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WORK IN PROGRESS AND LESSONS LEARNED

Systems Analysis by a Cross-Sector Workgroup to Address Housing Insecurity in Cancer Survivorship

Nikka Khorsandi[a], Mikal Giancola[a], MPH

[a]Louisiana State University Health Sciences Center
School of Public Health
2020 Gravier Street, 3rd Floor
New Orleans, Louisiana 70112 USA

Address correspondence to: Nikka Khorsandi, LSUHSC School of Public Health, 2020 Gravier St., 3rd Floor, New Orleans, Louisiana 70112 USA, [nkhors@lsuhsc.edu], phone 337-242-9914

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This investigation was approved by the Louisiana State University Health Sciences Center-New Orleans Institutional Review Board.

Authors' Contributions
All authors are responsible for reported research, have participated in the concept and design, analysis and interpretation of data, drafting or revising of the manuscript, and have approved the manuscript as submitted.

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ABSTRACT

Background: Cancer survivors face many financial burdens that generate additional stress such as housing insecurity or homelessness. Because this leads to worse health outcomes, it is essential for healthcare and housing organizations to begin mobilizing resources to support this vulnerable population.

Objectives: Create a "Housing in Cancer" workgroup to conduct systems-led analysis of housing insecurity in cancer survivorship in the Greater New Orleans area.

Methods: A cross-sector workgroup employed a systems analysis toolkit to explore the system. The group engaged in systems analysis exercises and generated observations on the current system.

Results: The complex problem was discerned into three components. Through reflection, the group created a new focus to support housing policies in cancer survivors and one group member was awarded a grant to provide financial assistance to cancer survivors.

Conclusions: The workgroup's insights identified systemic policies and additional funding for sponsoring organizations who expressed authority over this issue.

KEYWORDS: Cancer Survivor, Long-Term Cancer Survivor, Housing, Cancer, Systems Analyses, Systems Thinking

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Introduction

"Financial toxicity" refers to the distressing personal financial burden placed on those getting cancer treatment and includes incurred healthcare-related payments and other household finances (food costs, housing costs, etc.)[1]. Almost half of cancer survivors face financial toxicity—with disparate survivorship populations including female, younger, low-income, or those with a recent diagnosis[2]. In addition, the cost-burden of cancer can also force patients to delay or skip chemotherapy due to increasing cancer drug prices[3,4]. Financial toxicity has wide-reaching, detrimental effects, significantly decreases the quality-of-life of cancer survivors, and must start being considered when helping survivors[5,6].

Annually, an estimated 27,800 people in Louisiana are diagnosed with some form of cancer[7]. For many, this diagnosis brings mental, physical, and emotional stress, an increased reliance on health and social services, and associated financial burdens[8]. These financial hardships are exacerbated by decreased earnings and income, career development, retirement planning, and a diminished sense of self-efficacy[3]. In addition, cancer patients are at a 2.65 times greater risk of declaring bankruptcy when compared to people without cancer[9]. Declaring bankruptcy leads cancer patients to have 79% higher mortality rates than those who can afford cancer treatment by reducing health-related quality-of-life and quality of care—creating a major health disparity for lower-income cancer patients[1].

Between 2012 and 2016, an average of over 4,600 cancer diagnoses were made annually in the New Orleans region[10]. In 2018, the United Way Foundation identified that 57% (over 155,000) of Orleans parish households are classified within an asset-limited, income-constrained, employed (ALICE) population[11]. With higher cancer deaths being associated with lower socioeconomic status and the expected increase in ALICE population in coming years,

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addressing financial toxicity in cancer patients is only becoming more pressing[12]. As one of the largest components of financial burden, housing insecurity affects 44.2% of all New Orleans area residents while an estimated 33,000 additional affordable housing units are necessary to address the current crisis[13,14].

Engaging in cancer control and survivorship support across sectors is increasingly necessary in achieving health equity in cancer survivorship[15]. With the need clearly established in the New Orleans area, this paper summarizes results, lessons learned, and future directions of a cross-sector workgroup to explore housing insecurity in local cancer survivorship. The issue's complexity and poorly contrived nature, coupled with a poor understanding of the relationship between housing insecurity and cancer survivorship, places it squarely in the definition of a "wicked problem"[16]. Due to this wicked nature, the workgroup employed systems-led analysis to describe the relationships within this system and leverage these perspectives in sensemaking and decision making[17]. Using a systems-led design, the group gained a useful set of tools to learn about and intervene in this wicked problem and created a framework to understand this complexity.

Methods

Group Formation and Representation

Housing insecurity and financial toxicity in cancer patients is a complex problem that requires collaborative and multifaceted solutions[18]. To better understand this problem, the Louisiana Comprehensive Cancer Control Program Manager and graduate student worker (both authors) formed the cross-sector "Housing in Cancer" workgroup to share diverse perspectives on housing and cancer survivorship in the Greater New Orleans area and define potential systems-based solutions. The pair prepared for meetings using the *Wicked Solutions* toolkit (a

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systems analysis guide explained in the next section) and between meetings would debrief, reframe progress, and conduct initial data analysis for attendees to review at the following meeting. Representatives from four sectors engaged in discussions: hospitals/healthcare, cancer support non-profit organizations, state cancer monitoring, and housing advocacy non-profit organizations. Six individuals voluntarily agreed to participate in the workgroup, although one representative attended only the first meeting (Table 1). Workgroup members were invited based on their ability to provide unique perspectives about the current system of housing insecurity and the lack of education and resources specific to cancer survivors within the housing non-profit space. Specific details about each representative and their responsibilities can be found in Table 1. The Housing in Cancer workgroup was led by representatives of the state cancer prevention agency after reviewing literature identifying the impacts of financial toxicity in cancer survivorship but having no local data or context about the problem's magnitude. Invitations were sent to seven local and state-wide agencies identified as providing either housing support or cancer survivor healthcare/social support. Five organizations agreed to participate in the workgroup and all except the housing and charity non-profit convened monthly from January 2019 to August 2019 to conduct this systems-based analysis. No financial incentive was provided to participants, but the transactional value of participating in the workgroup aided each organization in better achieving their respective missions. As participation was voluntary, challenges to meeting attendance included staff turnover and prior time commitments. The workgroup acknowledged it would benefit from cancer survivors' perspectives but did not include them because of logistical constrains. Workgroup members drew from both personal experiences as caregivers of cancer survivors and years of professional experience assisting cancer survivors.

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Data Collection: Systems Analysis Toolkit

The workgroup employed the systems analysis toolkit, *Wicked Solutions*, to explore and intervene within the landscape of cancer survivors facing housing insecurity in the greater New Orleans area[19]. This approach was chosen because previous public health issues like obesity prevention and water delivery have shown improvement after employing systems-based analysis tools like *Wicked Solutions*[20–22]. This toolkit was designed to guide the investigation and intervention of any situation determined to be complex and unique[19]. After establishing the workgroup, the toolkit guided the group through 1. Drawing insights on the perspectives, inter-relationships, and boundaries of the problem, 2. Creating a "rich picture" to display each of the elements listed above and associated conflicts, and 3. Conducting a stake and stakeholders analysis to frame the perspectives of each relevant stakeholder previously identified. Stakes are defined as "[t]he values and motivations that stakeholders bring to a situation when enacting their stakeholder role"[19]. Analyzing what is at stake for stakeholders is a way to reveal critical heuristics in social systems. It is relevant to note the process was iterative in nature and required constant reflection on information learned from prior steps by workgroup leaders between meetings and participants during meetings. In the first step, the group drew insights on three aspects of the current problem, (1) the perspectives held by relevant stakeholders within housing and cancer survivorship, (2) the inter-relationships among the relevant stakeholders, and (3) the boundaries that outline these circumstances. In the second step, a visual graphic, or "rich picture", was created by listing out key stakeholders and stakes within the system and displaying the relationships between each. The final step required taking previously listed stakeholders, finding dominant relationships with other stakeholders, and exploring the relevance of those relationships. Questions drawn from the workbook were used to draw-out individual thoughts on

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each viewpoint. At the end of each step, members were asked what lessons were learned from the exploration and, between meetings, these insights were compiled into a single document and analyzed for major themes, seen in Table 2. Dominant themes were then shared at each workgroup meeting and any revisions voiced by members were adapted and approved.

Data Analysis

Both during and after the group's analysis of housing insecurity in cancer survivorship, the evolutionary document depicted in Table 2 was systematically analyzed to identify common themes, lessons learned, and potential solutions to be addressed. Meeting minutes as well as the "rich picture" and stake and stakeholder analysis supplemented the information generated in Table 2. Together, these program records were used by the workgroup founders to conduct a thematic analysis by individually reviewing the information, identifying common themes and patterns, refining definitions of themes, and summarizing the narrative of the workgroup's discussions[23]. This analysis led to the creation of this paper to summarize the results of group reflections as well as dissect the partnerships created among the group to identify benefits generated from creating it. This analysis of the documents generated by the workgroup was approved by the Louisiana State University Health Sciences Center Institutional Review Board.

Results

In the workgroup, the housing and cancer organizations used the *Wicked Solutions* toolkit to understand the problem of housing insecurity among cancer survivors in the greater New Orleans area. As the toolkit guided through constructing and analyzing the system, the group chose to dissect the problem into the three components recommended by the toolkit: perspectives, inter-relationships, and boundaries (Table 2). The problem statement, after

continual modification, reflects the previously established problem of financial toxicity in cancer survivors and sets a goal of identifying who should intervene in this problem and how.

From the discussions on *perspectives*, the group identified that housing insecurity and cancer survivorship is a broad problem and requires recognition of many perspectives from many stakeholders. These perspectives come from survivors, friends/family, caregivers, physicians, healthcare teams, clinics and hospitals, cancer survivor aid agencies, cancer monitoring organizations, social support agencies, insurance companies, local employers, and local government or public agencies. When a cancer survivor faces consequences of financial toxicity, the burden ripples through this entire network and begins to drain its resources; however, no single component is responsible for preventing that toxicity from occurring. The analysis revealed that stakeholders have incentives, including financial and market-driven, in the current system which makes relying on the stakeholder alone to change it unlikely. For example, lower-income and financially insecure cancer patients may experience barriers to cancer care that commercially insured patients do not face. One workgroup member stated that months-long waiting lists for medical appointments for Medicaid-insured survivors is a mechanism for generating higher revenues or conversely steering away publically insured patients with lower reimbursement rates.

Thoughts on the *inter-relationships* of the system identify that the many stakeholders within this problem's landscape have many relationships with each other. While a few of these inter-relationships are leaned on heavily by cancer survivors, like the relationship between cancer survivor and caregiver or cancer survivor and their physician/healthcare team, the remainder of the inter-relationships are loosely formed and do not provide a strong infrastructure for implementing change. In addition, most of the inter-relationships are monetary and fueled by

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grant funding, for example. However, the magnitude of the investments necessary are too great for one single organization. Identifying the leverage points to address this issue and developing synergistic relationships to maximize the impact of these limited resources is vital.

The workgroup clarified the *boundaries* of the problem to support residents with a cancer diagnosis that are facing housing insecurity or homelessness. Since this workgroup acts at the intersection of housing and cancer support, building common definitions for boundaries was emphasized early in discussion. Due to different funding sources, organizations within the workgroup held varying definitions of who is "at-risk" and requiring support. For example, risk was measured in the housing community by a person's median income, whereas in the healthcare community, this risk was defined in relation to the federal poverty line, creating two different groups of those "at-risk". The group jointly defined this "at-risk" population as the low-to-moderate income populations, minority populations, people with labor-intensive jobs, and younger cancer survivors with less generational wealth.

At the workgroup's creation, members identified that both the housing crisis and poor support for cancer survivors were subjects requiring improvement. However, the housing group representatives were unaware of what housing needs were specific to cancer survivors, while cancer treatment and support representatives felt unfamiliar with housing assistance resources. Cross-sector collaborations were not unfamiliar to each agency as the housing support non-profits had worked with the local Veterans Affairs hospital to diminish homelessness in the veteran population, whereas the health care representative and regional cancer survivorship non-profit had previously worked with the local food bank to reduce food insecurity in cancer survivors. All members identified that by participating in workgroup discussions, they had gained knowledge about the problem faced by cancer survivors and are interested in continuing

to work on the topic. They also recognize that this population is yet another group of vulnerable people that will not receive the support necessary to address the problem until the appropriate resources are invested into developing its solution.

Conclusions

Through the *Wicked Solutions* toolkit, the Housing in Cancer workgroup identified that housing insecurity in the cancer population has been minimally addressed in the greater New Orleans area because it is an expensive problem. For example, $21.5 million was invested in Portland to build just 400 units of affordable housing[24]. After mapping the problem's landscape, the group identified that much of the network surrounding the cancer patient is formed by weak connections consisting of financially disincentivized inter-relationships that prevent any single stakeholder or group of stakeholders from taking responsibility. The insights garnered from the workgroup led to the identification of systemic policies to generate funding and strengthen relationships while sponsoring organizations who can express authority over this problem—similar to recommendations found in the literature[18,25]. Examples include expanding the funding for oncology social workers to be patient advocates so cancer survivors can speak freely regarding their financial toxicity as well as assist survivors in navigating the complex process of relocating a residence. Other innovations taken to alter the housing insecurity in local cancer survivors include creating a novel policy focus for the community-led housing non-profit and a successful grant application for the regional cancer survivorship support non-profit. The community-led housing non-profit added the new policy focus to "engage stakeholders and cancer survivors to explore services and research data to develop housing policies that accommodate cancer survivors"[26]. The regional cancer survivorship non-profit leveraged the improvement in their understanding of the housing crisis in the area to successfully

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apply for a grant that now allows the organization to provide more financial housing assistance to clients.

More broadly, this paper exhibits what happens when public health practitioners operate as leaders and conveners of actionable, strategic initiatives. The field of public health has called upon its practitioners to recognize the use of systems thinking to create innovative models of health, understand dynamic relationships surrounding health, and ultimately reach vulnerable populations[27–29]. Without the proper training, public health practitioners may not feel proficient enough to handle this departure from the traditional method of seeking health improvement through individual and group education. The use of systems thinking tools guides the evolution of the public health practitioner from reductionist approaches that emphasize isolating linear variables for causal analysis into one that understands how relationships between systemic elements influence each other[30]. While systems thinking training and practice takes years to master, actionable tools like the *Wicked Solution* toolkit are built to apply to almost any complex situation. In this case, the work was co-led by a student worker and a program manager with formal public health training, thus demonstrating how easily it translated to professional practice. As this specific toolkit has also been successfully applied to many complex problems, other investigators should feel empowered to employ this tool for generating systems-based interventions. The cost of this toolkit (under $20) requires minimal financial investment by researchers and practitioners.

To better understand the problem of housing insecurity and homelessness in cancer survivors, this cross-sector collaboration was necessary to gain local perspectives about the housing crisis as well as financial toxicity in cancer survivorship. With a rising interest in defining the relationship between health and housing, facilitating rapport between agencies will

only be more useful as the two sectors grow more intertwined. Learning and understanding this situation among workgroup members empowered them to take steps thereafter that enhanced service capacity for a vulnerable population. Participants working in the health sector identified housing as one of a litany of problems cancer survivors face, while housing representatives indicated cancer survivors as one of a growing number of populations at great risk of becoming homeless. With a limited set of resources, each agency must thoughtfully determine the best leverage points for improvements. By formally participating in this workgroup, representatives identified that the inter-relationships between cancer survivorship, cancer treatment, and housing support have been emboldened and each agency feels more comfortable and more responsible to invest further resources into this problem. In addition, workgroup members felt that engaging with a greater number of stakeholders in this methodology will only continue to strengthen the inter-relationships within the system and compel each to begin sensing the responsibility owed to cancer survivors.

The group identified the most relevant limitation of the work as not including the voice of the housing insecure cancer survivor. With the regional cancer survivorship support non-profit director and hospital social worker working directly with survivors, the group felt that anecdotes from these representatives could adequately represent the survivors' experiences; however, in further meetings, the group recognized that direct perspectives from survivors would create a more holistic analysis. Additionally, due to staff turnover of the housing and charity non-profit and the recognition that their expertise was also represented by the community-led housing non-profit, the group felt comfortable continuing without representation from the housing and charity non-profit. An important next step would be to host focus group discussions with local cancer survivors that face financial toxicity and housing insecurity to gain an understanding of where

they feel the biggest gaps lie. Information from focus groups can be paired with data gathered in this workgroup to continue identifying where limited resources can be leveraged to generate the largest impact. The overarching lesson learned from this workgroup is the necessity of redefining values as individuals learn more about the system's stakes and stakeholders. For example, prior to this work, cancer survivors may have been referred to housing support agencies, however, they were not viewed as an at-risk, housing insecure population. Through this work, housing agencies now recognize the financial impacts (including housing insecurity) created by a cancer diagnosis. As this work continues, these values will continue to need to be redefined to generate more effective strategies aimed at the central sources of this problem. While this work has been halted due to the COVID-19 pandemic, the synergy created from this initial foray into the current landscape of housing insecurity and homelessness in cancer survivors generates exciting momentum into ensuring responsibility is shared among stakeholders in tackling this complex problem.

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Table 1: Organizations and Individuals Represented within the Housing in Cancer Workgroup and Relevant Contributions

Type of Agency (# of representatives)	Representative Role in Agency	Agency's Mission	Role in Project
State Cancer Prevention Agency (2)	1. Program Manager 2. Student Worker	To eliminate suffering and death by focusing on cancers that can be prevented or detected early and cured.	-Organized and facilitated work group meetings. -Recorded data during meetings and analyzed the data. -Provided population-level data on cancer incidence and survivorship in Louisiana.
Regional Cancer Survivorship Support Non-Profit (1)	1. Executive Director	To assist local cancer patients and their families by providing support that will enable them to continue their treatment.	-Provided individualized anecdotes and experiences of the problems faced by cancer survivors in the Greater New Orleans area. -Provided statistical information about the cancer survivors currently being served by the organization.
Community-Led Housing Non-Profit (1)	1. Program Coordinator	A partnership between community leaders, public, private, and nonprofit organizations to solve New Orleans' affordable housing crisis.	-Provided individual-level and city-level data on the housing crisis in the Greater New Orleans area. -Identified similar housing programs focused on supporting those with specific health concerns. -Provided individual anecdotes on experiences of housing insecure individuals in the Greater New Orleans area.
Hospital and Comprehensive Cancer Center (1)	1. Housing Social Worker	To offer patients a comprehensive approach to cancer care by providing a single location for clinic visits, treatment planning, surgical needs, and treatment services.	-Provided information about the clinical care and services offered at the comprehensive cancer center. -Provided information on experiences and barriers faced by cancer survivors in the Greater New Orleans area.
Housing and Charity Non-Profit (1)[a]	1. Program Director	To create a just society by welcoming the most vulnerable and supporting	-Provided individual anecdotes on experiences of housing

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		housing, behavioral health, and refugee service needs.	insecure individuals in the Greater New Orleans area. -Provided initial guidance on the current housing crisis in the Greater New Orleans area.
a. Representatives from this agency were only able to attend the first workgroup meeting because of competing priorities and a lack of resources.			

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Table 2: Problem Definition, Insights, and Potential Solutions Generated by the Workgroup

Problem/Purpose: Many cancer patients may also face housing insecurity and homelessness. Establishing a stable home is important so they can focus on healthcare. A cancer diagnosis leads to additional financial burdens, which amplifies housing insecurity and can lead to homelessness. Once homeless, patient's health spirals downwards. One goal is to identify who can/should intervene, when and how.		
Perspectives	**Inter-Relationships**	**Boundaries**
	Insights Into the Problem	
Insight 1: These burdens place additional stress on the whole system. Due to the problem's breadth, without stakeholder communication, it gets addressed on many small fronts, as opposed to a synergistic, united front—or it fails to be addressed at all. **Insight 2:** A cancer diagnosis can cost from a quarter to three quarters of a million dollars. Given 50% of the state being ALICE (Asset-limited, income constrained, employed), even if this population qualifies for insurance and support, the diagnostics and treatment are significant time and cost burdens for the patient/caregivers. Most new cancer patients and families do not have a clear idea of the true costs of successful cancer treatment. **Insight 3:** No one payer is responsible for the solution, which leads to a deflection of responsibility. There is a need for more state funded services. **Insight 4:** Screening is prime time for patient contact. Can that point of contact be used to alert	**Insight 1:** There are a variety of resources and partners invested in addressing this problem, however without a single entity taking responsibility the ball gets dropped when addressing housing insecurity/homelessness. **Insight 2:** A clear list of what organizations offer which services would be a great help to patient support services, social workers, and healthcare providers. **Insight 3:** Case managers and counselors inside hospitals can provide wrap around services (medical transport, bus passes, uber, emergency phones, etc.) on the spot at check-in. **Insight 4:** Housing is a health issue, but healthcare does not feel responsible for addressing the problem. **Insight 5:** Hospitals and doctors are not communicating clearly with patients and surprise billing (hospital in-network, but doctor is not) generates huge financial burden. **Insight 6:**	**Insight 1:** With the stigma of housing insecurity/ homelessness, people may not be willing to identify themselves as within our boundaries. Aligning boundaries with other organizations that are focused on reducing this problem will be necessary. **Insight 2:** Screening for homelessness could help identify homeless patients or those at risk. Since the boundary is cancer patients or caregivers, the hospital social worker and patient support organizations would be optimal at identifying housing insecurity or homelessness and housing agencies could forward clients with a cancer diagnosis to these organizations. **Insight 3:** Those with low to medium income have limited resources and a difficult time accessing those resources because many over-qualify (in terms of income). **Insight 4:** We have two problems: Housing insecurity and homelessness. Do we need to pick just one? **Insight 5:**

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people who can help or intervene before the problem of housing insecurity escalates? **Insight 5:** The state looks at cancer as a screening issue, however organizations look at the perspective of treating cancer and addressing social determinants. How do we get people all on the same page? **Insight 6:** Patient's perspective seems quite apparent to everyone in the room. Are people in the community or in other organizations aware of this problem?	Are there so many resources/information out there for patients, providers, navigators, etc. that it starts to overwhelm people?	The ALICE (Asset-limited, income constrained, employed) population is 50% of the state. **Insight 6:** Greater NOLA area is our current geographic boundary. **Insight 7:** Financial limitations are a big problem. Housing is an expensive problem to fix so our solution needs to be sustainable. Many organizations also have a limited number of employees/resources, so we must work within those limitations.
Opportunities/Potential Solutions:		
• Oncology Social workers have a perspective that needs to be heard. We can add them to the workgroup, create a survey to understand their views/needs, and/or create a seminar for them. • We need to align our terminology. In healthcare, the poverty line is commonly used to define who qualifies for resources. In housing, the area median income is used to define who qualifies for resources. • What opportunities at the state level exist to begin tackling this problem? • Public awareness should be created to understand the problem of cancer and homelessness.	• There needs to be better coordination between resources and partners to provide united care. • Look at legislative success stories (e.g. passing legislation to get payers to cover breast-reconstructive surgery post-mastectomy) to use as models of success. • Look at successes with other consortiums (e.g. Justice Reinvestment Task Force NOLA that focuses on changes to get more public safety from criminal justice system) • Create policy that fast tracks those with cancer and homeless to housing facilities.	• Policy opportunity to find funding would help generate some financial incentive to address this problem as well as generate political will towards a solution. • Create a central location to identify what services are available could help synergize efforts from current relief organizations.