screening (Goal 1) and the pilot financial navigation clinic (Goal 2). The research team in partnership with the NCCH financial workgroup (see letter of support) will work to make sure that patient flow and referral streams are clear between existing financial navigators and incoming social work students.

**Goal 1. Develop a financial distress screening strategy for high-risk NCCH outpatients.** The study team will evaluate several methods to screen for financial distress. To date, there are only a few screening tools designed to measure levels of financial distress. These tools include the **Comprehensive Score for Financial Toxicity (COST)** measure which has been validated among advanced cancer patients and the **InCharge Financial Distress/Financial Well-being Scale**, validated among the general US population. These tools may not be the best way to screen UNC patients due to health literacy, cultural concerns (beliefs, values, attitudes, traditions, and language preferences)(14,15), and health practices of diverse populations. Based on the patient feedback plan proposed below, we may modify the currently used **Distress Thermometer** tool to include an insurance or finance-related item or create our own financial distress tool.

To determine the efficacy of the screening options above, we will conduct interviews with 15 NCCH patients to get their opinions on financial screening measure options. We will recruit patients who are determined to be potentially “in need” of extra financial help, e.g., self-identified as uninsured, Medicaid insured, and/or privately insured with high deductibles. We will ask patients about wording preferences, timing of the screening process, and other process-related factors attributed to successful implementation. After transcribing the interviews and conducting a rapid qualitative analysis process, we will modify the screening tool to incorporate patient feedback and begin screening patients in the clinic/disease group identified in Goal 1. As part of our alternative staffing plan, masters level social

work students will be embedded in the multidisciplinary and breast cancer clinics to conduct financial distress screening with patients identified by CCSP staff and/or social workers as appropriate for screening. Patients (n=50) who screen positive for high financial distress will immediately be given information about available financial programs and referred to the new financial clinic developed in Goal 3.

**Goal 2. Establish a Financial Navigation Clinic at the NCCH.** We will develop a financial navigation clinic for patients identified with high levels of financial distress during the above screening process. This clinic is designed to: 1) **build capacity** (for the social work students and hospital staff); 2) **educate patients** about programs and services that may “remedy” their financial distress; 3) **assist patients in applying for programs and services** (e.g., disability, subsidized insurance coverage, SNAP benefits, etc.); and 4) **refer patients to community partners** who may assist patients with certain matters (e.g., appeals for public benefits, housing assistance/mortgage foreclosure assistance, credit counseling, etc.).

The model for this new financial clinic is based on the UNC Cancer Pro Bono Legal Clinic, a collaboration with UNC School of Law and Legal Aid of North Carolina’s Medical-Legal Partnership Program. Established in 2013, this project utilizes volunteer law students, who work under the supervision of volunteer attorneys, to provide Health Care Powers of Attorney, Living Wills, and Durable Powers of Attorney, at no cost, to cancer patients. Legal Aid of North Carolina provides training and on-site supervision for the project volunteers, administrative support, and oversight of the legal work. To date, the UNC Cancer Pro Bono Project has served over 500 NCCH patients and executed 355 legal documents.

Given the success of the Legal Clinic, the new financial navigation clinic will use a similar infrastructure of scheduled appointment slots, staffed by student volunteers working 8-hour clinic days. In addition, the new clinic will include a financial education ‘primer’ consisting of 5-10 minute video modules on each of the existing financial assistance programs so patients can review the videos at their convenience prior to attending their financial clinic appointment.

In collaboration with the UNC School of Social Work, we will identify appropriate 1<sup>st</sup> year social work masters students to staff the financial navigation clinic as part of their required field placement for the 2018-2019 academic year (see letter of support). All student volunteers will meet immunization requirements and receive regulatory training for UNC Hospital volunteers that involve patient contact off the floors. This includes: infection control, confidentiality, privacy and information security, compliance and code of conduct, fire safety, emergency preparedness, and incident reporting. These students will then be trained by UNC financial personnel and the study team prior to staffing the clinic. Given the sensitivity of this topic, our training will include modules on paperwork security. The training will also include an overview of eligibility requirements for each financial assistance program (named below) and an orientation to the NCCH.

The new clinic will consist of two appointment options: 1) an **initial appointment** for those patients who screen positive for financial distress (at the time of positive screening if patient schedule permits); and 2) a **follow-up appointment** to return to the clinic with the paperwork and applications necessary to apply for the resources identified during their initial appointment. Both appointments will include one-on-one consultation with a trained social work masters student. At the initial appointment, students will review patients’ individual situation, including employment status, current NCCH billing information, insurance status and other indicators used to triage patients to the appropriate financial resource(s). Patients will leave this initial appointment with a checklist of resources they are eligible for and the personal paperwork (tax forms, W-2, pay stubs) needed to apply. During the follow-up appointment, we will review the initial appointment sheet, verify the patient has the necessary paperwork and review applications for completeness or work with the patient to complete the resource application(s). Patients will be educated on and referred to the following internal financial resources: NCCH’s Charity Care, Pharmacy Assistance, and Medication Assistance Programs as well as external financial and community resources e.g. Medicaid, Social Security and Disability, and Legal Aid. Each clinic will be staffed by the research team and NCCH’s Patient Assistance Coordinator who will be available to help

social work students and patients as needed during clinic hours. Patients will be contacted every 2 weeks after their financial clinic visits in order to assess progress toward their financial assistance goals. If patients score positive on the financial distress screening but do not want to attend the financial clinic appointments, they will be given an educational packet including a list of resources they may be eligible for and followed up with every 2-3 months after their financial screening.

**Program Evaluation.** The project staff will gather data on all patients participating in this project from screening through financial assistance application funding decisions. We will track the number of patients screened, the number of patients who screen positive for financial distress, the number of patients who attend financial clinic appointments, and the number of financial clinic appointments/patient. In addition, the team will record the type of financial resources the patient is eligible for, the number of programs the patient is referred to, how many applications are submitted and application outcome (success or denial). Patients will also complete follow up distress measures and a patient satisfaction survey to evaluate the screening process and the financial clinic. These outcomes will also inform scalability and sustainability efforts described below.

**1.4. ALIGNMENT WITH MISSIONS** This study embodies the UNC HCS vision of being the nation’s leading public academic health care system and the UNC School of Medicine mission of improving the health and wellbeing of North Carolinians. By screening patients early to help identify those with high levels of financial distress and implementing an innovative financial navigation clinic to more effectively connect patients with available financial assistance resources, we are directly impacting the emotional and financial health of NC cancer patients. Our scalability and sustainability plans described below will help UNC HCS serve as a statewide leader in the development of financial toxicity interventions. Further evidence of strategic alignment is our leveraging of patient need, NCCH’s need for more financial assistance personnel, and the desire for real-world patient experience and capacity building for UNC School of Social Work students into a replicable model for other service lines across the UNC HCS.

**1.5 PROJECT TIMELINE**

Table 2.0 Timeline	2018		2019	
	Quarter 3	Quarter 4	Quarter 1	Quarter 2
IRB Exemption Application				
Convene planning group for Goal 3 clinic development				
Determine clinic or disease group for financial distress screening pilot				
Patient interviews for screening methodology				
Rapid qualitative analysis of patient interview data				
Modification of screening tools				
Create/adapt materials (videos, website, packet) for pre-clinic 5-10 minute video modules on each financial assistance program				
Train social work students to screen patients and staff clinic				
Implement financial distress screening				
Implement financial clinics				
Patient satisfaction survey creation				
Participant evaluations				
Track referrals to internal and external resources				
Track cost savings, successful applications				
Data/survey evaluation				
Evaluation & data analysis to Innovation Center				
Manuscripts				

**1.6. POTENTIAL BARRIERS/RISKS** A potential barrier to program implementation is buy-in from the selected clinic/disease group identified in Goal 1 for financial distress screening. Recently, the NCCH created a formal financial navigation workgroup comprised of multiple oncologists, pharmacists, health

system administrators, researchers and other stakeholders whose priority is financial navigation. We serve on this workgroup and this group will help us ensure buy-in from the multidisciplinary and breast groups. We do not expect many barriers related to Goal 3 since we have approached and received buy-in from the Department of Social Work, NCCH social workers, community partner organizations, and NCCH administrators (see letters of support). However, patient attendance at scheduled clinic appointments may be uneven. To mitigate “no shows,” the financial clinic days will be held on the same day of the week as the target disease group’s medical oncologists’ clinic days. In addition, we will place 3 reminder calls prior to the scheduled financial clinic visit, including on the day before the appointment.

**1.7. LIST OF PARTNERS** The research team’s experience in the area of financial toxicity, as well as, clinical and public health ensures successful implementation of the project. Dr. Rosenstein serves as the Director of the LCCC Comprehensive Cancer Support Program (CCSP), a program dedicated to helping patients and caregivers cope with cancer treatment, recovery and survivorship. His research focuses on various psychosocial consequences of advanced cancer including financial distress. Dr. Wheeler’s research focuses primarily on cancer outcomes in vulnerable populations, with particular emphasis on understanding and reducing health disparities. She has experience compiling and linking primary and secondary data from various sources to enable a more complete understanding of complex healthcare issues, including cost. Drs. Rosenstein and Wheeler currently serve as Co-PIs on a National Comprehensive Cancer Network (NCCN)/Pfizer grant to improve access to recommended medications and reduce FT for uninsured and underinsured patients with metastatic breast cancer.

TABLE 3.0 Project Partner	Organization	Project Role
Comprehensive Cancer Support Program	UNC	To provide additional staffing support to project including additional hours for the Project Coordinator, Research Assistant, and the CCSP Patient Assistance Coordinator as needed
Department of Social Work	UNC	To match masters social work students with NCCH for field placement between Aug 2017-May 2018
NCCH Administration	UNC	To provide financial consultant time for Goal 1 to assist in obtaining EPIC data and determining intervention population
Medical-Legal Partnership Program	Legal Aid of NC	To provide consultation on financial clinic model creation and start up and to serve as a community referral source for patients in need

**1.8. SCALABILITY and SUSTAINABILITY PLAN** We believe this program model is sustainable because it is: designed to be cost-effective and possibly cost-saving; modeled after the current Pro Bono Legal Clinic at NCCH; utilizes permanent CCSP staff; leverages the social work field education program; and uses student-volunteers to keep the clinic staffing charge at zero outside of CCSP staff oversight. Furthermore, this pilot financial navigation clinic model could be replicated within other hospital service lines as long as the service line has financial assistance resources and a supervisor for students during patient interactions. Utilizing the same general structure, program components could be modified per patient area: referral stream, point of access and checkpoints, number of visits, video modules, etc. This program can also be replicated

statewide using the existing NC-Cancer Survivorship Professionals Action Network (NC-CSPAN) run by Dr. Rosenstein (see map). In 2014, Dr. Rosenstein developed this network to disseminate cancer survivorship interventions across NC, through funding from the University Cancer Research Fund and The Duke Endowment. Over 3 years, his team has developed relationships with 23 organizations, several of whom are members of the UNC HCS. This network exists to deliver this type of program and dissemination could begin summer of 2019. Finally, after study completion, the team will have the critical pilot data needed to support an R01 application to the National Cancer Institute to better understand the impact of a financial navigation program in multidisciplinary oncology settings across North Carolina.



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