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Health, well-being, and urban refugees and asylum seekers: an agenda paper

Kelly Ann Yotebieng ±

Abstract

Health and well-being have been historically uncommon areas of focus in studies of forced migration within the social sciences, where the focus has more often been focused broadly on identity, liminality, and social suffering. Urban refugees have also been largely excluded from the narrative. Yet, urban refugees represent the majority of the world's refugees, which means we are effectively excluding the majority of the refugee experience from our research. Health is often a central marker of inequality and marginalization. Understanding the entanglement of forced migration to urban areas and health bears enormous potential for policy and practice. This paper will outline what we know, and set an agenda for the study of urban refugee health.

Keywords: urban refugee; health; slum; legal precarity; biolegitimacy.

Introduction

In 1948, the World Health Organization (WHO) defined health as "a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity." Well-being, however, is a trickier concept to grasp. Fischer (2012: 9) argues that "to understand the good life we have to take seriously not only material conditions but people's desires, aspirations, and imagination." However, many studies of well-being have had a heavy materialist focus, and less have been associated with health (Fischer, 2012). While not undermining the important links between happiness, well-being, and income, studies that rely disproportionately on economics miss many other important components of well-being that are also inextricably linked with health. In line with Fischer's (2012) concept of well-being, I argue that we cannot study or understand health without delving into some of the more complex, subjective, and emotional components of well-being, notably: "aspiration and agency, opportunity structures, dignity and fairness, and commitments to meaningful projects" (Fischer 2012: 2).

In this manuscript, I argue and lay out an agenda for a concerted focus on health and well-being among refugees and asylum seekers residing in urban areas of the developing world. While there is certainly some overlap and applicability to other immigrant groups, particularly internally displaced persons (IDPs), in this manuscript I define refugees using the United Nations 1951 Geneva convention definition of a person who has had to flee their country because of "a well-founded

± Kelly A. Yotebieng, Department of Anthropology, The Ohio State University, 4046 Smith Laboratory, 174 W. 18th Avenue, Columbus OH 43210, United States. E-mail: Yotebieng.3@osu.edu.

fear of persecution for reasons of race, religion, nationality, political opinion or membership in a particular social group." In this manuscript, I consider asylum seekers to be persons who meet the criteria for a refugee who are applying to become a refugee in their host country, even if their status has been rejected or revoked under a Cessation Clause or other mechanism (Yotebieng, 2017).

A focus on health allows us to shift our focus away from more pathogenic approaches where specific ailments are studied at the expense of leaving out the larger picture (Chaudry, 2008). Anthropological perspectives can allow us to better understand "what matters most" to populations, what are the most important components of their well-being, and how do these link with their overall health (Kleinman, 2006: 231). Anthropological research demonstrates with strong consensus that health is not to be overlooked among refugees for a variety of reasons, including differential access to services and inequalities in their host countries, but also, the pervasive effects that conflict and structural violence have on health (Clinton-Davis & Fassil, 1992). The United Nations High Commissioner for Refugees (UNHCR) and other service providers have yet to define and agree upon acceptable models to support urban refugees and have called for additional research and development of appropriate guidelines (UNHCR, 2009; UNHCR, 2014).

Much of the research on forced migration has been focused on the minority of refugees, those who have been resettled in developed countries or are living refugee camps, while we are unsure of the numbers and situations of those living in urban areas of developing countries (Kihato & Landau, 2016). For this reason, much of the available research cited in this agenda paper is garnered from studies outside of urban areas, but I argue that it is imperative that we shift our focus and coalesce this research with that of a bourgeoning area of research studying health in slums and informal settlements of developing countries. Urban refugees in developing countries constitute over 60% of the world's refugees, so the focus on resettled and camp-based refugees represents a significant blind spot in our understanding of health issues over the full range of refugee situations (Agier, 2011; Landau, 2014). This paper underlines the need to focus on the reciprocal relationship between migration, health, and well-being with a particular emphasis on forced migration to urban areas.

Migration and health

While this appears to be changing, a health lens has been historically uncommon in studies of forced migration, where the focus has more often been on identity, liminality, and social suffering (Ager, 2014; Agier, 2011; Castañeda, 2010; Malkki, 1995; Sommers, 2001). Yet, as Ager (2014) astutely argues, health is often a central marker of inequality, marginalization, and suffering that can be explored within the causes of forced migration, situations of displacement, and resettlement.

A recent editorial published in the Lancet (2015) served as an urgent call for pragmatic action to understand and respond to health issues in an era of increased global migration. This is especially important because conflict often undermines the abilities of populations to continue to care for their health and cope with other shocks including changing environmental conditions. The editorial rightly acknowledged however that refugees are not a homogenous group, and that there is a need for more research on the different health issues, ranging from child and maternal health to increasingly prevalent chronic diseases facing refugees (Lancet, 2015). The double-burden of infectious and chronic disease is well documented in urban areas of the developing world, and refugees are often at exacerbated risk with strained access to healthcare (IOM, 2015).

Forced migration can provide new opportunities, such as safety or economic opportunities, for individuals. However, forced migration can equally result in a deterioration of social structures that previously provided a source of support and social and cultural capital (Bourdieu, 1977; Locke et al., 2000). When studying forced migration, research is often divided into relatively simplified phases of pre-migration, or conditions in the place refugees are coming from, flight or migration, and post-migration, or conditions in the place where refugees find themselves after fleeing (Crowley, 2009). While these are certainly not mutually exclusive, nor do they adequately capture the full range of refugee experiences, they can be useful when conceptualizing forced migration and health in terms of the potential issues at the different points of the refugee experience. Pre-migration conditions may include persecution or already degraded health infrastructure, as well as direct experience with conflict or forcible recruitment into armed groups (Crowley, 2009). During flight or migration families may be separated from each other, witness or be victims of acts of violence, or experience hunger or lack of access to medical care (Crowley, 2009).

Post-migration is often met with a new set of challenges, including disappointment at the political, bureaucratic, linguistic, cultural, or other obstacles faced in a new land, unemployment, separation from family members, access to healthcare, and the loss of social networks or status in a new place (Crowley, 2009; Miller & Rasco, 2004). Often times in the migration literature, post-migration factors focus on the small percentage of refugees resettled in developing countries, but I suggest this needs to be extended to the protracted situations of most of the worlds' refugees who are living in urban areas in developing countries. Protracted displacement in urban areas can result in a multitude of health repercussions that has not been given adequate attention.

It is well documented that most refugees and individuals in their social networks have experienced multiple traumatic events on their journeys (Carswell et al., 2011; Mollica, 2006). Keller et al. (2006) estimate that up to 35% of refugees have experienced torture or some form of extreme human rights abuse in addition to direct or indirect exposure to conflict. This has serious psychological consequences

(Keller et al., 2006). Furthermore, the massive amount of forced displacement we are witnessing in the world not only has negative health repercussions on those forcibly displaced, but also bear implications for their host communities and those who they leave behind (Clinton-Davis & Fassil, 1992; Satya, 2010).

Urban health and refugees

Chronic disease

Chronic diseases are now responsible for 61% of deaths and 46% of disease in the low and middle-income countries that the majority of refugees come from (Yun et al., 2012). Behavioral health, hypertension, and obesity are the most common diagnoses where data does exist (Yun et al., 2012). Amara and Alunid (2014) suggest that growing urbanization across the world influences the probability that refugees would have lived in or migrated to cities, a known risk factor for developing a variety of chronic and non-communicable diseases. Their literature review revealed few studies focusing on chronic and non-communicable disease among urban refugees, but where they existed, findings of high prevalence among urban refugees, with notably high prevalence of hypertension, musculoskeletal disease, diabetes, and respiratory diseases (Amara & Aljunid, 2014). Keboa et al. (2016) also found high rates of oral health issues with little access to care which can cause increase infections or higher risk for other chronic disease including diabetes and cardiovascular disease among refugees through a thorough literature search.

Much chronic illness goes untreated for periods of time because of lack of access to healthcare, or poor diagnostics (Amara & Aljunid, 2014). Both diagnostics and the long-term, continued care needed to adequately care for chronic disease are an expensive luxury to many, and the interruption of often already crumbling healthcare infrastructure or moving to new places can lead to periods where diseases are left untreated. In line with Kleinman's explanatory models, Schenker et al. (2014: 9) argue that it is important for anthropologists to conduct "careful etiologic studies, ideally involving the populations in both countries of origin and those receiving" when studying non-communicable diseases among immigrants and refugees in order to better understand the reactions between exposures to different environmental factors, diet, medicine, and behaviors in the host and origin countries and how these may influence the disease's progression.

Slums and informal settlements

An important environmental factor to not overlook in research and programming with urban refugees is that many refugees in urban areas of developing countries live in informal settlements or slums. There have been increased calls to look at health in the shared physical and social environments of slums rather than just the links between health and poverty (Davis, 2006; Elsey et al., 2016; Ezeh et al., 2016; Lilford et al., 2016; Subbaraman et al., 2014; UN Habitat, 2003). The research on health in slums is sparse, but could shed some light onto potential overlap with

refugee health for those living in these areas. Exemplifying the dearth of health issues that may be faced in slums, in a small survey in Kathmandu's slums, Elsey et al. (2016) found that 7% of household members experienced a major health problem in the year preceding the survey. They found that the main drivers of illness were gastrointestinal diseases and respiratory disease often associated with hygiene and sanitation, as well as accidents and injuries (Elsey et al., 2016). Ezeh et al. (2016), in a special issue of the Lancet calling for an increased focus on slums in health research, drew lines to the complicated and intersecting risk factors associated with slum-life including environmental contamination (fecal and industrial), overcrowding, stagnant water, physical hazards, home quality, and both indoor and outdoor air pollution. These are combined with the structural violence associated with high levels of violence, poor access to jobs, and discrimination and stigma (Ezeh et al., 2016). While there are many syndemic conditions which drive health issues in slums, issues such as mental health and chronic disease are arguably under-represented in the research, but highly associated with slum living conditions (Elsey et al., 2016; Ezeh et al., 2016; Singer, 2013; Willen et al., 2017).

Legal precarity

Among urban refugees, all of these issues are complicated by legal precarity hanging over their heads, as they may be afraid to access healthcare for chronic health conditions or HIV, with the fear that this may somehow interfere with their asylum applications (Castañeda, 2009; Clinton-Davis & Fassil, 1992). While most research on pending or rejected asylum applications focuses on individuals living in developing countries, this is also an increasingly important issue in the developing world (Church World Services, 2013; Kuch, 2016; Yotebieng, 2017). On the other side of the spectrum, anthropologist Didier Fassin (2009) argues that these chronic or more severe health conditions may be the factor that leads to the "biolegitimization" of their right to be a refugee, and over-emphasized in a way that a person becomes equated to their illness as a condition which allows their access to their new society while simultaneously serving to further marginalize them.

Legal precarity is also often associated with strained access to healthcare. Access to healthcare as a major challenge in refugee healthcare across settings has garnered increasing attention in research and practice (Ager, 2014; Castañeda, 2009; Spiegel & UNHCR, 2010). Willen (2012: 813) argues, for example, that refugees and asylum seekers, especially those with irregular status, "around the globe face categorical exclusion both from prevailing social contracts and from the health care systems accessible to citizens and authorized residents." In creating these ideas of biolegitimacy, often rooted in xenophobia, a rhetoric is propagated that somehow refugees are undeserving, and often the root cause of society's social and physical ills (Fassin, 2009; Willen, 2012). In urban areas of developing countries, this is further emphasized by the fact that much of the host community

is also struggling to get by, therefore leading them to question why refugees cannot just suffer the same existence (Landau, 2014). The United Nations High Commissioner for Refugees (UNHCR) has acknowledged that this is increasingly important as the majority of the world's refugees now reside in non-camp settings, were it is anecdotally understood that access to healthcare is an issue, but the qualitative data on what the barriers are and what are the potential solutions to overcome them remains vague (Spiegel & UNHCR, 2010).

Cultural models and etiologies of health and illness

Central to anthropological studies of health is an emphasis on the importance of understanding etiologies of disease and multiple explanations behind the causes, symptoms, and possible treatment routes (Kirmayer, 2003; Kleinman et al., 1978; Kleinman 1980; Kleinman 2006). Related to etiologies, suffering is often seen as the root cause of mental illness, when it becomes embodied experience (Coker, 2004, El-Shaarawi, 2015). In exploring how discrimination negatively affects health, Krieger (1999) relies on the notion of "embodiment" which aims to understand how social experiences are incorporated biologically into the human experience, creating differential patterns of health and disease. Clear examples of the embodiment of social inequalities faced by refugees include societal arrangements that constrain access to resources and/or force someone to work in strenuous labor conditions, or how some individuals may be forced to live in different, less safe or healthy, ecological contexts because of their social positions where they are more susceptible to pathogens over their lives (Coker, 2004; El-Shaarawi, 2015; Krieger, 1999).

Social Determinants of Health

Anthropologists and other social scientists recognize the various social, political, and economic causes that lie at the root of the refugee experience, arguing that it is hardly possible to examine refugee health through a singularly biomedical lens (Coker, 2004; Foucault, 1975; Link & Phelan, 2002). Link and Phelan (2002) demonstrate that people's vulnerability and exposure to a broad range of negative social circumstances is often directly linked with their socioeconomic capital. While these factors are not always included in models that aim to understand health, they have enormous impacts on population health (Link & Phelan, 2002). In other words, we cannot understand health or illness without also understanding the social conditions that cause disease (Link & Phelan, 2002).

Castañeda (2010) and Arévalo et al. (2015) suggest that over-emphasizing cultural explanations and leaving out the underlying structural explanations that are at the root of inequalities that create many of the health issues we observe in refugee populations, is a fallacy. Instead, Castañeda et al. (2015) argue that we should emphasize structures and use a social determinants of health approach to examine the various structural factors driven by social and economic inequality. Critiquing public health models that tend to individualize behaviors that are largely influenced

by their broader contexts, when studying health among refugees, we need to be mindful that migration completely changes these structures, and often with health repercussions that have been duly noted in the literature (Castañeda et al., 2015). At the root of many social determinants of refugee health is structural vulnerability. Walbert's (2014) research with urban refugees in Cameroon suggested that health programs aimed at refugees were mainly focused on treating the health problem, but not the underlying issues that may be causing or exacerbating these health problems, including supporting education access for children so that a vicious cycle of structural violence is not perpetuated.

Setting an agenda

As demonstrated above, health and well-being among urban refugees is an overlooked area of research which creates a significant blind-spot in refugee studies. I argue that social scientists need to coalesce around the interconnected and multidimensional nature of health, well-being, and urbanization among refugees if we are to advance the field of refugee studies. Furthermore, this will allow social science to provide meaningful research to guide interventions as the humanitarian community continues to struggle with ways to develop programs to support urban refugees in a global environment of increasingly tight resources and growing needs (Acevedo-Garcia, 2012; Spiegel & UNHCR, 2010). Panter-Brick (2010) eloquently argues that while conflict and violence have been clearly demonstrated to be detrimental to health, we need to better understand the different physical, social, and emotional consequences of violence, including the impacts of some of the more nuanced structural and symbolic violence that refugees and forced migrants are exposed to on their journeys. Below I outline key areas that I suggest need to be better explored in studies of health and well-being of urban refugees, as well as our obligations to share our research with the humanitarian community.

First, going back to the earliest points of this paper related to well-being, I argue that rather than creating universal rubrics to measure well-being, we need to step back and understand urban refugees' varied aspirations for the future. This includes how they define well-being in their lives, and what their desired futures look like. This approach often stands in stark contrast to the way that humanitarian programs are designed and implemented, according to rigid standards for well-being that are not necessarily shared or prioritized the same way, and focused on meeting basic needs and the present. While the humanitarian paradigm is traditionally designed for acute emergency situations, increasing numbers of the worlds' refugee situations are long-term and protracted. Hence, the humanitarian community needs to adjust their approach towards understanding and taking seriously imagined and desired futures of refugees, and how they can be supported (Abramowitz et al., 2015; Brun, 2016). Guidance and methods and theoretical models that can guide this work include work by Fischer (2012), Appadurai (2004,

2013), and Brun (2016) on understanding well-being, as well as aspirations and imagined futures among the world's most marginalized.

Second, once we understand the cultural models for well-being and imagined futures, we need to understand the obstacles towards achieving them. In studying urban refugee health, we need to come together and understand, across a wide range of urban settings across the developing world, the social determinants of urban refugee health. Much of the research cited above has documented these social determinants in the context of refugees across the developed world or refugee camps, but this gap needs to be addressed in future research so that we can better understand what these social determinants are across contexts. This includes specific gender issues that may come to play in cities across the developing world, including variations in exposure to violence in the home or society of refugees across genders and sexual minority groups. This may also include shifting gender roles in cases where refugees have relocated from camps or rural areas to urban settings. Furthermore, the role that legal precarity among refugees and asylum seekers plays in impeding health and well-being in urban areas of developing countries is still anectodal at best, often extrapolated from the experience of asylum seekers with irregular status in developed countries (Yarris & Castañeda, 2009). Yet, this is an increasingly prevalent issue across the developing world too as refugees and asylum seekers are either unaware of how to apply, or denied official refugee status (Kuch, 2016; Yotebieng, 2017). Willen et al. (2011) argue that anthropologists need to coalesce around a clear theoretical framework in which to situate studies of illegality, and that we need to better engage with other disciplines so we can contribute to each other's understanding of the phenomena and potential actions that should be taken (Willen et al., 2011). Documenting the effects of humanitarian policy as a social determinant of health and well-being of urban refugees is therefore imperative. This includes examining the ways in which differential policy or changes in other social determinants of health may affect access to healthcare, especially in the case of prevalent chronic illness that requires sustained treatment over time.

Thirdly, we need to explore the links between health, well-being, forced migration, and urbanization. This can, in some cases, also contribute to the aforementioned calls for research on health in slums, as many urban refugees spend at least some time living in informal settings of developing countries (Davis, 2006; Elsey et al., 2016; Ezeh et al., 2016). Explicitly including the urban context into research on refugee health can uncover the different ways in which urban areas offer opportunities or barriers to health and well-being, as well as the differential roles of social support, networks, and host-refugee relations in urban areas. It may also shed light onto what opportunities for innovation and creative solutions may exist in urban areas. Studying this across contexts can allow us to build a better understanding of the urban context as it pertains to forced migration, and the ways in which urban refugees across contexts are overcoming challenges from one urban context to another.

Lastly, the focus on urban refugee health and well-being can allows us to explore and document how, despite the odds stacked up against them, some refugees manage to do well in their new homes (Castañeda et al., 2015). Findings from this type of research can inform future programs aimed at improving immigrant health and allow them to capitalize on community strengths. As the Lancet (2015: 1013) aptly describes, migration is "today's crisis." The massive global scale of migration driven by conflict, economic factors, and climate change are "inextricably entwined" (Lancet, 2015: 1013). This means that populations need to proactively prepare for how they are going to meet the needs of populations that arrive in their cities, including improved infrastructure so that already strained resources do not crumble, resulting in further conflict and suffering (Lancet, 2015). I suggest that if the four broad areas above are used as a road map for future research with a concerted focus on refugees residing in urban areas of developing countries, we will be able to make significant progress towards understanding the complicated and multidimensional nature of urban refugee health and well-being, and contribute towards concerted action towards improving the situation of many refugees in urban areas across the developing world. In other words, over half of the world's refugees.

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