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Influences of the Homeless Shelter Environment on the Personal Experience of Tuberculosis Disease During a Large Outbreak in Atlanta, Georgia

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An abstract of
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Abstract

Influences of the Homeless Shelter Environment on the Personal Experience of Tuberculosis Disease During a Large Outbreak in Atlanta, Georgia

By William J. Connors

INTRODUCTION: Homeless persons represent a key high-risk population for tuberculosis (TB) among whom TB disease has outsized public health implications. Little is known about how homeless persons experience TB illness and prevention and control measures implemented in response to a TB outbreak. This qualitative study aimed to explore homeless persons' TB disease experiences in the context of a large TB outbreak involving overnight homeless shelters in Atlanta, Georgia.

METHODS: In-depth interviews were conducted with a purposive sample of homeless persons with active TB disease residing in Atlanta during the shelter outbreak. Key themes were identified through analysis of coded data. Following interviews a demographic questionnaire was completed and participants' medical records were reviewed.

RESULTS: Ten participants (9 male, 1 female, all African American and US born) with baseline high-risk profiles for TB were interviewed. Nine participants had sputum culture positive disease, five (56%) had the TB strain associated with the ongoing homeless shelter outbreak and four had distinct TB strains. Interviews contained five pervasive themes: (i) health and behavioral impact of the homeless shelter context, (ii) influence of homelessness on disease experience, (iii) role of acute health care services, (iv) experiences with shelter-based interventions implemented in response to the TB outbreak, and (v) sources of TB knowledge and health literacy. The central theme to emerge from analysis was that stressful social environments of homeless shelters shape illness experiences, healthcare-seeking behaviors, and limit the influence of shelter-based prevention and control measures implemented in response to a TB outbreak.

CONCLUSIONS: Homeless shelter related stress may have important implications for the prevention and control of TB outbreaks in this setting, hindering case finding and supporting a model of supplemental TB education and latent tuberculosis infection testing services at proximal community venues. Systematic qualitative assessments in the context of evolving public health responses may provide novel insights that can strengthen TB elimination efforts.

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CHAPTER 1: Introduction

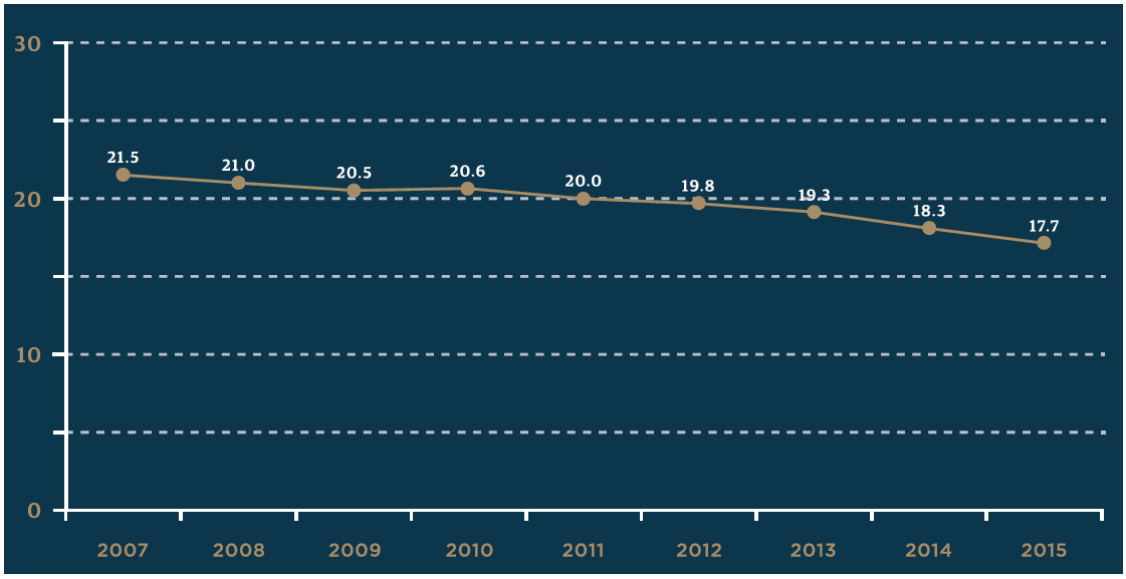
1.1 Introduction and rationale

Tuberculosis (TB) – human infection caused by the bacterium *Mycobacterium tuberculosis* – was responsible for an estimated 1.8 million deaths globally in 2015, surpassing HIV as the leading infectious disease cause of death (1). This tremendous human toll occurred in spite of TB being both preventable and curable. The persistence of the TB pandemic reflects its intimate association with social determinants of health; poverty, malnutrition and the crowding and pollution associated with urbanization represent key global determinants of TB burden (2). While at the national level TB burden is greatest in low- and lower-middle-income countries of Africa and Asia, in the United States and other high-income countries, the prevalence of TB within certain key populations may be equal or greater than that in low- and lower-middle-income countries (1, 3). Homeless persons are one such key population along with prisoners, long-term care facility residents, and persons with substance use disorders (4).

Despite being a highly developed country, homelessness remains a major public health issue in the US. The US Housing and Urban Development Department defines homelessness as living in an emergency shelter, transitional housing program, or a place not meant for human habitation, such as a car, abandoned building, or on the streets (5). It is estimated that 1% of Americans experience homelessness in a given year and a national point-in-time count in January 2015 identified 564,708 homeless individuals (6). This estimate translates into a rate of 17.7 homeless people per 10,000 of the general population, representing a 2% year-to-year decrease in homelessness compared with 2014 and continuation of longer term downward trend (Figure 1). While the majority of homeless individuals access some form of shelter or transitional housing (69.3% in 2015), among individuals

who have been homeless for over a year (14.7% of total homeless population) this proportion drops significantly to 34.1% in 2015 (7). Beyond the challenge of addressing short and long term shelter needs of this population, there is a disproportionate burden of acute and chronic diseases among homeless persons that further compounds the societal costs and public health urgency of homelessness (8).

Figure 1: Point-in-time national overall homelessness rate (per 10,000 persons) - United States, 2007 to 2015. Data and graphic by National Alliance to End Homelessness (7).



Tuberculosis and homelessness more than just co-occur, they represent conditions that interact synergistically. The interconnectedness of homelessness and TB represent a 'syndemic,' conceptualized by Singer and Clair as the synergistic interaction of two or more health and social problems resulting in excess disease burden within a population (9). When present together, the conditions of TB and homelessness result in worse disease outcomes and greater public health implications than either alone. Illustrating this concept, homeless persons have been found to have a 10-fold increased incidence of TB compared with the general population. Once infected with TB,

homeless persons require longer hospitalization, have lower treatment completion rates, and are linked to more acute large cluster transmission events compared with non-homeless persons in the US (6, 10-12). The existence of higher burdens of substance use disorders and HIV as well as rates of previous incarceration - each an independent risk factor for TB disease - among homeless persons further amplifies TB disease burden (6, 13). From a public health perspective, homelessness and tuberculosis pose unique prevention and treatment challenges. These challenges include difficulty locating individuals for testing and treatment, increased scale and complexity of contact tracing, and increased rates of treatment-associated adverse events relating to higher burdens of comorbid disease (6, 10, 14).

Acknowledging the unique challenges and pressing public health concern of TB among those who are homeless in TB low-incidence countries, the Centers for Disease Control and Prevention in both the US (CDC) and Europe (ECDC) have issued specific management guidelines for this population (15, 16). However, given a lack of empiric research involving homeless populations, nearly all recommendations are extrapolated from research with non-homeless populations and as a result are of low evidence quality.

Factors limiting research in this field include the sporadic nature, geographical dispersal, relatively small size and extended duration of TB outbreaks among homeless persons, making study design and implementation challenging (10). Furthermore, demographic and health condition heterogeneity, along with social instability, limit the capacity for comparative analyses and pose challenges to research study recruitment and retention (6). In contrast to quantitative methodology studies, qualitative methods research would seem ideally suited for this setting given its orientation to the individual, smaller sample size requirements, and ability to characterize behaviors and experiences so as to inform the design and evaluation of interventions. However, to date there has

been very limited qualitative research of tuberculosis among homeless persons in low incidence countries.

1.2 Problem statement

The first and most important element of effective tuberculosis control is case finding: the detection and diagnosis of TB using tests, examinations or other procedures that can be applied rapidly (17). Without efficient and complete case finding it is not possible to identify case contacts and prevent further transmission. For the social and individual reasons noted above, this primary element of TB control is particularly difficult among homeless populations. Typically, case finding is a passive process predicated on the idea that affected individuals will seek care. However, in the setting of tuberculosis among individuals that may face barriers to accessing care, such as those who are homeless, active case finding is recommended by the CDC Advisory Council for the Elimination of Tuberculosis (15). An understanding of individuals' health experiences and behaviors is required to inform the design and implementation of effective active case finding. In the case of tuberculosis among homeless persons in low incidence countries, this foundational knowledge is missing. As highlighted by the recent CDC Division of Tuberculosis Elimination report on TB trends in the US, accomplishing the national goal of TB elimination will require greater emphasis on research into ways to interrupt ongoing TB transmission among homeless persons (18). Since 2008, Fulton County, Georgia, the largest county within the metropolitan Atlanta area, has been experiencing a large ongoing outbreak of tuberculosis among homeless persons (19). This outbreak underscores the need for improved TB control measures and presents a unique opportunity for research.

1.3 Purpose statement

In response to the TB outbreak among homeless persons in Fulton County, Georgia, a Tuberculosis Task Force has been established and a series of public health measures have been implemented including health care provider education, mass screenings, changes to homeless shelter administrative processes, and homeless shelter specific education of staff and residents. The development of these measures was informed by findings from public health efforts to control similar outbreaks in other municipalities, as well as a local stakeholder survey. However, the impact of these interventions on individual patient experiences remains unknown. Qualitative assessment, by way of in-depth interviews and subsequent thematic analysis, can begin to address this knowledge gap by exploring the impact of TB prevention and control measures on homeless persons' TB illness experiences and health behaviors. In addition to informing ongoing control efforts in Fulton County this research will represent a novel contribution to the larger body of research into tuberculosis control among this key sub-population that continues to pose a significant challenge to TB elimination efforts.

1.4 Research questions

To inform public health efforts to eliminate TB among homeless persons in the US, this exploratory qualitative study seeks to answer the following research questions:

- How did homeless persons who developed active TB disease during the outbreak in Fulton County experience their illness, diagnosis, and treatment?
- How did homeless persons with active TB disease experience the shelter-based prevention and control measures implemented in response to the TB outbreak in Fulton County?

1.5 Significance statement

The importance of tuberculosis control to global health is immense. In 2015, 10 million people globally developed TB disease and 1.8 million died, with an estimated 4400 deaths occurring each day (1). Although only a very small fraction of this disease burden occurred in the US (9557 cases of TB disease and 807 related deaths in 2015), TB continues to have an outsized health impact among key populations and a significant financial impact on public health services (3). Homeless persons in the US have a 10-fold increased risk of TB disease and 10-20% increased cost of treatment compared with non-homeless individuals (6, 11). At an estimated per case treatment cost of $10,000 to $20,000 for drug-susceptible disease and over $135,000 USD for drug-resistant disease, TB represents a significant financial burden on the public health sector, which covers the cost of the vast majority of homeless persons' TB related care (20, 21). Beyond the financial cost of TB, the moral imperative of caring for those most marginalized in society also underpins US (22) and World Health Organization (WHO) (23) commitments to eliminating TB. In the US, hard-to-reach populations, such as homeless persons, continue to represent a significant barrier to achieving these commitments (4). Research aimed at better understanding the experience of TB among these hard-to-reach populations can serve to inform evolving TB control efforts by rooting decisions in evidence that to date has been elusive.

1.6 Definition of terms

Homelessness – the state of living in an emergency shelter, transitional housing program, or a place not meant for human habitation, such as a car, abandoned building, or on the streets

High income country - defined by the World Bank as a country with a gross national income per capita above US$12,475 in 2015

Latent Tuberculosis Infection (LTBI) – Tuberculosis infection that is in latent asymptomatic and non-infectious state but has the potential to reactivate and cause active tuberculosis disease that is typically both symptomatic and infectious

Low- and low-middle-income countries - defined by the World Bank as countries with gross national income per-capita of less than $4,238USD in 2014

Shelter - a type of homeless service agency that provides temporary residence for homeless individuals and families

Tuberculosis (TB) – human bacterial infection caused by *Mycobacterium tuberculosis*. Primarily transmitted from human-to-human via inhalation of airborne droplet nuclei. Once in the host *M. tuberculosis* infection may remain in a latent asymptomatic state (*latent TB* or *TB infection* - LTBI) or progress to an active illness (*active TB* or *TB disease*)

Tuberculosis low-incidence countries - defined by the World Health Organization (WHO) as those with a TB notification rate of ≤ 100 cases (all forms) per million population a year

CHAPTER 2: Literature Review

2.1 Epidemiology of tuberculosis among the United States homeless population

As the overall incidence of TB in the US has steadily declined, TB among the US homeless population has remained relatively stable and isolated from overall public health gains. For the first time in 20 years the US had an increase in total incident cases of TB and a leveling of the national incidence rate of TB in 2014-2015 (18) (Figure 1). Whereas TB among foreign-born individuals – thought to predominantly reflect pre-immigration infection - continues to represent the largest proportion of total TB cases in the US (66.4%), the plateauing of the national incidence rate occurred despite continued decline among this group. In contrast, the TB incidence among US-born individuals has not declined since 2013, highlighting a key challenge to elimination efforts (18). Among domestically acquired TB cases, homelessness has remained a major risk factor. Despite concerted public health efforts, the proportion of total TB cases occurring in homeless persons in the US – representing 5.5% of all cases in 2015 (3) (Figure 2) – has not decreased since 2009.

Figure 1: Tuberculosis incidence overall and among US- and foreign-born persons, by year – United States, 2000 to 2015. Data and graphic by United States Centers for Disease Control and Prevention (CDC) (18).

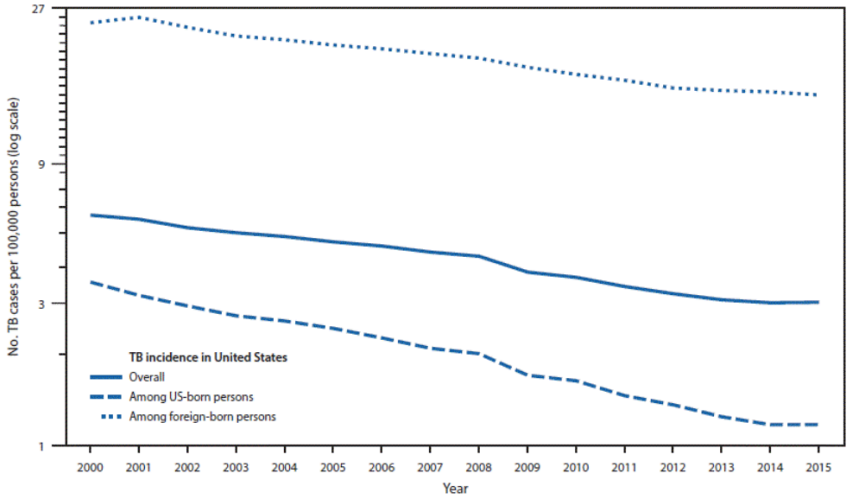
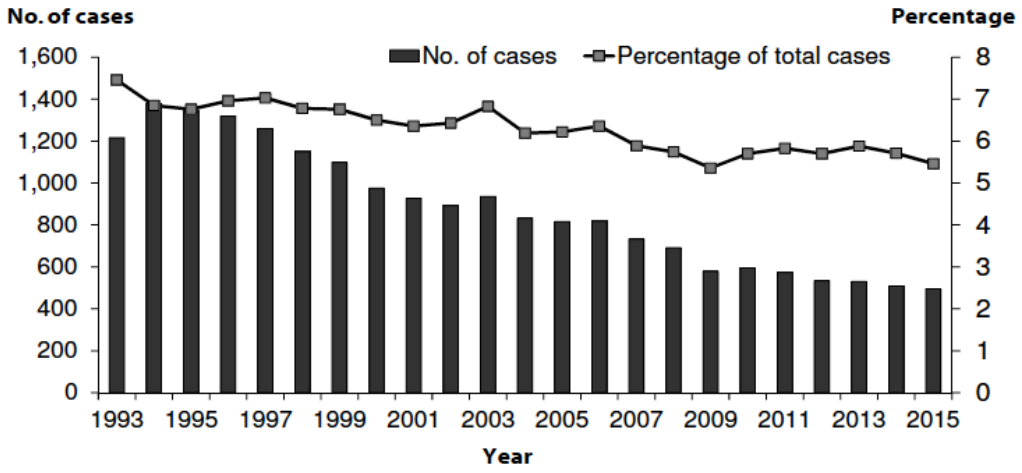


Figure 2: Tuberculosis cases reported among homeless persons (during the year before diagnosis),

age >14 years - United States, 1993 to 2015. Data and graphic by CDC (3).



The most recent comprehensive review of the epidemiology of TB among homeless populations in the US estimated the TB incidence rate at 36 to 47 cases per 100,000 between 2006 and 2010 (6). In the same time period, the overall national TB incidence rate was 10-fold lower, ranging from 3.6 to 4.6 cases per 100,000 (3). Although the relative difference has narrowed over the past 20 years, US-born homeless persons, in contrast to those who are foreign-born, continue to represent the vast majority of homeless TB cases. In 2010 US-born homeless persons accounted for nearly 3-times as many cases as foreign-born homeless persons (6). Comparing US-born homeless and non-homeless TB cases, a number of notable demographic and clinical differences exist. Between 1994 and 2010 there were over 13,000 cases of TB among US-born homeless persons, 10% of all US-born TB cases. Compared with non-homeless TB cases over this period, male gender, African American race, substance misuse, prior incarceration, and HIV infection were all significantly more common among homeless TB cases (6). Homeless individuals with TB also pose an outsized public health risk. Compared with non-homeless TB cases, homeless individuals more often present with advanced and infectious disease, less often complete treatment, and are responsible for more frequent and larger outbreaks of TB (6, 12). TB Outbreaks among homeless persons, defined by the

CDC as ≥3 epidemiologically linked TB cases within 2 years (24), represent unique public health challenges because of both their scale and the logistics of case investigations and treatment.

Between 2000 and 2016, seven TB outbreaks among homeless persons in the US were detailed in the peer-reviewed literature (25-31). While these TB outbreak reports are not an exhaustive list of outbreaks among this population over this period, together they provide useful insights regarding the features of a number of larger well-characterized recent outbreaks. These outbreaks entailed an average of 36 cases (range 7 -99), lasted on average 4.1 years (range 1-8), and all involved suspected TB transmission in one or more homeless shelters. Demographics of the homeless persons involved were similar to those outlined above, with US-born African American males representing over 85% of cases across all outbreaks. Co-infection with HIV was common, with HIV prevalence within outbreaks ranging from 11 to 57%. Among the three reports that included death statistics, 13% of cases (20/150) died by the conclusion of the outbreak investigations (25, 26, 30). Secondary contact-tracing outcomes were reported for six outbreaks, across which a total of 7886 high-risk contacts were identified (range 146 – 4300 contacts/outbreak) (25-29, 31). Together these outbreaks clearly illustrate the scale, both in terms of cases and public health response, and characteristic demographics of recent TB outbreaks among homeless persons in the US. They also provide context for the research presented herein which took place in the setting of an ongoing large TB outbreak among homeless individuals in Fulton County, Georgia.

2.2 Qualitative research on the homeless health experience

Qualitative research evaluating the health experience and care seeking behaviors of homeless persons with tuberculosis in low incidence countries is limited to a single study by Craig and

colleagues in London, UK, published in 2014 (32). The dearth of research on this topic likely in part relates to the specificity of the research question, but also may reflect the slow acceptance of qualitative research approaches in health science disciplines (33). Despite the relative lack of directly comparable research, a review of qualitative research on health and healthcare perspectives of homeless persons in general provides a conceptual foundation for the current study.

2.2.1 Healthcare system experiences & their influence on health seeking behaviors

The existing research on healthcare system experiences and their influence on health seeking behaviors of homeless persons is characterized by the pervasive influence of numerous perceived and actual barriers to accessing healthcare. Perceptions of unwelcomeness and discrimination in the healthcare system were common across studies in this field. Health prioritization and individuals' health literacy appear to be key factors that could positively influence the timing of healthcare seeking. In contrast, past negative experiences and barriers while seeking care can contribute to a loss of perceived control in the healthcare seeking process. A theme of resourcefulness has also been identified, highlighting the adaptability of this population. To better understand the context and research methods used to identify these themes a more detailed review of relevant studies follows.

The experiences of homeless persons accessing and receiving care within the healthcare system was evaluated in four studies. First, with the stated aim of informing healthcare providers of the barriers created by the situation of homelessness, Nickasch & Marnocha conducted a series of iterative semi-structured in-depth interviews with a convenience sample of 9 homeless adults in northeastern Wisconsin (34). Participants for this research were recruited by snowball sampling

via an emergency shelter and affiliated medical clinic. The period of preceding homelessness experienced by participants was relatively short (average 7 weeks, range 4 days to 6 months). Through the application of grounded theory, this research identified that homeless individuals expressed an external locus of control regarding healthcare system experiences. Participants highlighted the inability to meet basic needs, financial insecurity, limited options for healthcare access, and lack of compassion from healthcare providers as key contributors to this lack of control. This study concluded that perceived lack of provider insight into the needs and barriers faced by homeless individuals might impede health outcome ownership among homeless persons.

Research conducted by Martins elaborated on the theme of perceived external barriers to accessing effective care while identifying an additional theme of underground resourcefulness - survival driven alternate methods of accessing necessary services (35). Applying Colaizzi's descriptive phenomenological method – an approach to examining phenomena as they are experienced without consideration of psychological genesis – to in-depth interviews, this research identified four major themes among 15 homeless adults attending a free inner-city health clinic in Connecticut. Participants described how living without essential resources compromised health, that many barriers exist to accessing healthcare, that prior healthcare system experiences and existing barriers lead to delayed seeking of care until "crises" arise, and how underground resourcefulness aids in overcoming barriers. Key perceived barriers described by participants included discriminatory social triaging within the system, a feeling of being stigmatized, absence of a system to provide healthcare to the homeless, and a feeling of being "invisible" to care providers. In the setting of these perceived barriers, participants described underground resourcefulness in the forms of sharing medications, enrolling in research studies to access basic care, using deception such as feigning symptoms to access care, and self-medicating with alcohol and drugs to numb medical symptoms.

Exploring further the themes of perceived disrespect and delayed presentation to care, research by Wen and colleagues evaluated healthcare interactions using interpretive content analysis to assess perceptions of 'welcomeness' and 'unwelcomeness' (36). From a convenience sample of 17 homeless adults from 5 different homeless shelters in Toronto, Canada, these researchers found that the majority of participants felt unwelcome when receiving healthcare. Participants reported feeling dehumanized by encounters containing perceived acts of discrimination and that a resultant sense of 'unwelcomeness' lead to avoidance of healthcare encounters. The authors of this research concluded that discrimination of homeless persons during healthcare encounters is prevalent and that it may reduce health-seeking behavior of this population.

More recent research by Rae & Rees sought to explore further the link between perceptions of healthcare encounters and healthcare seeking behaviors among a sample of 14 homeless adults from a shelter and non-residential day center in the United Kingdom (37) Through interpretive phenomenological inquiry, the researchers identified that perceptions of individual health and attitudes from prior healthcare encounters influenced health-seeking behaviors. Regarding perceptions of individual health, the researchers found that although homeless persons recognized health problems, the need for healthcare interventions was not always prioritized. They concluded that this non-prioritization along with obstacles to accessing care, both perceived (e.g. discrimination) and actual (e.g. transportation), leads to delayed healthcare seeking among homeless persons.

To better understand healthcare decision prioritization among homeless persons, Swigart and Kolb used constant comparative content analysis – a process through which newly collected data is systematically compared against previous data – to evaluate semi-structured interviews focused on

the basis for decisions to accept or reject tuberculosis screening (38). From a sample of 55 adult homeless persons from 7 shelters in Pittsburgh, Pennsylvania, five key factors were identified as positively influencing acceptance of the public health service: presence of a pre-existing health condition related to service offered (e.g. lung disease and tuberculosis screening), baseline concerns about social behavior health consequence (e.g. smoking), personal desire to maintain health, encouragement from shelter personnel, knowledge of disease risk factors (e.g. homelessness and tuberculosis risk). Additionally, deterrents to accessing care were identified as: fear about results, inconvenience of accessing service, and concern about being labeled ill. This research effectively characterized the complex calculus entailing both perceived benefits and risks that goes into homeless persons' decisions of to access healthcare, providing valuable guidance for the development of effective models of care for this population.

2.2.2 Qualitative research on the homeless health experience specific to TB

A small literature base exists around homeless individuals' health experiences as they specifically relate to TB. This research can be divided into that exploring knowledge, attitude, and risk perception about TB and that which evaluates illness and treatment experiences of those with TB. Information on the former comes from research by West and colleagues in North Carolina, US, done with focus groups comprised of 3 sub-populations at high-risk for TB: Spanish-speaking immigrants, homeless shelter residents, and persons attending a substance use rehabilitation program (39). Using a standard list of open-ended questions aimed at evaluating knowledge, attitudes, and beliefs about tuberculosis, the researchers conducted 11 focus groups, including six sessions at 4 homeless shelters. Through a process of grounded theory analysis the authors concluded that among these high-risk populations there was a general understanding of how TB may affect an individual's health, however there were frequent false beliefs about the cause, transmission and treatment of

TB, and sentiments of fear and aversion of those ill with TB were pervasive. Unfortunately, demographics of the homeless participants were not collected and the researchers did not report findings by sub-group, limiting the comparison of these findings with the current study.

Research evaluating illness and treatment experiences among homeless persons with TB is limited to a series of related publications by Craig and colleagues evaluating a cohort of unstably housed adults receiving care at an inner city TB clinic in the UK (32, 40). As part of an initiative evaluating the role of a TB caseworker in developing collaborative care pathways, this research included a sample of 17 participants representing typical 'critical case' experiences. Participants were majority male (70%), had a mean age of 44, and had a diversity of additional tuberculosis risk factors beyond homelessness (41% foreign-born, 65% with substance use disorders, 24% HIV positive, and 41% with prior incarceration). Informed by a critical health psychology perspective – an approach that views illness behavior within social, political, and cultural contexts – this research applied theoretical thematic analysis to identify thematic areas relating to both illness experience (symptoms and resultant health seeking behaviors) and the social context of tuberculosis treatment.

From the analysis looking at the TB illness experiences of this diverse group, 5 key thematic areas were identified. Together these themes were conceptualized as a "route-to-care" in the following order: personal accounts of health, TB susceptibility knowledge, recognition of symptoms, access and barriers to healthcare, and managing risk associated with accessing care. This conceptual framework effectively mirrors the natural history of untreated tuberculosis, an evolution from asymptomatic infection to progressive disease over time. At the beginning of this 'route' participants often defined their health in functional terms, frequently using the need for hospitalization as the benchmark for no longer being healthy. TB susceptibility knowledge among this group was found to be highly variable, with a generally poor understanding of personal risk

and a common perception that TB 'happened to other people'. Regarding symptom recognition, normalization was common. While most participants reported experiencing progressive symptoms, the non-specific nature of symptoms resulted in attribution to other previously experienced conditions (e.g. influenza, pneumonia, substance withdrawal). Participants' descriptions of seeking and entering care were highly variable, often characterized by missed or delayed diagnosis over time culminating in acute illness that would lead to hospitalization.

Once in care, it was found that participants report both physical and social factors as compromising their ability to stay engaged. Among those with histories of substance abuse, reported barriers and perceived risks of continuing care often related to substance dependency, with both the effects of intoxication and fear of withdrawal impacting decisions. Although many participants reported to struggling physically to tolerate medications, non-adherence to treatment was predominantly reported as relating to social rather than medical factors. Lack of adequate social support and perceptions of institutional discrimination and social stigma were the predominant reported social barriers to care adherence.

In all, the limited research exploring illness and treatment experiences among homeless persons with TB highlights that the 'route-to-care', and path within care, experienced by this population is highly non-linear. Limited baseline health literacy and access to resources, compounded be pre-existing conditions (e.g. substance use disorders), have emerged as important factors influencing TB illness and treatment experiences among this population. In order to determine the transferability of these findings further qualitative research involving homeless populations in different settings is needed. The current study aims to evaluate this and expand this currently limited but critically important body of research.

CHAPTER 3: Manuscript (prepared for International Journal of Tuberculosis and Lung Disease)

TITLE: Homeless Shelter Context Influences Tuberculosis Disease Experiences During Large Outbreak in Atlanta, Georgia

ABSTRACT

INTRODUCTION: Homeless persons represent a key high-risk population for tuberculosis (TB) among whom TB disease has outsized public health implications. Little is known about how homeless persons experience TB illness and prevention and control measures implemented in response to a TB outbreak. This qualitative study aimed to explore homeless persons' TB disease experiences in the context of a large TB outbreak involving overnight homeless shelters in Atlanta, Georgia. METHODS: In-depth interviews were conducted with a purposive sample of homeless persons with active TB disease residing in Atlanta during the shelter outbreak. Key themes were identified through analysis of coded data. RESULTS: The central theme to emerge from analysis was that stressful social environments of homeless shelters shape illness experiences, healthcare-seeking behaviors, and limit the influence of shelter-based prevention and control measures implemented in response to a TB outbreak. CONCLUSIONS: Homeless shelter related stress may have important implications for the prevention and control of TB outbreaks in this setting, hindering case finding and supporting a model of supplemental TB education and latent tuberculosis infection testing services at proximal community venues. Systematic qualitative assessments in the context of evolving public health responses may provide novel insights that can strengthen TB elimination efforts.

KEY WORDS: Tuberculosis, United States, Homeless Persons, Qualitative Research

RUNNING HEAD: TB illness experiences among homeless persons

INTRODUCTION

Among domestically acquired TB cases in the United States (US), homelessness represents a major risk factor (18). Despite concerted public health efforts, the proportion of total TB cases among homeless persons has not decreased since 2009 – representing 5.5% of all cases in 2015 (3). Although TB among homeless persons represents a minority of overall TB cases in the US annually it has outsized individual and public health implications.

Compared with non-homeless individuals, homeless persons in the US have a 10-fold increased risk of TB disease (6). Those who develop active TB disease are more likely to require hospitalization and have worse disease outcomes (11). Further, TB outbreaks among the homeless population are associated with increased TB transmissions resulting in larger outbreak clusters (12). An important perspective is largely missing from both guidelines and research in this field: that of affected homeless individuals themselves. Understanding this 'emic' perspective of illness can allow for more defensible public health decision-making and is essential to the implementation of appropriate control measures and effective risk communication (41, 42).

Since 2008, a large outbreak of drug resistant TB has been occurring among homeless individuals in Georgia, involving multiple overnight homeless shelters in the metropolitan Atlanta area. This outbreak has resulted in over a hundred cases of active TB disease and been linked to cases in 9 additional states (19). The resultant large-scale multifaceted public health response has involved close collaboration with overnight homeless shelters to develop and implement a host of prevention and control measures (43). The development of these measures was informed by a stakeholder survey and findings from public health efforts to control similar outbreaks elsewhere. However, it remains unclear how these interventions are experienced by homeless individuals at

risk or infected with TB. With the unique opportunity to interview homeless individuals with active TB disease in the setting of an ongoing outbreak and evolving public health responses, the aim of our study was to explore how these individuals experience their illness and shelter-based interventions. The goals of this research were to inform ongoing TB control efforts and contribute hypothesis-generating data for further research on TB elimination in this setting.

METHODS

Context

This study was conducted in Atlanta, Georgia, USA during an ongoing drug-resistant TB outbreak among homeless individuals that began in March 2008 (19). Atlanta is in the ninth largest metropolitan area in the United States, with a population of about 5.7 million and a homeless population point-in-time count of 4317 in 2015 (44, 45). The metropolitan Atlanta area is primarily located in Fulton County where between 2008 and 2015 there averaged 55 cases of TB per year, and 36% of TB cases occurred among homeless individuals (19). A component of the public health response to the ongoing TB outbreak was shelter-based prevention and control interventions implemented across all homeless facilities by the beginning of 2015. These interventions, informed by existing municipal (46, 47) and national recommendations (15), consisted of: TB screening requirements for admission to shelters, active TB case-finding measures (e.g. intake symptom screening, cough logs), increased availability of voluntary latent tuberculosis infection (LTBI) screening, TB education activities (e.g. shelter staff and resident teaching, educational posters), and environmental control measures (43, 48).

Design

This qualitative study used in-depth interviews with a purposive sample of homeless persons with active TB disease. A demographic questionnaire was subsequently administered to all participants,

and a medical record review was performed. Interviews took place between May 2016 and January 2017. The interviews were semi-structured, conducted one-on-one, and lasted between 30-60 minutes. The interview guide (Appendix 1) consisted of questions related to 6 domains with optional probes, including: (i) homelessness history and experience, (ii) homeless shelter context, (iii) health literacy, (iv) healthcare seeking behaviors and experiences, (v) TB illness experience, and (vi) homeless shelter TB outbreak public health response. Questions were grouped chronologically (pre-diagnosis, post-diagnosis and treatment, post treatment) to allow exploration of changes in knowledge, behavior, and experiences over the trajectory of TB illness. Interviews were conducted in English in a private room by a male interviewer (WJC) with public health and qualitative methods training. Following each interview, the interviewer documented his reflections and noted emerging themes, and used this information to revise the interview guide in an iterative manner. All interviews were digitally recorded and transcribed verbatim by a professional service, then reviewed along with recordings to ensure accuracy.

After each interview, participants answered a brief questionnaire (Appendix 2) documenting demographics, TB risk factors, patterns of homelessness over the preceding 2 years, and TB illness history. Each participants' TB clinic medical record was subsequently reviewed to document clinical/microbiological TB diagnoses and epidemiologic/genotypic linkage to the ongoing TB outbreak among homeless individuals.

Recruitment and consent

The majority of homeless individuals with active TB disease in Fulton County receive treatment through the TB Control and Prevention Program of the Fulton County Department of Health and Wellness (FCDHW). FCDHW disease investigation specialists, homeless shelter outreach team members, and TB Clinic staff distributed recruitment flyers to eligible participants. Study eligibility

criteria were: ≥ 18 years of age, clinical diagnosis of active TB disease, homelessness during the year preceding TB diagnosis, and prior contact with city of Atlanta homeless shelters. Homelessness was defined as living in an emergency shelter, transitional housing program, or a place not meant for human habitation, such as a car, abandoned building, or on the streets.

Interested participants called the primary investigator (WJC) on a designated study phone and were provided basic information about the study. Those interested and eligible had interviews arranged at which time study details were reviewed and subsequently informed consent was obtained. At the completion of interviews participants were provided with written copies of study information and an incentive of $15 USD. Recruitment continued until no new themes were found to be emerging from interviews, indicating thematic saturation. Emory University and the Georgia Department of Public Health (Project 160401) determined this study did not constitute human subjects research because it was concerned with a specific outbreak and response, and waived the requirement for institutional review board review.

Thematic analysis

Transcripts were analyzed using the qualitative data management software package MaxQDA (VERBI software, Berlin, Germany). Thematic analysis was conducted to identify patterns in the experiences of participants across interviews. Themes were identified inductively through a structured process of data familiarization, preliminary theme identification, thematic mapping, theme refinement and naming (49). The qualitative codebook was developed and refined through a process of preliminary identification and definition of salient concepts, initial coding in parallel with each interview, discussion among authors about code attributes and dimensions across the body of interviews, refinement of code definitions, and re-coding of all transcripts to ensure consistency with final code definitions.

RESULTS

In addition to homelessness, our sample of 10 participants (9 male, 1 female, all African American and US born) had particularly high-risk profiles for TB with 50% having been previously completed treatment for TB (4 active TB disease, 1 latent TB infection), 50% having HIV, a majority (n=7) reporting substance misuse, and all having history of prior incarceration (Table 1). Of the nine cases that had sputum culture positive disease, genotyping demonstrated that five (56%) had the TB strain associated with the ongoing homeless shelter outbreak (Table 2). The remaining four participants had distinct TB strains, suggesting a degree of TB endemicity among the homeless population in Atlanta beyond the current outbreak.

Interviews identified five pervasive themes regarding the experience of TB among the homeless: (i) health and behavioral impact of the homeless shelter context, (ii) influence of homelessness on disease experience, (iii) role of acute health care services, (iv) experiences with shelter-based interventions implemented in response to the TB outbreak, and (v) sources of TB knowledge and health literacy.

(i) Health and behavioral impact of the homeless shelter context

Participants described homeless shelters as being environments of severe psychological and physical stress, which posed significant health risks. Stress came from the social context of homeless shelters, where violence was described as common. Half of the participants (n = 5) attributed the violent behavior of shelter residents to mental illness and substance use. The stressful social conditions in homeless shelters resulted in an anti-social environment in which residents were guarded about disclosing illness or seeking assistance*; "everybody keep it* [health

status] *quiet. They don't want to* [disclose symptoms or seek help]—*they feel like they'll be discriminated against and stuff like that*" (Participant (P) 7).

The environmental stress of homeless shelters was viewed as overwhelming:

> *"You won't believe your eyes. I hardly believe my eye when I see* [Shelter 3]*. It's like a knife, knife to the heart, trust me. It's not so much the place itself but the type of people you have there. You have to sort of have to mingle with people, that's what I'm trying to say, there are so many people there they be sardines in a can. It's like one of them worse slave boats, out on the ocean. Profound. It is beyond reproach. I'm surprised I dealt with* [Shelter 3] *mentally for a while."* (P1)

> *"In the shelter, you have to watch your back. You have to watch your step 'cause you never know who have a gun in there. 'Cause I done seen a lot of them got killed in there, shot. It's not a place for a suitable human being to be living* […] *I'm telling you, it's not a livable situation. It's unlivable"* (P9)

In additional to a pervasive risk of physical violence, the poor general health of shelter residents was identified as posing a risk to participants' own health through communicable disease. Most (n = 7) directly attributed their recent TB infection to time spent in homeless shelters, specifically noting the physical crowding of 'coughing' individuals. This may reflect TB education received as part of their recent diagnosis and treatment, yet participants clearly viewed homeless shelters as posing significant tuberculosis risk:

> *"I am trying to stay away from the shelters. 'Cause you catch TB quickly in a shelter. Got a lot of sick people there."* (P2)

> *"*[…] *people coughing, yeah, these things, germs, you know* […] *they're coughing, see, and you're in this closed-in area, and the germs spread.* (P6)

The environmental stress and perceived health risk associated with homeless shelters led most participants (n = 8) to express an aversion to using homeless shelters, with two explicitly stating they would rather sleep on the street. Participants highlighted severe weather conditions as the primary reason to return to homeless shelters. Overall homeless shelters were viewed as repressive environments and were equated to poignant references to loss of life and freedom:

> "*I would rather be hung from a tree than to sleep in there* […] *again."* (P6)

> "*I don't want to go back to the shelter. It's worse than jail without the bars"* (P1)

(ii) Influence of homelessness on disease experiences

Across all interviews, reports about the hardships and uncertainties inherent to homelessness were inter-related with disease normalization, symptom minimization and health de-prioritization. Regular exposure to harsh weather conditions and limited access to food were frequently referenced as root causes for recurrent illness and poor general health:

> *"It's hard to take care of yourself the way you need to be taken care of. You need to stay warm, dry, and eat good. You can't do that on the street 'cause you don't know where you might get nothing to eat. One day, you might get something to eat. One day, you might not. One day, you don't get nothing to eat."* (P10)

> "*I had noticed that I was kind of losing weight a little bit, but since I wasn't getting no meals, nothing on a regular basis, I chalked it up to that* […] *the cough, I just chalked that up as just, just a minor virus or something."* (P5)

In the face of these hardships, participants routinely normalized their symptoms and it was only on retrospection that a majority of participants (n = 6) identified the presence of TB symptoms preceding their diagnosis. Rather than limited access to care (discussed further below), participants referenced lack of awareness of being ill as the key reason for not seeking care. The degree of symptom minimization is apparent in that seven participants were severely ill requiring hospital-based care at time of first presentation and diagnosis:

> *"I didn't think I had* [TB] […] *I felt that I probably got wet, and when, when I was drinking and I had this seizure, I thought that I probably just caught a cold and stuff, but I didn't know that I caught TB".* (P4)

> *"I was coughing a little bit. I usually keep a cold all year around* […] *I thought I was just getting old, and I do a lot of walking. I just couldn't walk as far as I used to be able to walk. I started getting short of breath while I were walkin'. I never did think nothing' of it, I just put it on old age"* (P7).

Three of these participants also avoided care because of fears about the health and social implications (i.e. isolation or losing shelter) of a medical diagnosis: *"*[…] *like cancer, people would rather just die of it than to go find out that they have it"* (P5).

> *"A lot of people that they don't know about they have it, and afraid, don't wanna go to the doctor. A lot of people probably afraid to find out other symptoms or stuff they might have."* (P9)

Substance abuse was also common among participants (n= 7) and may have contributed to de-prioritization of health among some individuals:

> *"I really didn't take time because of the drug habit. I didn't take time out to go and take care of myself, 'cause I was too busy trying to chase that crack* [cocaine]*."* (P9).

(iii) Role of acute healthcare services

Prior to TB illness, hospital emergency rooms (ER) represented the primary access point for all forms of medical care among participants. Additional, less frequently reported sites were community clinics (n = 2), church health fairs (n = 2), and a mobile health unit (n = 1). The ER at Grady Memorial Hospital (GMH) represented the single most common site to access care. GMH is Atlanta's public hospital, the largest in the state of Georgia, located in proximity to homeless shelters and providing a significant level of care to low-income, uninsured, and vulnerable populations. All participants reported receiving prior care at GMH and eight participants were diagnosed with TB there. Lack of adequate health insurance was reported by all participants as a barrier to regularly accessing community health services and a determinant for accessing ER services at GMH: "[GMH] *is available, so, you know, you can always go to* [GMH] *Emergency without money, without insurance."* (P5).

During TB illness the majority of participants (n = 7) reported no healthcare contacts prior to being diagnosed. Following TB diagnosis, the role of acute health care services was replaced by community-based health services. Nearly all participants (n = 9) remained in ongoing community-based TB care at the time of interview. Describing current healthcare behaviors, participants reported no longer accessing acute health services and instead those requiring additional non-TB related healthcare services (n =7) had been linked to community services: HIV care (n = 3), medical specialists (n = 3), and primary care (n = 1).

A typical case representing patterns of healthcare engagement and the role of acute healthcare services is provided in Figure 1.

(iv) Experiences with shelter-based interventions implemented in response to the TB outbreak

There was a wide range of responses regarding specific shelter-based interventions implemented in response to the TB outbreak. The implementation of TB screening requirements for admission to shelters – 'TB card' program - appeared to be a particularly impactful intervention. This program required homeless individuals to undergo TB screening every 6-12 months, following which they were provided with a dated clearance card, specifying diagnosis and treatment status, that was required for shelter entry. All participants were aware of, or participated in, this program. Participants with recent shelter contact reported that the TB card program had become more uniform across different shelters and stringently enforced over the 2 years prior to their interview:

> *"You have to have a card. You have to be updated. Cannot be expired. They doing that now. Back a while, back a few years ago, they didn't. You would just go check in. Now you have to* […] *have a card out, before you come in."* (P9)

One participant (P3) was identified as having TB disease through the TB card program, illustrating the effectiveness of this intervention.

Although voluntary TB screening was made available at homeless shelters, participants did not access this. Instead, a majority of participants (n = 9) reported routine access to, and prior testing for, LTBI testing at venues other than homeless shelters. Church- and community- based health fairs and mobile health units were the most commonly reported sites for testing. While prior LTBI testing appeared to be pervasive, the follow-up for interpretation of results was variable. Among participants who were tested and followed-up for results, nearly half (n = 4, 40%) reported unclear messaging from healthcare providers about the management of results. Two were told their results were positive but "mild" or "not full blown" and not requiring treatment or follow-up, and two others were told their results were positive but were not directed to further care. Each of these participants went on to develop active TB within the following year, suggesting earlier LTBI intervention may have been warranted.

(v) Sources of TB knowledge and health literacy

Prior to the current TB diagnosis the majority of participants (n = 7) reported having no or inaccurate knowledge about the cause, symptoms, or risk factors of TB. This held true even for those who previously received treatment for TB (n = 5). Among this later group misconceptions about ongoing risk for TB were common - reported by 4 of 5 - and characterized by statements like,

"[…] *I had in my mind that since I already had it* [TB], *that um, I couldn't get it again"* (P2). Interestingly, health literacy regarding HIV among participants appeared high and several participants (n = 4) highlighted disparities in available information between HIV and TB:

> *"They don't have any at health fairs. They didn't have any pamphlets concerning TB. They have HIV, and stuff like that, but they didn't have awareness of TB at the health fair, the health screenings."* (P5)

Related to this disparity in health information, participants also commonly reported conflation of HIV and TB risk prior to their current diagnosis. An often-stated misconception was that TB could be sexually transmitted.

Primary sources of general health information prior to TB diagnosis were reported as church- and community- based health fairs and medical care providers, although TB specific education from these sources was only reported by a single participant. Only two participants reported receiving or being aware of TB specific health education in the shelter setting although this was implemented in response to the TB outbreak (48). Following TB diagnosis the majority of participants (n = 9) reported accurate knowledge about TB and identified the Department of Public Health and/or current medical providers as primary sources of health information.

DISCUSSION

Tuberculosis among the US homeless population represents a central public health challenge to the elimination of TB (6). Our qualitative study explored the insiders' perspective of TB illness among homeless persons during a large outbreak of drug resistant TB in Atlanta, Georgia. The central

theme to emerge from our analysis was that the social context of homeless shelters - along with hardships of homelessness itself – shapes illness experiences, healthcare-seeking behaviors, and limits the influence of traditional shelter-based prevention and control measures implemented in response to a TB outbreak.

Among our sample, health was deprioritized in relation to more immediate needs such as safety, shelter, and food. In this context, symptoms of TB were routinely normalized and as a result, healthcare services were often not sought until TB disease had progressed to an advanced and debilitating stage. This delay has substantial impact as it increases both individual morbidity and public health implications. One investigation of this TB outbreak (2008-2015) determined that among 110 cases the average estimated infectious period was greater than three months, 85% of cases required hospitalization for diagnosis or management of TB, and there were 10 TB-related deaths (19). Similar themes of health deprioritization and symptom normalization relating to delayed presentation for care were identified in a pair of qualitative studies involving homeless persons, including those with active TB disease, in the United Kingdom (32, 37). While these studies did not specifically explore the influence the of homeless shelter social environment, the consistency of reports about the stressful social conditions of homeless shelters among our sample suggests it plays a formative role in illness experiences and healthcare-seeking behaviors. Further support for our concept of the social context of homeless shelters affecting health behaviors can be found in our sample's experiences – or more often 'non-experiences' - with shelter-based prevention and control measures implemented in response to the TB outbreak.

The shelter-based prevention and control measures implemented in response to the ongoing TB outbreak in Atlanta involved both mandatory and voluntary/passive elements. The mandatory active TB screening for shelter admission – 'TB Card' program – was uniformly experienced by our

sample, however the voluntary/passive measures of LTBI screening, education, and symptom-reporting were either not experienced or under-engaged. While all participants described receiving previous and often repeated LTBI testing prior to their current TB infection, they reported exclusively doing so at venues outside the homeless shelter setting. Similarly, shelter-based TB education was minimally experienced by our sample. The majority of participants reported accessing health education from community-based sources, although TB specific health education was seldom available at these venues.

Church- and community- based health fairs represented key points of contact for both LTBI testing as well as general health education. Although the motivations for these patterns of extra-shelter health behaviors were not explicitly explored, we conceptualize that the social context of homeless shelters was a central factor. Support for this can be found in pervasive reports among our sample about fear of discrimination, social isolation and loss of access to shelter as a result of disclosing illness or seeking health services in the shelter setting. Furthermore, the concept that health behavior patterns of homeless individuals are often motivated by fears of being labeled ill, facing discrimination, and being socially isolated is well described in previous qualitative studies exploring healthcare decision prioritization (38), perceived external barriers to accessing healthcare (35), and attitudes about TB illness (39). This pattern of accessing LTBI testing and health education outside of the shelter setting may also have public health implications in the form of incomplete case finding and delayed care seeking - longer infectious periods - among homeless persons who develop active TB disease because of limited TB specific health literacy.

Regular access and consistent messaging are necessary to maximize the impact of TB-related risk-communication and LTBI testing procedures (50, 51). While general health and HIV related educational resources were reported as regularly accessible at community venues, TB specific

education, even in the context of a local multi-year TB outbreak, was not similarly accessible to our sample. Such reports suggest that outbreak response related shelter-based TB education measures may have been more impactful if expanded or relocated to community venues where general health education was more regularly accessed, such as church- and community- based health fairs. Regarding LTBI testing, although a majority of our sample reported previously being tested at community venues, follow-up and messaging about results appeared to be sub-optimal. As has been identified in other homeless population studies, the need to return for LTBI test results – typically in 72 hours when Tuberculin Skin Testing (TST) is done – was reported as a barrier to both being tested and obtaining results (38, 52). Furthermore, reports of ambiguous messaging – "mild" or "not full blown" – and lack of follow-up treatment arrangements for TST results among those who received LTBI testing (all of whom went on to be diagnosed with active TB disease within a year) suggests a need for more systematic LTBI testing procedures at community venues.

Although our findings suggest targets for current and future TB control efforts, they are peripheral to the central issue: homelessness. Until the root issue of homelessness is addressed, it is unlikely that TB programs will be able to move from TB control to elimination. In order to break the chronic cycle of homelessness and TB, a concurrent collaborative priority of TB prevention and control efforts needs to be housing the homeless. As our study illustrates, through provision of temporary housing during active disease management and by facilitating linkages to community medical care, TB programs can serve as catalysts for longer-term socio-medical stabilization of this population. However to fully realize these health benefits, sustained investments into resources and research targeting the unique needs of this population are urgently needed.

Limitations

There are a number of limitations to our research and conclusions. Social instability and lack of fixed habitation were inherent to our study population and made recruitment particularly challenging. As a result, our sample predominantly consists of homeless individuals who were undergoing TB treatment at the time of participation, given they were more accessible while in temporary housing provided by the Health Department. While this may have minimized recall bias, recent diagnosis and engagement in care at the time of interviews may mean that the high levels of current TB specific health knowledge among our sample are simply conditional and temporary. As well, the predominance of recently diagnosed participants may limit the transferability of themes identified from this sample to homeless individuals no longer in care or affected by TB in early phases of the Atlanta outbreak. However, it is worth noting that most predominant demographic and clinical characteristics of our sample (age, gender, ethnicity, nationality, HIV status, substance use, incarceration history, and hospitalization rate) were similar to those of homeless individuals diagnosed with TB during the current outbreak between 2008 and 2015 (19). Additionally, our sample's near universal denial of barriers to accessing care is in stark contrast to findings of multiple prior studies evaluating healthcare seeking behaviors of homeless persons (32, 34, 36, 37), suggesting further limits to transferability of our findings. We postulate that this largely reflects the unique healthcare service environment created by GMH (elaborated on in Results section).

CONCLUSIONS

Our study is among the first to specifically analyze TB disease experiences among homeless persons and is unique in that the assessment was done in the context of a large ongoing TB outbreak. Homeless persons with active TB disease face many stressors in their lives and among our sample most prominent was the highly stressful social context of homeless shelters. Homeless shelter related stress may have important implications for the prevention and control of TB outbreaks in

this setting, hindering case finding and supporting a model of supplemental TB education and LTBI testing services at proximal community venues. Systematic qualitative assessments in the context of evolving public health responses, such as the work presented here, have the potential to provide novel insights that can strengthen public health decision-making and as such represent an important complimentary research tool in the fight to end TB (42, 53).

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Table 1: Participant demographics and route to TB diagnosis

Participant (P) - age (yrs), gender, ethnicity	**Type of Habitation*** (prior 2 years)	**Education**	**Path to TB Diagnosis**	**Location of Diagnosis**
P1 – 58 M, AA	Shelters	Post secondary	Sought care while acutely ill	ED
P2 – 60 M, AA	Shelters	< GED	Sought care while acutely ill	ED
P3 – 57 M, AA	NFA (primary), family residence	< GED	Identified via shelter 'TB Card'** program	DPH
P4 – 62 M, AA	NFA (primary), subsidized housing, family residence	GED	Sought care while acutely ill	ED
P5 – 60 M, AA	Shelters (primary), NFA	Post secondary	Sought care while acutely ill	ED
P6 – 64 M, AA	Shelters	GED	Diagnosed when presenting for unrelated care	ED
P7 – 64 M, AA	Shelters (primary), friends residence	Post secondary	Referred to ED by shelter staff	ED
P8 – 56 M, AA	NFA (primary), shelters	GED	Sought care while acutely ill	DPH
P9 – 50 M, AA	Jail (primary), shelters	< GED	Sought care while acutely ill	ED
P10 – 34 F, AA	NFA (primary), jail	< GED	Sent to hospital by family	ED

AA, African American; DPH, Department of Public Health; ED, Emergency Department; F, female; M, male; GED, Graduation Equivalency Degree (high school or substitute diploma); NFA, no fixed abode/sleeping on streets

* Habitation defined as place where one stayed overnight with 'primary' being majority of nights when more than one site of habitation reported

**'TB card' program; shelter-based administrative controls requiring regular TB screening for shelter entry

Table 2: Participant tuberculosis profile and diagnostics

Participant	Additional TB Risk Factors				Reported TB History	TB Diagnosis (current)	TB Genotype * (outbreak linkage)
	HIV	Incarceration	Substance use	Chronic disease			
P1	N	N	N	None	"Positive" TST in shelter (not linked to care) = 3 months prior to TB	Pulm. TB, clinical diagnosis	No isolate
P2	N	N	N	DM	Prior TB = 9 months treatment, 2007	Pulm. TB, smear positive	Outbreak strain
P3	N	Y	Poly	CLD, COPD	"Mild" TST result in community (no treatment) = within year prior to TB	Pulm. TB, smear positive, cavitary disease	Non-outbreak strain
P4	Y	Y	Poly, alcohol	None	None	Pulm. TB, smear positive	Non-outbreak strain
P5	N	Y	Poly	COPD	Prior TB = 9 months treatment, 1997	Pulm. TB, reactiv-ation, smear negative	Non-outbreak strain
P6	N	Y	N	COPD, DM	Prior TB = 6 months, 1960's	Pulm. TB, smear positive	Outbreak strain
P7	Y	Y	Poly, IDU	CLD	Prior TB = 1 year treatment, 1991	Pulm. TB, smear negative	Outbreak strain
P8	Y	Y	Poly, alcohol	None	"Not full blown" TST result in community (no treatment) = within year prior to TB	Pulm. & GU TB, smear negative, cavitary disease	Non-outbreak strain
P9	Y	Y	Poly, alcohol	None	Prior LTBI = 6 months treatment, 1996	Pulm. TB, smear negative	Outbreak strain
P10	Y	Y	Alcohol	None	"Positive" TST in jail (not linked to care) = 7 months prior to illness	Pulm. TB, smear positive	Outbreak strain

Y, yes; N, no; P, participant; TB, tuberculosis; Poly, poly-substance uses which may include non-injection cocaine, opiates, and/or marijuana; IDU, injection drug use; DM, diabetes mellitus; COPD, chronic obstructive pulmonary disease; CLD, chronic liver disease; LTBI, latent tuberculosis infection; Pulm, pulmonary; GU, genito-urinary;
*Genotype determined on basis of spoligotyping and 24-locus mycobacterial interspersed repetitive unit variable number tandem repeat typing (MIRU-VNTR)

Figure 1: Typical case representing patterns of healthcare engagement

Participant 9 was born in rural Georgia and moved to Atlanta as a young adult. Around age 30, while in prison, he had been diagnosed with HIV and completed treatment for latent TB infection. Over the following decades he was in and out of prison several times. Impeded by having a criminal record, after his most recent release from prison he was unable to secure a job. He began living on the street where he started using crack cocaine. He stayed in homeless shelters only sporadically when weather was harsh, otherwise avoiding them because of their 'violent' and 'unlivable' conditions. Without health insurance and unable to arrange or attend community medical care, he only took HIV medications until they ran out following each release from prison. As a result of his addiction he did not take care of his health and only sought emergency room care when severely ill. He had been progressively unwell for nearly a month before paramedics found him incapacitated on the street and brought him to Grady Memorial Hospital ER where he was diagnosed with active TB disease at age 50. Given overall poor health and advanced TB disease, he required hospitalization for treatment. After several weeks he was transitioned to community TB treatment and provided temporary housing and social support that allowed him to link to community HIV care. Although he found his year of TB treatment to be isolating and 'very hard', he is now cured of his TB, continues with regular HIV follow-up, and resides in subsidized housing.

CHAPTER 4: Recommendations

The research outlined herein sought to characterize the diverse challenges faced by a group of homeless individuals with active TB disease identified during a large outbreak involving homeless shelters in Atlanta, Georgia. Observations and hypotheses generated through this research support the following interrelated immediate and longer-term action, research, and policy recommendations. As some of these measures may already be in place or development, these recommendations should serve as re-enforcement of their importance.

1. **Understand and improve homeless shelter social environments**: The highly stressful social environment of homeless shelters and it impact on health behaviors emerged as the central theme from our analysis. While participants' reports provided anecdotal descriptions of the sources of stress in this environment, a more detailed and comprehensive understanding of this issue is required. Through collaboration with the numerous existing stakeholders -- individual shelter staff, administrators, and residents, the Metro Atlanta Task Force for the Homeless, and the Atlanta Homeless Continuum-of-Care, to name a few – and building on existing research in this field, we propose that ongoing efforts to characterize, quantify and address this issue be prioritized. Such efforts would not only facilitate TB control and prevention efforts but also more broadly promote health at the individual, institutional, and community levels. Rather than a condemnation of current homeless shelter practices, this recommendation should be viewed as an acknowledgement of the essential services they provide, the complex challenges they face, and a need for greater ongoing support.

2. **Enhance collaboration and coordination with community-based organizations**: Community-based organizations (CBO) were common sources of health information and LTBI testing for participants in our study. Enhancing collaboration with these organizations has the

potential to amplify TB prevention and control efforts. Given the importance of regular access and consistent messaging to maximizing the impact of TB related health services, ongoing efforts to ensure standardization and coordination between CBOs should be prioritized. Related to LTBI testing, increasing utilization of tests that do not require delayed follow-up for interpretation - such as Interferon Gamma Release Assays - and strengthening treatment referral pathways for individuals who test positive, represent potential priority initiatives. Related to TB education, our observation that HIV-related risk communication appeared to have greater uptake relative to TB-related risk communication suggests that coordination and idea sharing between these education campaigns may be valuable. The use of innovative spatial methods, such as activity space analysis (54), to determine areas where homeless persons affected by TB are most concentrated could facilitate the identification and prioritization of CBOs for collaboration.

3. **Intensify linkage to medical and social services during TB treatment:** Active TB disease treatment among homeless persons is extended and intensive, typically entailing six or more months of daily-observed therapy and often the provision of temporary housing throughout. Among our sample the treatment phase of their TB illness represented a period of relative stability compared to their pre-illness and pre-diagnosis conditions. While centered on TB treatment, this period of regular medical evaluation also serves to address overall health and when needed linkage to additional specialty services such as HIV care – as occurred for half of our sample. Maximizing linkage to not only medical but also social services during this period is essential to ensure TB cure and optimal health outcomes as well as to minimize the risk of TB reoccurrence. The fact that half of our sample previously received treatment for TB suggests that past linkage to medical and social services during TB treatment may have been sub-optimal. High rates of HIV, substance use, and prior incarceration among our sample, and more broadly homeless individuals who have contracted TB during the current Atlanta

outbreak (19) and previous US outbreaks (6), suggests that these may be particularly important issues for which intensified linkage to support services during TB treatment may be high yield.

4. **Integrate qualitative assessment into TB outbreak response:** Qualitative research is often overlooked in public health decision-making. However, qualitative analysis can provide rich experiential data from an insiders' perspective that may not be captured in quantitative studies. Incorporating qualitative assessment into an evolving public health response, such as a TB outbreak response, can expand the epidemiological and biomedical understanding of the issue, reorient health program priorities as the response evolves, and inform the development of effective public health interventions and models of evaluation (42). We recommend that qualitative approaches be incorporated into ongoing and future TB outbreak investigations to compliment traditional quantitative evaluations. Well-structured rapid qualitative assessment is recognized as a key component in acute public health event management and should be become routine in TB outbreak responses (41).

5. **House the homeless:** Tuberculosis among homeless populations is simply an epiphenomenon to the homeless condition itself. Without addressing the underlying issue of homelessness it is unlikely that TB programs will ever be able to move from TB control to elimination. In order to reduce the persistently elevated TB incidence rate among the US homeless population, the much larger societal challenge of housing those who are homeless needs to be a concurrent priority of TB prevention and control efforts. While many challenges exist in addressing the diverse biopsychosocial needs of homeless individuals, addressing the most basic human need for safe and secure shelter is of primary importance. 'Housing First' programs, providing rapid re-housing and permanent supportive housing tailored to individuals' needs, show promise as effective, sustainable, and cost-effective models for reducing homelessness (55-57). To this end,

we recommend that individuals and public health agencies involved homeless population TB prevention and control efforts use their voices to advocate for increased support of Housing First models and collaborate with existing housing service providers to improve current housing programs.

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APPENDIX 1: Interview Guide

Fulton County Homeless Shelter Tuberculosis Patient Experience Study - Interview Guide

Script:

Introduction

Thank you for talking to me today. We are conducting these interviews to better understand the experience of homeless people who get TB. My name is William and I am doing this as part of University work with Emory University. Our goal is to improve TB care for the homeless in Atlanta. Everything that you share with me today will be confidential; it will not be shared with anybody outside of my research team. I will be asking you questions about your health, where you have lived, TB infection, and the treatment you received. I will need to record this interview, but all information that could identify you in the recording will be kept private. Are you ok with this?

[Obtain informed written consent]

Opening questions

1. *To begin, tell me about yourself.*

Probes: *Where did you grow up? What work have you done? How long have you been in Atlanta?*

2. *Tell me about your experience living in homeless shelters.*

Probes: *What led you to first stay in a homeless shelter? Looking back over 2 years, in what types of places have you been living? [Probe specific types of accommodation/timing (see table) as needed]*

Location	2 years ago	1year ago	6month ago	Current
Shelter				
No fixed address (Street)				
Independent accomod.				
Shared accomod.				
Family residence				
Other (specify)				

NOTES: Mark all that apply at each time period: majority of time (1), occasionally (2). Atlanta (ATL) & outside of Atlanta (non-ATL) for each

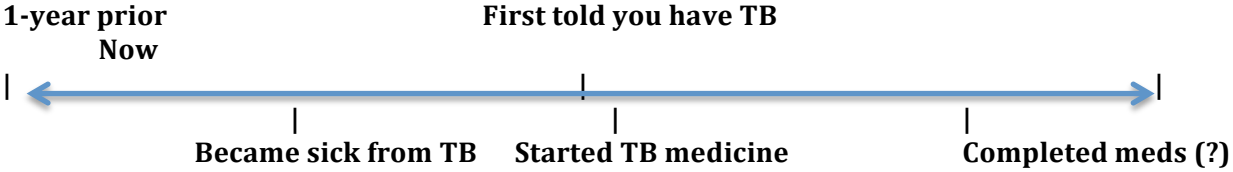
Context of TB diagnosis

I would now like to learn about when you were first told you had TB and about if or how you were sick before this.

Probe: [if difficulty reporting initial timeline] *I see you were told you had TB* **XX-XX-XXXX** (date obtained from TB Clinic records and will be related to interviewee along with temporally associated

significant event in Atlanta - major weather events, significant local happenings etc. – so as to aid memory)

[Visual Timeline Tool (example below, full page visual will be used) used to show key time points from chart and temporally related significant events. Will be used to frame timeline of discussion for subsequent questions]



1. *Tell me about when and where you were told you had TB.*
   [**Domains:** Disease experience, importance of symptoms]
   Probes: *Where were you? (hospital?) How were you feeling? How long had you been sick? How were you told you had TB? Who told you?*

2. *Tell me about when you first became sick with TB, if at all.*
   [**Domains:** Disease experience, importance of symptoms]
   Probes: *Where were you? What were you feeling? How did you know you were sick? How did your sickness change how you lived?*

3. What types of difficulties did you face, if any, in getting the health care needed to tell you that you had TB?
   [**Domains:** Availability/accessibility of healthcare]
   Probes: *Were there people you could go to for health problems? Could you get to appointments? How did communication (telephone, mail, etc.), transportation, and/or money influence this?*

<u>Context prior to TB illness</u>
I would now like to learn about the time before you became sick with TB. [Will refer back to visual timeline tool to facilitate as needed]

4. *Tell me about your health before getting TB.*
   [**Domains:** health literacy, healthcare experience/familiarity]
   Probes: *What experiences did you have with doctors, clinics, or hospitals previously? Did your health limit what you were able to do?*

5. *What did you know about TB before you had it?*
   [**Domains:** TB specific knowledge, education, myths/misconceptions]
   Probes: *Had you heard about TB? Did you know anyone who had TB before? Did you know how TB could spread? Did you know who was at risk for TB? Did you know the symptoms of TB?*

6. *Had you previously been tested for TB?* [if needed, will explain that this can be in form of blood (IGRA) or skin test] *If so where and why?*
   Probes: *Was this because you thought you might have TB? Were you in contact with someone who had TB? Rules at your shelter or for work?*

7. *Before getting TB, how important was your health compared to other things going on in your life?* [**Domains:** health value/need]

8. *Before getting TB, why would you go see a doctor?*
   [**Domains:** Healthcare needs, goals of healthcare access, health values/needs, prior specific linkage with care]
   Probe: *What was the last reason you saw someone about your health?*

9. *Before getting TB, where did you get help with your health?*
   [**Domains:** Health care access, TB care seeking context, barriers to healthcare, past experience]
   Probe: *Who could assist you to find help? What made getting help easier or more difficult (cost? Location? Transport? How you were treated before?)*
10. *Before getting TB, what was the main way you learned about health?*
    [**Domains:** Sources of health information, health knowledge]
    Probes: *TV, health magazines, friends, primary care doctor, parents, internet, Facebook/Twitter, etc.?*

11. *Before you were told you had TB, what information or activities around TB did you see at your shelter?*
    [**Domains:** Shelter-based education, screening/testing, TB assessment requirements]
    Probe*: Tell me about when and how information or activities were introduced?*

Have you had/faced any barriers to accessing healthcare? Difficulty getting the care you need?

<u>Context post TB diagnosis:</u>
I will now move to asking questions about the time after you were told you had TB. Some of the questions will be similar as I would like to learn how what you know and do has changed because of the TB.

12. *What can you tell me about TB now? What do you know about it?*
    [**Domains:** TB specific knowledge, education, myths/misconceptions]
    Probes: *How does it spread? Who is at risk? What are the symptoms?*

13. *Since getting TB, how important is your health compared to other things going on in your life?*
    [**Domains:** health value/need]

14. *Since getting TB, where do you get help with your health? How has this changed since before your TB diagnosis?*
    [**Domains**: Health care access, context of TB care seeking, barriers to healthcare, past experience]
    Probe: *Who can assist you to find help? What makes getting help more difficult (Cost? Location? Transport? How you were treated before?)*

15. *Since your TB diagnosis, have you had more tests for TB?* [if needed, will explain that this can be in form of chest x-ray, blood (IGRA) or skin (TST) test] *If so where and why?*
    Probes: *Was this because there was concern you were sick with TB again? In contact with some one who had TB? Rules at your shelter of for work?*

16. *Since getting TB, what is the main way you learn about health? How has this changed since before your TB diagnosis?*
[**Domains:** Sources of health information, health knowledge]
Probes: *TV, health magazines, friends, primary care doctor, parents, internet, Facebook/Twitter, etc.?*

17. *What did you think of people who had TB before you were told you had TB?*
[**Domains:** Stigma, myths/misconceptions]
Probes: *Had you known other people with TB? If so, how did you and others treat them?*

18. *What do you now think about people who have TB? What do people around you now think about people who have/had TB? Have you been treated differently since you got TB?*
[**Domains:** Stigma, social consequences, myths/misconceptions]
Probes: *Do you know other people in your shelter with TB? If so, how are they treated by others? Are you afraid to tell others about your TB?*

19. *Since having TB, what TB related information and activities are around you at your shelter?*
[**Domains:** Shelter-based education, screening/testing, TB assessment requirements]
Probe*: Are shelter staff talking about TB? Tell me about when and how this information or activities were introduced?*

Leading up to you diagnosis how did your financial situation influence you health? Timing of TB Dx

Since TB diagnosis how has TB treatment been influenced by your financial situation ? How has it influenced you financial situation?

<u>Closing Questions</u>

20. *Where are you in your TB treatment now?*
Probe*: Tell me about how you did with treatment?*

21. *What do you wish other people knew about what it's like to have TB when you are homeless?*
Probe: *What would you tell other homeless people? What would you tell shelter staff? Doctors? Nurses?*

22. *Is there anything that would have made this experience easier for you?*
Probe: *When you were you were first diagnosed? When you were in treatment?*

23. *Is there anything else you would like me to know about your experience?*

This is the end of the interview.

APPENDIX 2: Post-interview Questionnaire

Fulton County Homeless Shelter Tuberculosis Patient Experience Study – Questionnaire

Demographics:

Age (DOB):

Place of birth: □ US, □ Non-US, location_____

Race/Ethnicity: □ Black non-Hispanic, □ Hispanic, □ White non-Hispanic, □ Asian/Pacific Isl., □ Other

Education (highest level): □ <GED, □ Highschool (GED), □ Post secondary

Medical (all that apply): □ Smoker, □ DM, □ Chronic Lung Dz, □ Kidney Dz, □ Liver Dz, □ HIV
Substance use: □ PWUD (current; polysubs, cocaine, MMT, heroin), □ PWID (ever), □ ETOH (abuse Hx)
Incarceration/prison: □ yes

Tuberculosis History

How long were you sick with TB before being diagnosed? (weeks)

How many healthcare providers did you see before being diagnosed with TB?

Where were you diagnosed? □ Hospital, □ Clinic, □ Other_____

How did you get referred to the hospital or the clinic where your TB was diagnosed?

a. I was really sick and knew I could get care at the clinic/hospital.
b. A friend or family member encouraged me to come (or brought me) to the clinic/hospital.
c. A staff person at a homeless shelter or service organization told me to go to the hospital or health department. Please name facility _____
d. I was told by someone at a local health department clinic to come to the hospital.
e. Other (please describe)_____

Did your living situation change after being diagnosed? If so how: