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Title: “Like pouring salt in a wound”: A qualitative exploration of the consequences of unmet housing needs for cancer patients and survivors in New York City

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Abstract

Objective: To identify consequences of unmet housing needs in the period following cancer diagnosis.

Design: Qualitative descriptive design.

Participants: New York City-based cancer patients and survivors (n=21) who reported experience of unmet housing needs while receiving cancer treatment. Key informants (n=9) with relevant expertise (e.g. oncology social workers).

Methods: One-time semi-structured telephone or in-person interviews were conducted with all participants. Inductive thematic coding was conducted using a pragmatic paradigm.

Findings: Four categories of consequences emerged: 1) cancer management and health (rest and recovery, illness/ injury risk, medical care); 2) psychological (stress and anxiety, lack of control and independence, self-esteem/ pride, sadness/ depression, cancer coping); 3) social (relationships, consequences for others, isolation); and 4) standard of functional living.

Conclusion: The simultaneous experience of cancer and unmet housing needs is broadly burdensome.

Implications for Psychosocial Providers: Screening and resources for addressing unmet housing needs must be prioritized to holistically care for patients.

Background

Adequate housing is a requirement for wellbeing, but some cancer patients grapple with managing unmet housing needs on top of managing their disease. Cancer itself may create new needs, by conferring disabilities requiring accessibility modifications or prompting relocation for therapy.¹⁻³ By causing financial hardship, cancer creates or exacerbates housing challenges that are financial in nature, such as difficulty affording housing costs, eviction or foreclosure threats, and poor and unsafe living conditions.^{1,4-7} Descriptions of unmet housing needs among cancer patients often appear in the literature about financial hardship,^{3,6,8-10} an interrelated but distinct problem that has been correlated with worsened quality of life, strained relationships and higher mortality.¹¹⁻¹³ Roughly 28% of cancer patients responding to an optional module of the 2015 Behavioral Risk Factor Surveillance System survey reported worry about affording rent or mortgage in the past year.¹⁴

Researchers at the American Cancer Society recently published a “blueprint” to advance cancer health equity, underscoring the importance of multilevel and socioecological research approaches addressing social determinants of health, including consideration of structural inequalities and living environments.¹⁵ Indeed, the importance of housing stability, quality and safety, affordability, and neighborhood environments to health are widely acknowledged,^{7,16-18} with plentiful research examining impacts of housing on health for other diseases, such as HIV/AIDS.¹⁹ However, less is known about how housing affects the health of people living with cancer. With over 1.9 million new cancer diagnoses estimated for 2022²⁰ and widening housing disparities in the wake of the COVID-19 pandemic,²¹ these relationships are especially important to understand.

There has been growing recognition of the importance of housing in the cancer context,⁷ with a 2022 systematic review describing associations between housing insecurity and worse cancer care or outcomes,²² and a recent cohort study of cancer patients finding greater hazard of mortality among

those experiencing housing instability.²³ Unmet housing needs have also been linked to food insecurity and missed medical appointments.^{24,25} Unhoused populations have been shown to experience disparities and challenges such as higher cancer incidence, more advanced stage at diagnosis, higher mortality rates,²⁶ and care challenges such as difficulties in follow-up communication and limited end-of-life care options.²⁷

In a related qualitative study that explored types of unmet housing needs experienced by cancer patients and survivors in NYC, we catalogued difficulty with: 1) housing costs (e.g. rent, mortgage, utility bills, upkeep); 2) home loss (e.g. eviction, foreclosure); 3) doubled-upⁱ/ unstable housing (e.g. tension with hosts, shelter environments); 4) housing conditions (e.g. overcrowding, lack of utilities); 5) accessibility (e.g. stairs, treatment proximity); and 6) safety (e.g. crime, building hazards).¹ The purpose of the present study is to qualitatively describe the breadth of consequences of these unmet housing needs for cancer patients and survivors in the period following diagnosis.

Methods

This study was theoretically grounded in medical sociologist Michael Bury's work describing patient experiences with chronic illness as biographical disruption with practical consequences, as well as the social ecological model, which situates individual health within interpersonal and ecological contexts.^{28,29} We used a pragmatic paradigm, approaching the research through the lens of real-world problem-solving. All human subjects research activities were approved by the Institutional Review Board at the George Washington University.

Study participants

ⁱ "Doubled-up" describes situations in which survivors live with other households, typically because they are unable to afford a place of their own.

Between June to September 2018, semi-structured interviews were conducted with 21 individuals undergoing active cancer treatment or in post-treatment survivorship. They will be collectively called “survivors.” Eligible participants reported: 1) receiving treatment for cancer in NYC, and 2) experiencing unmet housing need(s) in the period following cancer diagnosis. Given the study’s inductive approach, researchers deliberately refrained from defining “housing need” a priori during eligibility screening. Instead, prospective participants were allowed to identify what constituted a housing need for them, an approach with precedent in qualitative housing research.³⁰ Individuals were excluded if they were limited English-proficient (LEP), under 18, or not community-dwelling. We did not exclude based on time since diagnosis. While a patient in active treatment could describe outcomes with immediacy, a post-treatment survivor would be well-positioned to provide an equally valuable perspective on longer-term consequences. No additional exclusions or quotas were applied due to practical constraints and unknown underlying prevalence of our phenomena of interest.

Nine key informant interviews were conducted with individuals possessing professional knowledge of housing needs among cancer survivor populations, to triangulate survivor interviews.

Data collection

Survivors were recruited using venue-based and snowball sampling. Oncology PN and support group staff posted study flyers in public locations and shared them in person, via email, and verbally over the telephone. Study participants were encouraged to refer others. Efforts were made to purposively attain maximum variation across demographics, cancer type, time since diagnosis, geography, and housing need types.

Interested parties contacted author SP, a public health doctoral student and former patient navigator, who screened for eligibility and obtained informed consent. Survivors completed a background survey covering demographic, financial, housing, and cancer details. Author SP conducted

all interviews over the telephone, except three which took place in-person per participant preference. This study was part of a larger study on unmet housing needs; relevant interview guide questions are excerpted in Figure 1. Patients were asked to talk holistically about their everyday lives, and more specifically, about types of unmet housing needs experienced, events preceding them, and impacts. While the interview guide was structured chronologically, each interview was conducted as a flexible conversation allowing interviewees to share their stories organically. Referrals to PN and psychosocial services were offered to participants who expressed distress or interest in support.

Author FG, a physician leading oncology PN and disparity-reducing programs, and author SP identified a convenience sample of key informants through personal and cold contacts. Key informants were strategically selected to reflect diverse disciplines and geographic areas of service catchment. Informants were interviewed about their professional context, types and patterns of unmet housing needs encountered among clients, impacts of unmet housing needs, and recommendations. Four were interviewed prior to the start of survivor data collection to ensure appropriateness and relevancy of survivor interview guide questions, and five were interviewed following completion of survivor interviews to reflect upon initial findings.

Interview length ranged from 30-120 minutes. Each participant received a \$50 gift card in compensation. Permission for re-contact with clarifying questions or preliminary findings was requested after each interview.

Data analysis

All interviews were audio-recorded, transcribed verbatim, checked for accuracy, then stripped of identifiers. Transcripts from survivor and key informant interviews were analyzed together in NVivo 12, utilizing an inductive approach and thematic content analysis. The process of open coding began during data collection. Memos were written after each interview and throughout the coding process to engage

in self-reflexivity and constant comparison. Initial codes were iteratively refined. Three interviewees were re-contacted to validate the accuracy of interview accounts. An early draft of codes was shared with three survivors and five key informants for feedback to enhance credibility and trustworthiness of findings. Key informants, who have the benefit of numerous client interactions, were able to confirm that near saturation of unique outcomes was reached and filled gaps in survivor interviews with their own observations. All transcripts were coded by author SP, and three were double-coded independently by author DB, a public health doctoral student with expertise in health-related social needs. Coding discrepancies were resolved by discussion, resulting in codebook refinements. The final codebook was reviewed by all authors, including authors CH and SR, public health professors with expertise in qualitative methodology, and applied to all transcripts.

Results

Survivor interviewees (n=21) were mostly female (76.2%), aged 50-64 (52.4%), black (71.4%), renters at diagnosis (71.4%), and U.S.-born (61.9%) (Table 1). Breast cancer was the most common diagnosis (42.9%). Most survivors received their diagnosis less than two years prior (42.9%) or 2-5 years prior (42.9%). Co-occurring unmet housing needs were typical, with the majority reporting housing cost concerns (66.7%). Key informants (n=9) were mostly female (77.8%) and hospital-based (66.7%) with backgrounds in social work, PN, and other fields (Table 2).

Code definitions and illustrative quotes from survivors (S) and key informants (KI) are shared in Table 3. Quotes are attributed by participant number; Table 2 can be referenced for contextual information about each interviewee. Since our study purpose is to describe the breadth of housing impacts rather than prevalence, we include quotes most demonstrative of each code, even if they are novel. Within themes, most commonly reported codes are presented first.

Survivors described experiences of unmet housing needs during cancer with language like: “life sucks sometimes,” and “it was rough.” The struggle of simultaneously facing two high priority crises was compounding:

“If you don't have a roof over your head when you're in the middle of treatment... that's like pouring salt in a wound. The fact that I had to worry about that initially, it was a lot of burden to carry.” (S#2)

Consequences were grouped into four categories: 1) cancer management and health, 2) psychological, 3) social, and 4) standard of functional living. Codes were interrelated and overlapped with consequences of general financial hardship.

Cancer management and health

Interference with rest, symptom management, and recovery. Too much noise, lack of privacy, overcrowding, poor conditions, and uncomfortable spaces hindered rest, recovery, and symptom management. A breast cancer patient described undergoing chemotherapy while doubled-up with family after losing her apartment:

“It was eight people living in a two-bedroom apartment. So, it was very, very difficult. I was screaming of my pain and had to wake up the whole house. There's one restroom. There was days when I would only sit in the bathroom just throwing up and...diarrhea.” (S#6)

She described modesty concerns post-mastectomy, in having to wear clothing at home all the time despite it being uncomfortable on her upper body. Meanwhile, a lymphoma survivor reported that her decreased tolerance to cold was especially problematic because of inadequate heat in her apartment.

Housing needs also interfered with rest and recovery by usurping survivors' time and energy. Despite recent surgeries or other active treatment, survivors were occupied with housing court

appearances, benefits applications, and fruitless searches for affordable apartments. In addition, survivors worked during treatment to sustain income for rent and general living costs:

I'd be so exhausted because I used to work all day, and on the next day that I was off, I would go get chemo....I don't even know how I did that, but... I think I should've just slept. (S#17)

Work also took the form of domestic work, which was sometimes coerced for survivors with doubled-up living arrangements who were expected to “earn their keep” regardless of how they were feeling. Inadequate living environments and the stress of housing burdens affected survivors’ ability to eat and sleep well and practice other health-promoting behaviors.

Risk of illness and injury. Survivors expressed suspicions that exposures in their homes were responsible for their cancer, worsened symptoms, recurrences, other health conditions, or health conditions among neighbors:

“There’s a lot of people who died from...exposure to their bodies and stuff in these apartments....We was right next to the World Trade Center, who knows where I got this cancer from?” (S#18)

Accessibility and existing safety concerns related to crime or poor maintenance became heightened after cancer imposed new physical limitations affecting speed and balance. A colorectal cancer survivor who used a cane and lived in a walk-up apartment building frequented by drug dealers, said: *“I don't want nobody try to hurt me, because I can't move how I used to move.” (S#8)* Immunocompromised survivors also worried about becoming ill from unhygienic spaces.

Interference with medical care. Unmet housing needs posed barriers to surgery, hospital discharge, medical appointment attendance, medication adherence, and treatment decisions. Four survivors described experiences in which housing affected their cancer care. For example:

“Choosing paying my \$620 COBRA every month so I could keep those really good doctors or paying my rent. I had to make a choice.” (S#2)

Severe cases, such as those immediately affecting survival, tended to be shared by key informants, such as this oncology social worker:

“...we went to housing court with a new letter and literally said to the judge, ‘it’s a life and death situation. If you evict [the patient] he’s gonna die. He’s not gonna transplant.’” (KI#3)

Psychological

Housing impacts on survivors’ psychological wellbeing were pervasive in our sample, especially feelings of stress and lack of control. Survivors also expressed resilience and the determination to overcome and put their cancer and housing-related hardships behind them. They shared sentiments like: *“you have to just let it go”* (S#21) and *“I just got up and did what I had to do”* (S#10).

Feeling stressed, anxious, overwhelmed. Survivors commonly attached feelings of stress to a variety of housing concerns ranging from poor conditions to conflicts with host family members. The threat of eviction or foreclosure was a particular source of anxiety for survivors:

“I was a nervous wreck. I just had my surgery and all I was thinking, I’m going to be homeless!” (S#7).

Survivors expressed feeling overwhelmed: *“you’re ready to pop”* and *“something just needs to be steady.”*

Lacking control and independence. Though grateful to not be homeless, unstably housed survivors commonly described the inability to feel mentally at ease or in control without a space of their own:

“Right now we have to do everything in accordance to...everybody else. And if we have our own comfortable environment, I'm the head of my household.” (S#20)

Survivors also expressed feeling “stuck” or frustrated, in being unable to get out of their unsatisfactory living situations.

Self-esteem and pride. Survivors acutely felt the stigma of unmet housing needs, and expressed feelings of embarrassment, failure, and wounded pride:

“I tried to hide it from my daughter, I didn't want to tell her. I felt that was me failing her, as a mom... To keep a roof. And that had never, ever happened to us before, you know?” (S#17)

Key informants and survivors described the worry of being “drains” on others when needing financial help or a place to stay for an extended period of time. Some avoided asking for help because they did not want others to misunderstand, act annoyed, judge, or offer help and then start “acting funny.” Some survivors emphasized that they had been self-reliant their entire lives.

Feeling sadness and depression. Housing-related hardships caused feelings of sadness and loss:

“It has an influence in my head space. I feel depressed...I feel angry and annoyed. I'm frustrated. I feel loss.” (S#4)

Survivors ascribed these feelings generally to simultaneous health, financial, and housing struggles. A few described clinical depression or suicidal ideation.

Interference with cancer coping. Unmet housing needs distracted survivors from emotionally coping with their cancer diagnosis. As a psychologist described:

“[The patient] would come to counseling...but...the housing distress was so much that she couldn't focus on her anxiety about her diagnosis, her treatment, her medical needs. She had to just focus on how can I get out of this apartment, and get another one.” (KI#6)

Living arrangements lacking in privacy, such as shelter or overcrowded environments, also deprived survivors of the space they needed to cope emotionally with their cancer.

Social

Consequences for social relationships. Both cancer diagnoses and unmet housing needs affected relationships. A prostate cancer survivor described familial strain after doubling-up for an extended period: *“As time go by...you watching them to be less welcome.” (S#5)* However, others appreciated caregiving benefits from living with others and had relationships affirmed when friends and family stepped in to provide emotional or material support.

Consequences for other people. Survivors' unmet housing needs had spillover effects on their friends and family, who offered resources and opened their homes. Survivors spoke strongly of their commitment to their children. However, children had to cope with their parent's cancer while also facing the fallout of housing issues. A housing advocate expressed concerns for the elementary-aged children of her client who simultaneously faced eviction and a leukemia diagnosis with poor prognosis:

“He's gonna lose the apartment...it's not just like dad's sick...you're gonna lose dad, you've lost your friends, you've lost your school...It's these multiple losses...because of not having a stable place to live.” (KI #1)

Inducing isolation. Respondents ascribed feelings of isolation or alienation to both cancer and housing. Housing issues induced isolation when survivors socially withdrew to avoid spending money, hid their struggles, needed to relocate, physically had trouble leaving their homes, or were too stressed

or busy to socialize. A uterine cancer survivor who moved states due to housing instability described: “I hardly see anybody. I’m always by myself.” (S#4)

Standard of functional living

Respondents reported sacrifices to their standard of living to afford rent and other living expenses:

“Sometimes you have something that you love, and when you don't have [money] to come up, you got to sell it and pay...your bills. My music and all those things. I did have two TVs, everything is gone.” (S#21)

Other sacrifices included walking instead of taking public transportation, reducing food, cutting utility use, reducing social spending, seeking discounts, eliminating travel, and avoiding expenses that were not absolutely necessary. Sacrifices, poor living conditions, poor accessibility, and doubled-up arrangements made routine errands and functional tasks inconvenient and life generally uncomfortable.

Discussion

In our diverse, majority renter sample, unmet housing needs affected all aspects of survivors’ wellbeing. Many outcomes described by participants were also documented in a research review on eviction threat, including: psychological distress, stigma, isolation, negative physical symptoms, and worse health behaviors.³¹ Reviews on foreclosures and unaffordable housing described similar consequences in addition to financial trade-offs, poor self-reported health, and cost-related medical non-adherence.^{32,33} Some associations from past research that are notably missing from our findings include: substance abuse, child abuse, increased emergency department use, and other specific impacts on health (e.g. increased blood pressure).^{31,32,34} Interviewees may have omitted mention of these issues if they felt social desirability bias or did not perceive connections to housing needs. Our sample of

survivors may have also been uninclined to abuse substances while receiving cancer treatment. It is also possible that these issues would have been captured upon sampling additional participants.

Comparisons to other chronic disease literatures reveal both strong commonalities and idiosyncrasies particular to cancer. Patients with diabetes or congestive heart failure (CHF) also faced competing priorities in which housing and survival priorities displaced health and disease management.^{32,35} Similar mental health outcomes included lack of control, stigma, and stress.³⁵ However, there were differences in key mechanisms through which unmet housing needs affected disease management. Diabetic patients' housing barriers interfered with their ability to store medical supplies and establish daily routines around medication management and glucose monitoring.³⁶ Among CHF patients, housing instability and conditions made adherence to strict dietary restrictions challenging.³⁵ Meanwhile, in our study, though medication adherence and diet were mentioned, cancer survivors' space concerns typically centered upon the need for private, clean, comfortable, and accessible areas in which to rest undisturbed, manage symptoms, and emotionally cope.

Unsurprisingly, we observed close relationships between housing and financial needs. Interviewees' descriptions of making sacrifices to defray housing costs echo literature on managing catastrophic cancer-related financial burden.^{5,37,38} Medical expenses have been the historical focus of financial toxicity literature³⁹ with growing attention on employment changes.⁴⁰ Both issues were reported in our sample, but lack of income was the main stressor affecting housing. Experiences shared in this study provide possible explanatory pathways for how and why, through housing, cancer-related financial hardship has been associated with treatment non-adherence; delays in care; and poor mental and emotional health, satisfaction with social activities and relationships, and survival.^{11-13,37,41,42}

Practice and policy implications

Study respondents' experiences highlight the importance of improving policy and practice to reduce the impact of housing needs in all domains. Some housing issues, such as falling behind on rent, blindsided survivors and escalated unnecessarily. Financial and sociolegal concerns arising from cancer are underdiscussed between patients and oncologists.^{4,7,41} There is a need for greater structural competency among clinicians, to have an awareness and understanding of systems-level social inequalities affecting health.⁴³ Early and regular screening for social determinants^{4,24} and early referrals to social workers and patient navigators can address barriers to care, mitigate financial hardship, and provide access to financial and housing resources.^{2,7,24,44-46} Many unmet housing needs have legal solutions. Attorneys can forestall eviction, compel landlords to make needed repairs, make government benefit appeals, or request work accommodations that allow continuation of work income. Medical-legal partnerships may be a promising approach to addressing survivors' needs, improving quality of life, and decreasing stress.^{4,47,48}

Our finding of significant mental health consequences points to the importance of psycho-oncological supports such as counseling, support groups, and peer networks. However, survivors experiencing financial hardship have higher risk of forgoing psychological services.⁴¹ Efforts must be made to ensure that mental health services are accessible and strong recommendations made for their use. Family members who provide support to survivors experience significant burden and have needs that are underacknowledged.^{49,50} Psychosocial services should be inclusive of survivors' children, hosts in doubled-up situations, and caregivers, while also taking care to remain sensitive to survivors' feelings of stigma.

Root causes at the policy level must also be addressed. NYC has been facing a housing crisis with few units affordable to lowest-income renters.^{51,52} Against this backdrop, many are tenuously housed and unable to withstand the financial shock of a cancer diagnosis, and lack options to leave unsatisfactory living arrangements. Our study predated the COVID-19 pandemic, which has only

worsened rates of rental arrears.⁵³ Study findings are especially sobering when simultaneously considering cancer patients' immunocompromise and increased risk for severe illness from COVID-19, and the implications of housing instability and overcrowding for infection control.^{54,55} Support for policies and public resources that improve housing affordability, stability and conditions is critical.

Study limitations

Housing need and cancer are both stigmatized topics, and the influence of social desirability bias on responses cannot be discounted. This was a small volunteer sample engaging in a one-time interview, and survivor interviewees did not include LEP nor unhoused individuals living outdoors. Bias from self-selection is possible, and a larger sample may yield additional codes. Survivor interviewees reflected a diverse mostly renter population in an expensive city with a robust safety net; findings may have limited transferability to dissimilar contexts.

Future directions

Housing is a complex, multifaceted concept. Our study provides an initial exploration of consequences of unmet need; future research should examine specific types of needs in greater depth, particularly in this post-COVID era. Unhoused and LEP survivors likely face the most severe impacts; targeted research on these populations is warranted. Systematic data collection is necessary to quantify the prevalence and magnitude of housing issues and their consequences. Opportunities to rigorously evaluate the outcomes and cost-effectiveness of protective policies and programs should be seized to better understand and advocate for beneficial cross-sector housing interventions.

Conclusions

This study is the first to our knowledge to explore the breadth of consequences that unmet housing needs have on cancer survivors. Inadequately addressed housing concerns are burdensome and

can make it difficult for cancer patients and survivors to have the best opportunity to rest, cope, focus on treatment, and stay mentally, socially, and physically well. We recommend policies, resources, and protections at all levels to improve housing stability and conditions for cancer patients.

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Ethics approval: Research study activities were reviewed by the GW Office of Human Research and approved.

Consent to participate: Informed consent was obtained from all study participants.

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Figure 1. Semi-structured interview guides

Survivor interview guide questions
<ul style="list-style-type: none">• How did your housing situation change, if at all, after your diagnosis?• What impact did the housing needs have on you and others around you?
Key informant interview guide questions
<ul style="list-style-type: none">• Please describe the types of housing needs that you have seen among cancer patients and survivors. What are some common issues?• What effect do these housing needs have on your clients?

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Table 1. Survivor participant characteristics (n=21)

Characteristic	n (%)
Gender	
Female	16 (76.2%)
Male	5 (23.8%)
Age	
34-49	7 (33.3%)
50-64	11 (52.4%)
65+	3 (14.3%)
Race/ Ethnicity*	
Black	15 (71.4%)
Hispanic	4 (19.1%)
White	3 (14.3%)
Asian	2 (9.5%)
American Indian	2 (9.5%)
Multi-racial	5 (23.8%)
Nativity	
U.S.-born	13 (61.9%)
Foreign born	8 (38.1%)
Education	
High school or less	7 (33.3%)
Some college or more	14 (66.7%)
Borough of Residence	
Bronx	8 (38.1%)
Brooklyn	5 (23.8%)
Queens	5 (23.8%)
Manhattan	3 (14.3%)
Last time worked	
Currently working	5 (23.8%)
< 1 year ago	2 (9.5%)
1-2 years ago	3 (14.3%)
>2 years ago	11 (52.4%)
Monthly Income at Diagnosis (median)	\$1667
Rent/ Mortgage Cost at Diagnosis (median)	\$850
Housing tenure at diagnosis	
Renting (apartment, part of house, or room)	15 (71.4%)
Doubled up	4 (19.1%)
Homeowner	2 (9.5%)
Cancer Type	
Breast	9 (42.9%)
Blood cancers	4 (19.1%)
Colorectal	2 (9.5%)
Prostate	2 (9.5%)
Uterine	2 (9.5%)
Other	2 (9.5%)
Recurrence	
Yes	6 (28.6%)
No	15 (71.4%)
Time since diagnosis	
< 2 years ago	9 (42.9%)
2-5 years ago	9 (42.9%)

RUNNING HEAD: CONSEQUENCES OF UNMET HOUSING NEEDS IN NYC

>5 years ago	3 (14.3%)
Categories of housing needs experienced*	
Housing costs	14 (66.7%)
Home loss (including worry/ threat of home loss)	12 (57.1%)
Doubled-up/ unstable housing	11 (52.4%)
Housing conditions	13 (61.9%)
Accessibility (including proximity to care)	10 (47.6%)
Safety	8 (38.1%)

*Categories are not mutually exclusive.

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Table 2. Key informant and survivor characteristics, by study identification number

KEY INFORMANTS							
ID#	Gender	Area of Professional Expertise			Practice Setting	Service Location	
1	Female	Housing advocacy			Non-profit	Bronx	
2	Male	Oncology patient navigation			Hospital	All boroughs	
3	Female	Oncology social work			Hospital	Bronx	
4	Female	Oncology patient navigation			Hospital	Queens	
5	Male	Oncology social work			Non-profit	All boroughs	
6	Female	Psychosocial oncology			Hospital	Bronx	
7	Female	Oncology administration/ Clinical oncology			Hospital	Queens	
8	Female	Medical legal services			Non-profit	All boroughs	
9	Female	Population health			Hospital	All boroughs	
SURVIVORS							
ID#	Age	Gender	Race	Tenure at Diagnosis	Job at Diagnosis	Cancer Type	Summary of housing concerns
1	50-59	Male	Black, American Indian	Own	Electrician	Colorectal	Mortgage, Foreclosure, Rent, Worry about eviction, Proximity to treatment, Crime
2	50-59	Female	Black	Rent	Social worker	Breast	Rent, Threat of eviction, Cleanliness, In-home accessibility
3	40-49	Female	Multi-racial	Doubled up	Student	Breast	Overcrowding, Guest dynamic, Cleanliness
4	50-59	Female	Hispanic	Rent	Multiple jobs	Uterine	Home loss (unrelated to cancer), Tension with hosts (doubled up), Guest dynamic, Forced to leave, Proximity to care
5	60-69	Male	Black	Doubled up	None - retired	Prostate	Tension with host household (doubled up)
6	40-49	Female	White	Rent	Multiple jobs	Breast	Rent, Utilities, Move without formal eviction, Overcrowding, Guest dynamic, Noise
7	60-69	Female	Hispanic	Rent	Case worker	Breast	Rent, Threat of eviction, Maintenance, Hazardous exposures, Cleanliness, Infestations
8	40-49	Female	Black	Rent	Home health aide	Colorectal	Rent, Stairs, Hazardous exposures, Cleanliness, Infestations, Maintenance, Building hazards, Building security
9	40-49	Female	Black	Rent	Community counselor	Lymphoma	Lack of heat, Maintenance, Stairs, Unit security, Crime
10	50-59	Female	Black, White, Asian	Own	Medical biller	Breast	Mortgage, Renovations/upkeep, Foreclosure, Hazardous exposures, Infestations, Shelter

RUNNING HEAD: CONSEQUENCES OF UNMET HOUSING NEEDS IN NYC

							environment, Stairs, Accessibility of amenities
11	60-69	Female	Black, American Indian	Rent	Ad hoc	Leukemia	Rent, Utilities, Payment disputes, Move without formal eviction, Lack of utilities, Noise, Maintenance, Cleanliness, Infestations, Stairs, Accessibility of amenities, Proximity to treatment, Crime, Landlord behavior, Building hazards
12	40-49	Male	Asian	Rent	Ad hoc	Stomach	Rent, Tension with host household member
13	50-59	Female	Black	Rent	Nursing assistant	Lymphoma	Rent, Utilities, Threat of eviction, Crime
14	60-69	Male	White	Doubled up	Construction	Skin	Tension with host (doubled up), Home loss
15	40-49	Female	Black	Rent	Project manager	Breast	Rent, Guest dynamic, Proximity to care
16	50-59	Female	Black	Rent	Home health aide	Uterine	Rent, Guest dynamic, Host behavior (doubled up), Infestations, Stairs, Proximity to health resources
17	60-69	Female	Black, Hispanic	Rent	Nursing assistant	Breast	Rent, Eviction (temporary), Stairs, Maintenance, Building security, Crime, Proximity to care
18	50-59	Female	Black	Rent	None - disabled	Breast	Hazardous exposures, Maintenance, Infestations
19	70-71	Female	Black	Doubled up	Ad hoc	Lymphoma, Kidney	Overcrowding
20	30-39	Female	Black, Hispanic	Rent	Home health aide	Breast	Rent, Move without formal eviction, Tension with host household (doubled up), Overcrowding, Guest dynamic, Forced to leave (deadline to move), Crime
21	60-69	Male	Black	Rent	Painter	Prostate	Rent, Worry about eviction, Crime

Table 3. Qualitative results: Consequences of unmet housing needs described by survivor and key informant interviewees.

Code	Definition	Illustrative quotes
CANCER MANAGEMENT & HEALTH		
<p>Interference with rest, symptom management, and recovery</p>	<p>Interference of housing issues with survivors’ ability to adequately rest, manage symptoms (e.g. nausea), and generally stay well (e.g. sleep, nutrition), whether due to de-prioritization/ distraction, or inadequate space. Includes descriptions of spending effort and energy on managing housing issues during treatment/ recovery period (e.g. continuing to work, searching for new housing), or feeling tired in relation to managing housing issues.</p>	<p>I haven't had any time to really...I've been busy....I'm still healing. I still feel where my ribs was cracked, I can't lift my arms...but I still have to go on, because life don't stop. I just need to find somewhere to live so at least that part I could breathe.” (S#20)</p> <p>I feel like I’m exhausted with just looking, and trying to find [a housing unit]. (S#16)</p> <p>It was terrible, it was just horrible. I lost so much weight because all I had to think about was that rent, that rent. Getting that rent money together. (S#7)</p> <p>I think the chemo patients...really need a little private space. They need a comfortable bed, they need a lot of sleep after their treatment because they’re just feeling so terrible...to not have that safe place to go home to just makes the treatment that much worse. (KI #2)</p> <p>We do have patients that take part time work even though they're feeling terrible and in any other circumstance they wouldn't be working. But they do it so they can come up with that money for rent. (KI#2)</p> <p>They pay high fees, exorbitant fees for rooms within a household line. Sometimes it’s not often very safe or clean and very often they’re treated like encumbered people...they’re forced to perform labor and work for residents in addition to a rent. So I think that they’re the most vulnerable...new immigrants who have cultural issues and various other barriers assimilating on top of their new cancer diagnosis. (KI#7)</p>
<p>Risk of illness and injury</p>	<p>Connection of illness or injury (including risk of illness or injury) to a housing concern (e.g. cleanliness, crime).</p>	<p>My living conditions...it start to work on me because I gotta depend on people to do for me. To wash for me, to clean for me, to clean where I is sleeping in the living room on the sofa. You got to clean round my everything, gotta sanitize everything. If there is dirty I goin' take up infection so fast I is back in the ICU. (S#3)</p> <p>They had to do a lot of cleaning of asbestos like ten years ago, and I really believe that got me and other people sick around here...Spraying the walls, getting rid supposedly the asbestos, then painted over it. And I find it interesting that my two husbands and myself, my neighbor, his wife, I mean so many sick people. All of us with cancer diagnosis, who knows how many more. (S#7)</p> <p>The neighborhood back then it was really good...Now it's a little bit dangerous. These days now with the gunshots and stuff like that...Now it's not safe, you have to be so careful now. (S#13)</p>

RUNNING HEAD: CONSEQUENCES OF UNMET HOUSING NEEDS IN NYC

<p>Interference with medical care</p>	<p>Any impact on cancer treatment/ medical care, including: non-adherence, refusal of care, taking housing-related issues into account when making medical decisions, and delays in care.</p>	<p>I had a lot of running around trying to get my services on for my lights, when I'd go to court. Running and back and forth...sometimes, I forgot my appointments." (S#11)</p> <p>A patient who's diagnosed with ovarian cancer and it's pretty late stage and she has to get treatment, but she says she has no one to take care of herself, she has to work otherwise she has no place to live. And so she declined the treatment. (KI#4)</p> <p>They couldn't discharge someone because they had just had a mastectomy and they had two tubes for drainage in their breasts and the shelter rejected them...and so one of the things that we see happens is they unfortunately have to stay in our inpatient unit until there's a place for them to discharge. (KI #9)</p> <p>...the person was not getting chemotherapy because they just kept believing that the landlord was going to show up that day to make repairs, so they would over and over miss treatment because they were waiting for the landlord. (KI#8)</p>
<p>PSYCHOLOGICAL</p>		
<p>Feeling stressed, anxious, overwhelmed</p>	<p>Description of feeling stressed, worried, anxious, overwhelmed, under pressure, or otherwise struggling.</p>	<p>It scared the heck out of me, because the first thing I thought when [the marshal showed up] was, 'oh my god, I have to go to the shelter!' (S#17)</p> <p>They were sending me from one office to another saying, 'This is not the office that you've got to go to. You've got to go here.' Making me wait in long lines...I was running down on money, and I needed help with it and they just wasn't helping me. I got to the point where I was having a breakdown and I stopped in the middle of street and just started crying. I felt like my soul had went out of my body, that I was dead. (S#11)</p> <p>That was basically all that I was worried about is rent being paid and the [utility company name] to keep the lights and stuff on...That was right away. Because like I said, I always worked...worrying about that, worrying about am I gonna survive thing. (S#13)</p>
<p>Lacking control and independence</p>	<p>Any report of feeling stuck or unable to control aspects of one's life; expressing the desire for or importance of having control, independence, autonomy, self-determination (often in reference to needing a place of one's own and/ or financial independence).</p>	<p>It made me feel like I have no sense of direction. (S#4)</p> <p>It does have an impact on me. The separation, losing your house, losing a car, you know? It's like losing your independence. (S#1)</p> <p>If I had my own apartment then I can do things for myself I keep my place clean. That would be better for me, but on and on I still can't afford an apartment so that I could have moved and do things better for me. (S#3)</p> <p>I would be okay if it's not big. You know, something where I feel like I'm in a house. I don't have to worry about anybody worrying about what I'm doing. I think [living with someone else] stagnated me just to be there. I felt like I couldn't get ahead. (S#16)</p>

<p>Self-esteem and pride</p>	<p>Description of feeling low, embarrassed, ashamed, burdensome to others, judged, or otherwise badly about oneself; references to pride, including a desire to protect one's pride or feeling proud to have overcome.</p>	<p>My biggest anxiety was really having them come with the marshals and my neighbors were now looking through the window and seeing what's going on. Because nobody is going to come out, everybody is going to be peeping through the window. That was my biggest fear. I couldn't stand that embarrassment. (S#10)</p> <p>I got behind on my rent. It was just ugly. It really, really was ugly. You have pride, and you want to be self- ... I should have did a Go Fund Me page or something, but I totally was just like, always so caught off guard because I didn't understand what triple-negative was. (S#2)</p> <p>People talk, and they make you feel bad, and I just felt that they would bring me down. (S#19)</p> <p>I feel like a lot of patients think that they're drains on whatever family or household they're staying with. And I think that's another psychological thing, you know, feeling like you really don't have that much to add and don't have a ton of worth. (KI#2)</p>
<p>Feeling sadness and depression</p>	<p>Description of feeling sadness or loss; includes references to depression and suicidal ideations.</p>	<p>Why do I lose my house? Why do I lose my car? Why do I lose my family? You got cancer...But you don't want this to hold you down. Everybody saying that they can't do it, well I'm gonna get it done. That is the struggle.... I'm gonna use the word, depressing. Very depressing. You have to be strong. (S#1)</p> <p>It made me more depressed...I have to get out of here. (S#8)</p> <p>I definitely think the financial made me more depressed and stressed than really cancer itself...Cancer's just a name. Cancer. It's everything that comes with it. Financial situation, living situation, family situation, chemo situation, radiation, side effects, baldness..it was very, very terrible knowing that I had to move in with my mother, knowing that I had credit card bills that piled up and everything. (S#6)</p> <p>I said to my manager, 'I could drive my car into the East River.' (S#10)</p>
<p>Interference with cancer coping</p>	<p>Interference of housing-related issues with the ability to emotionally cope with cancer (whether due to de-prioritization/ distraction, or lack of private space to grieve).</p>	<p>They said that breast cancer, in general, like traumatized. And then, I never really dealt with it by just going to work... and it's true, I just kept working, and working, and working, and going to work and not even thinking about it...and blocking it out. At that time I couldn't even talk about it like I'm talking about it now. (S#17)</p> <p>There were times when I used to ask my mother to leave the house so I could cry, because...she wouldn't let me cry. 'But I'm in pain. Do you understand? I need to let it out' ... She didn't wanna accept it...before cancer and after cancer, you have no privacy. (S#6)</p>
<p>SOCIAL</p>		
<p>Consequences for social relationships</p>	<p>Changes to social relationships, positive or negative, related to housing issues and</p>	<p>I think the best thing is to move. 'Cause it's family, I don't want to cause them, you know. Family feud. (S#5)</p>

RUNNING HEAD: CONSEQUENCES OF UNMET HOUSING NEEDS IN NYC

	their management; includes comments on relationships with hosts in doubled-up situations.	...sometimes they'll go and stay with family members temporarily, but that also doesn't work because if the family member was an option to begin with, they would have...chosen that first, but it wasn't, so usually there's a conflict with a family member. But they're doing it because it's the lesser of two evils at the moment. (KI#6)
Consequences for other people	Descriptions of spillover impacts of the survivors' housing issues on the people around the survivor (e.g. caregivers, children, hosts, friends, family).	[My kids are] suffering a little bit more because they can't... The neighborhood we're in now, I don't trust for my 10-year-old to be going outside by himself and stuff like that. If I can't take him or anything, he doesn't do anything. (S#20) [There are] people who have just come [to this country] very recently and might have only one family member and no friends. And then it becomes they don't really have any other [housing] options so they're kind of trapped. And I feel like that family feels like that too. (KI#2)
Inducing isolation	Disconnection and isolation from friends/family related to having and managing housing issues.	I was like a bear in hibernation not trying to spend any money. But I did want to go out and do things. So it affected me a little, because I would say no more to things. Not only was I tired I also didn't have a ton of money, and so I just was more recluse. (S#15) I would get complaints from everybody all the time say, 'why you don't come around no more?' Because I was so busy and tired...so it wound up making me a little secluded. (S#17)
STANDARD OF FUNCTIONAL LIVING		
Standard of functional living	Material sacrifices, inconveniences, discomforts, or other poor functional day-to-day experience related to housing issues and their management.	I turned the lights off, put the breaker off... I don't do no long, long cooking. I make salads a lot. I eat cold cereal, and I'm out... I only come home in the evening and use electricity. Sometimes I use a candle just to keep from using electricity. (S#11) If I have to go do laundry, oh it's difficult...I put my clothes in bag, then I have to throw them from the third floor to down... then I have to take everything, money, go down now and put everything in the shopping cart. Then leave to the laundromat. Finishing the wash, then come back. Now sometimes even when I come back I take only one bag, I leave all the rest down until before I sleep in the night, that I go back and fetch everything. Just so I have little rest, and little energy. (S#9) We fall behind [on rent], and we had to squeeze and give up. (S#12) We do have patients who don't pay for food, who walk to their appointments instead of taking a bus because they have to scrimp together money to pay their share of the rent...that's sort of the ultimate thing that they have to pay for. So a roof over the head is the most important thing and then everything else falls by the wayside. (KI#2)

¹S: Survivor; KI: Key Informant