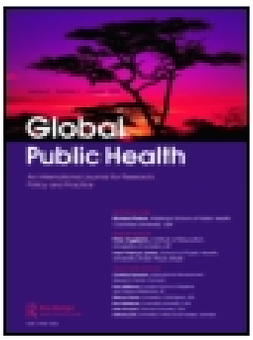

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Addressing chronic diseases in protracted emergencies: Lessons from HIV for a new health imperative

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ABSTRACT

Forcible displacement has reached unprecedented levels, with more refugees and internally displaced people reported since comprehensive statistics have been collected. The rising numbers of refugees requiring health services, the protracted nature of modern displacement, and the changing demographics of refugee populations have created compelling new health needs and challenges. In addition to the risk of malnutrition, infectious diseases and exposure to the elements attendant upon conflict and the breakdown of public health systems, many displaced people now require continuity care for the prevention and treatment of cardiovascular disease, diabetes, asthma, cancer, and mental health, as well as maternal and child health services. In some regions, most refugee health services need to be provided in dispersed settings within host communities, rather than in traditional refugee camps, and the number of refugees suffering protracted displacement is growing rapidly. These realities highlight a significant disconnect between the health needs of twenty-first century refugees, and the global systems that have been established to address them. The global response to the HIV epidemic offers lessons about ways to support continuity care for chronic conditions during complex emergencies and may provide important blueprints as the global community struggles to redesign refugee health services.

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Introduction

Forcible displacement has reached unprecedented global levels, with more refugees and internally displaced people reported since comprehensive statistics have been collected. Recent numbers are driven by conflicts in Syria, Iraq, South Sudan, and Ukraine, but war, conflict, and human rights violations are causing internal displacement and cross-border refugees on every continent (United Nations High Commissioner on Refugees [UNHCR], 2015). The Middle East is a displacement epicentre, with more than 4.8

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million Syrian refugees straining the socio-economic absorptive capacity of Lebanon, Jordan, Turkey, and other neighbouring countries. This ongoing crisis has critical health implications for Syria and its neighbours; it also highlights broader issues about changing health needs in complex and protracted emergencies worldwide.

While relief agencies and health organisations have traditionally largely focused on the prevention of infectious disease, treatment of acute illness, and provision of reproductive health services, all essential, the health needs of displaced people have expanded in recent years, reflecting changes in refugees' countries of origin and in the burden of disease in these countries. Although chronic non-communicable diseases (NCDs) such as cardiovascular disease, diabetes, cancers, and chronic lung disease are burdens for refugees and displaced people worldwide, they are particularly important causes of ill health in refugees from middle-income countries, such as Syria, Iraq, and Ukraine.

In addition to this changing burden of disease, today's refugees are often displaced for longer periods of time; three-quarters live in protracted refugee situations of five years or more, increasing their need for chronic health services (US Department of State, 2015). Another important change is that in some regions, refuges increasingly live within host communities rather than in camp settings, further complicating the provision of health services. For example, only 11% of Syrian refugees in the Middle East and Turkey are currently living in refugee camps.

The challenge of providing services for chronic illness in the context of displacement is a daunting one, given that a key element of effective care for NCDs is *continuity* – the need to deliver coordinated services over time. But evidence from HIV programmes shows that continuity care can be delivered in challenging settings – including in complex humanitarian emergencies – and suggests key priorities for NCD services for forcibly displaced people.

Burden of NCDs amongst Syrian refugees

The 10 countries identified by the United Nations High Commissioner on Refugees (UNHCR) as the largest source of refugees in 2015 all have significant NCD burdens, with NCDs accounting for 19–62% of total mortality (Figure 1) and with prevalence of high blood pressure ranging from 23% to 32% amongst adults (World Health Organization [WHO], 2015). A systematic review in 2014 found high rates of NCDs amongst urban refugees worldwide (Amara & Aljunid, 2014) and a 2012 study of diverse refugees arriving in the U.S. found that 51% of adults had at least one chronic NCD and 9.5% had three or more (Yun et al., 2012). Forced migration due to conflict is associated with somewhat higher levels of mental health disorders (Porter & Haslam, 2005), although resilience amongst refugees is also widely noted (Siriwardhana, Ali, Roberts, & Stewart, 2014).

Cardiovascular disease, diabetes, cancers, and chronic lung disease were the leading cause of death in Syria prior to the war (Institute of Health Metrics and Evaluation [IHME], 2015) and recent facility-based and community-based surveys confirm a significant prevalence of NCDs amongst Syrian refugees. In 2013, a review by UNHCR found the primary reasons for Syrian refugees to seek health care were diabetes, cardiovascular disease, and chronic lung disease (UNHCR, 2013). A cross-sectional survey of 1550 Syrian refugees in Jordan found that more than half of refugee households had a member with at least one NCD; hypertension, arthritis, diabetes, and chronic respiratory

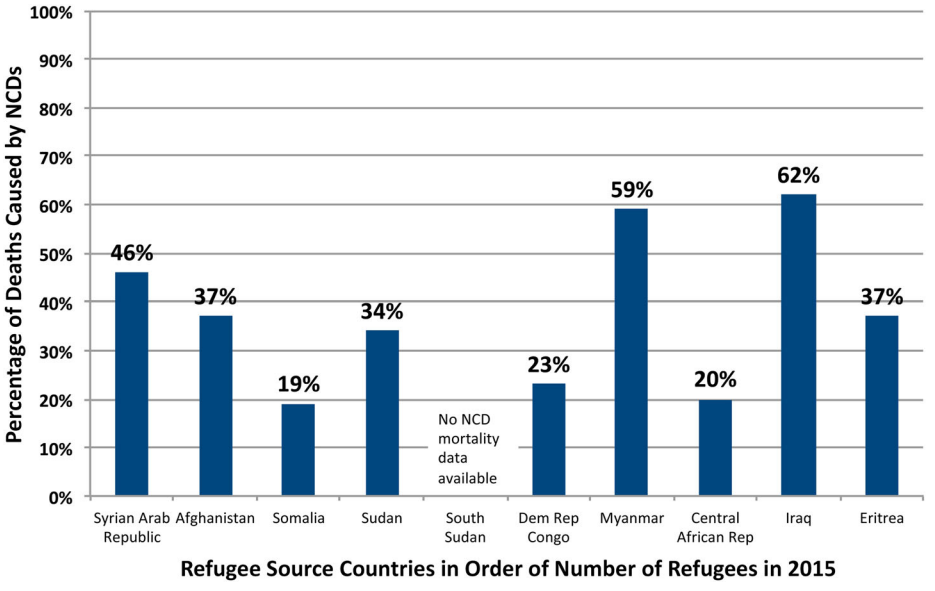

Figure 1. Percent of total deaths caused by non-communicable diseases in the largest source countries of refugees in 2014 (Adapted from: WHO NCD Country Profiles and UNHCR 2015).

disease were the most common examples (Doocey et al., 2015). Similarly, a recent study of 1400 Syrian refugees in Lebanon showed that 50% of households reported the presence of hypertension, cardiovascular disease, diabetes, chronic respiratory disease, or arthritis in one or more household members (Johns Hopkins University Bloomberg School of Public Health and Medicins du Monde, 2015). A smaller study of older Syrian refugees in Lebanon found that 60% had hypertension, 47% had diabetes, and 30% had heart disease (Strong, Varady, Chahda, Doocy, & Burnham, 2015). Additionally, in Tripoli and the Bekaa Valley in Lebanon, as well as in the Domiz refugee camp in northern Iraq, Médecins Sans Frontières conducted more than 17,900 consultations for displaced Syrians with chronic diseases in 2013 alone (Médecins Sans Frontières, 2014).

Available services and systems for refugees

With few exceptions, the health systems and services currently available to refugees were developed more than a half-century ago, and were designed for acute emergencies in lower income countries. UNHCR was established in 1950 with a mandate to safeguard the rights and well-being of refugees worldwide. The United Nations Relief and Works Agency for Palestinian Refugees (UNRWA) was founded in 1949, and now provides assistance to five million registered Palestinian refugees.

UNHCR advocates for free essential health services, which it defines as key primary health care services, emergency services, childhood vaccines, antenatal and delivery care, and care for communicable diseases such as tuberculosis. The agency and its partners provide primary health care and some secondary health services to registered refugees in Jordan and Lebanon, but secondary and tertiary care generally include co-payment requirements which may be unaffordable to refugees. In Turkey, registered Syrians

officially have access to the same health services as the general population, largely financed by the Turkish government with some support from external donors. In practice, however, fewer than 50% of Syrians in Turkey are thought to be registered, making it more difficult for them to access health services.

Adapting its systems to meet the needs of Palestinians, who have been displaced for decades, UNRWA provides selected NCD services to these refugees, including routine screening for diabetes and hypertension at UNRWA-supported primary health centres, where nearly 200,000 people with the two conditions were receiving care and treatment by end-2013 (Shahin, Kapur, & Seita, 2015). UNRWA's Family Health Team approach enables family-focused services including NCD prevention, management, and treatment. However, a recent cross-sectional study at UNRWA's 32 largest primary health care centres in Gaza, Jordan, Lebanon, and the West Bank noted that only 28% of diabetic patients had well-controlled blood sugar and blood pressure, indicating ongoing challenges (Shahin, Kapur, Khader et al., 2015).

Chronic care for refugees and displaced persons: lessons from HIV

Successful management of chronic diseases requires coordination of multidisciplinary services over time as well as the effective engagement and empowerment of patients to self-manage illness on an ongoing basis. Challenging in the best of circumstances, the delivery of continuity care is especially difficult for persons who are mobile, unstably housed, psychologically stressed, and lacking health coverage, characteristics typical of many refugees. Over the past 15 years, HIV programmes have amassed substantial experience delivering effective chronic care to populations with these challenges, in both resource-rich and resource-poor settings. In addition, HIV treatment has been successfully provided to refugees and internally displaced people; a 2014 review noted that 87–99% of forced migrants with HIV had achieved at least 95% adherence and positive treatment outcomes (Mendelsohn, Spiegel, Schilperoord, Cornier, & Ross, 2014). With the appropriate support, HIV treatment outcomes for forced migrants can be similar to that of the host community (Mendelsohn, Schilperoord et al., 2014).

Key lessons from HIV programmes (Table 1) include the importance of using an evidence-based public health approach to service delivery, including simplified standardised treatment regimens, streamlined clinical and laboratory monitoring, and an intensive focus on patient education, engagement, and empowerment via the use of counsellors, outreach workers, and peer educators (Rabkin & El-Sadr, 2011). The use of such multidisciplinary teams would assist providers to meet the complex needs of refugees, and enable more effective linkages between facility- and community-based care. As HIV programmes have shown, innovative approaches, such as community-based care, and community treatment groups provide flexibility and contextually appropriate services while decreasing reliance on facility-based health workers (Holmes & Sanne, 2015).

There are promising data on the use of mobile phones and text reminders to support retention in HIV treatment (Horvath, Azman, Kennedy, & Rutherford, 2012) and on the use of mobile clinics and electronic medical records to support displaced HIV patients during emergencies (Goodrich et al., 2013). In the case of forced migrants, cloud-based health records accessed via mobile phone applications could mitigate the challenges of maintaining medical information and test results while in transit, although it will be important to identify and address issues of privacy and security.

Table 1. Lessons from HIV.

Continuity care challenge	Lessons/innovations from HIV	Relevance to NCD services for refugees
Screening and diagnosis	Routine opt-out testing in high-prevalence populations is more effective than opt-in testing	Consider offering routine screening for common NCDs and NCD risk factors to forced migrants accessing other health services, especially for those 40 and older
	Point-of-care (POC) testing with immediate results is more effective than referral to laboratory services	Consider use of POC testing when screening for diabetes, high cholesterol, anaemia and other chronic illnesses
	Training and sensitisation of clinicians is important to ensure adequate coverage	Sensitise clinicians providing health services about the high prevalence of NCDs amongst refugees; provide training on screening and diagnosis
	Community engagement and feedback can optimise the design and delivery of testing services	Consider focused needs assessments, structured patient feedback, and outreach to refugee communities when designing NCD programmes
Linkage from testing to care; retention in care once enrolled	Counselling and education by trained peer educators can address key barriers to linkage and retention	Provide NCD services to refugees via multidisciplinary teams, including non-physician clinicians and peer educators/ patient navigators
	Appointment systems with active follow-up are needed to identify and contact patients who miss scheduled follow-up	Appointment systems (paper-based or electronic) should trigger follow-up if patients miss appointments. Patient-held records, mobile phone apps, and text reminders may facilitate retention in care
	Community-based health services, including mobile clinics, can support retention in care and improve patient satisfaction	In some contexts, refugee populations may benefit from innovative approaches to NCD treatment delivery
Adherence to treatment	Ensuring long-term access to medications includes dispensing larger supplies, enabling pharmacy and community-based drug pickup, and dispensing easy-to-use medications (e.g. pill boxes, blister packs) and reminders	Opportunities to enhance medication dispensing and supplies will vary greatly depending on the health system and context
	One-on-one peer education and patient support groups provide highly effective and practical advice for adherence support	The use of NCD peer educators and patient support groups is likely to have a significant impact on adherence to NCD treatment
	Costs and user fees, however small, reduce adherence; medications should be free whenever possible	The movement towards universal health coverage (UHC) should include refugees and forced migrants
Effective monitoring	Structured monitoring throughout the care 'cascade' is required to track whether or not treatment is effective	Programmes providing NCD services should monitor cohort progress throughout the care cascade – for example, the percentage of patients diagnosed who are linked to care; the percentage of those enrolled in care who are started on treatment; and the percentage of those on treatment whose NCDs are controlled
	Educating patients about monitoring schedules and the meaning/importance of monitoring tests can incentivise their participation – and enable them to remind clinicians as needed	Obtain refugee input into structure/format of easy-to-carry health records with essential information. Develop secure web-based storage and mobile phone applications to store data about diagnoses, test results, medications, and scheduled follow-up

Other critical lessons from HIV programmes include the importance of examining health worker roles, and addressing licensing and regulatory barriers to task-shifting and health workforce innovation. In the case of HIV, these innovations have largely focused on enabling nurses and other non-physician clinicians to prescribe and monitor HIV treatment – adaptations that will be equally useful in the case of NCDs.

Given the scarcity of Arabic-speaking clinicians in Turkey and European host countries, an additional priority may be finding creative ways to enable refugee health workers – for example, Syrian doctors and nurses – to swiftly return to practice even prior to formal resettlement.

Finally, the scale-up of HIV programmes in resource-limited settings has demonstrated the need for global solidarity and support, both for patients in need of health services and for the under-resourced health systems grappling with providing novel and complex health services to burgeoning numbers of patients in extremely challenging circumstances. Unfortunately, funding for UNHCR's 2016 Middle East Regional Refugee and Resilience plan only reached 14% as of March 2016 (United Nations High Commissioner on Refugees, 2016). It will be necessary to reproduce the successful advocacy that led to the Global Fund for AIDS, Tuberculosis and Malaria and the US President's Emergency Fund for AIDS Relief (PEPFAR) to support refugee health services. Including the issue of refugees and forced migrants in deliberations about Universal Health Coverage may also be a productive approach in some regions.

Gaps and opportunities

The international agencies tasked with care and support of refugees and internally displaced people face ever-increasing needs while experiencing substantial funding shortfalls. Host country health systems and their financial capacity are also strained, as they themselves often have rudimentary public sector NCD services. But the changing health needs of twenty-first century refugees require a reconceptualisation of the global frameworks, policies, and systems designed for their support, with attention to new challenges, such as chronic diseases, that may seem to fall between the mandates of emergency responders and development organisations. The growing burden of NCDs in both resource-rich and resource-poor countries, the extended timeframe of modern-day displacement, and the need for health care outside of refugee camp settings are imperatives that compel new thinking and new policies. The response to the HIV epidemic offers lessons about ways to support continuity care for chronic conditions during complex emergencies and may provide important blueprints as the global community struggles to redesign refugee health services.

Disclosure statement

No potential conflict of interest was reported by the authors.

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