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Title: Integrating community health volunteers into non-communicable disease management among Syrian refugees in Jordan: a causal loop analysis

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Abstract:

Introduction: Globally, there is emerging evidence on the use of community health workers and volunteers in low- and middle-income settings for the management of non-communicable diseases, provision of out-of-clinic screening, linkage with health services, promotion of adherence, and counselling on lifestyle and dietary changes. Little evidence exists on the role of this workforce in supporting non-communicable disease care for refugees who lack access to continuous care in their host country.

Methods: A multi-stakeholder and participatory causal loop analysis workshop with the Ministry of Health of Jordan, non-governmental organizations, the World Health Organization, and community health volunteers was conducted in June 2019. The goal was to evaluate the current roles of community health volunteers in the management of diabetes and hypertension among Syrian refugees. This was used to posit improvements for the current primary care model, to aid in the evaluation of an improved primary care models for non-communicable disease management among Syrian refugees.

Results: During the causal loop analysis workshop, participants collaboratively identified and mapped how CHVs might fill gaps in secondary prevention among diagnosed patients. Identified possibilities include the following: provide psychosocial support and foundational education on their conditions, strengthen self-management of complications (e.g., foot checks), and monitor patients for adherence to medications and collection of basic health monitoring data. Elderly refugees with restricted mobility and/or uncontrolled disease were identified as a key population where CHVs could provide home-based blood glucose and blood pressure measurement and targeted health education, to provide more precise monitoring. The final causal loop diagram was used to analyze and improve the current primary care model.

Conclusion: Community health volunteer programs were cited as a key strategy to implement secondary prevention of morbidity and mortality among Syrian refugees, particularly those at high-risk of decompensation.

Strengths and Limitations of this Study

- The findings of this study resulted from convening of a group of diverse stakeholders related to diabetes and high blood pressure among Syrian refugees in Jordan.
- This study provides concrete ways in which a CHV program might support Syrian refugees in Jordan with diabetes and hypertension.
- The findings of this study may have been limited by translations errors, or a lack of willingness to fully participate in a mixed-stakeholder setting.

Introduction

More than 5 million Syrian refugees are displaced throughout the Middle East as a result of the conflict in Syria, with 655,000 displaced in Jordan. [1] The majority of these refugees in Jordan live outside of camps.[2] Among non-camp Syrian refugees ≥18 years in northern Jordan, 9.8%, 17.2%, and 7.3% reported diagnoses of diabetes, hypertension, or both conditions.[3] Refugees have been displaced for many years, and may have developed these conditions after leaving Syria.[4] A community-based survey conducted by the authors among Syrian refugees living in Ramtha and Mafraq Governorates found that 22.9% of those with above-threshold random blood sugar, and 39.1% with above-threshold blood pressure did not report a previous diagnosis.[3] Prolonged displacement and a high burden of NCDs require that primary care traditionally delivered by non-governmental organizations (NGOs) be optimized to prevent severe morbidity and mortality. [5–9]

Syrian refugees in Jordan access health care in fragmented ways. In camp settings, non-governmental organizations (NGOs) typically provide clinical care through a primary care model that favors curative therapies over preventive care.[10] Syrian refugees in peri-urban and urban areas access care via a patchwork of multiple health providers. These include NGO facilities that usually provide primary care services and medications at low or no cost, Ministry of Health (MoH) clinics that provide services for low cost but often have limited resources, and private clinics which typically provide more expensive services. While NGO clinics do often provide free services, referrals to secondary and specialist care, diagnostics, and laboratories typically require out of pocket payment.[11,12] Essential medications may have limited availability due to funding issues and stock-outs at both NGO and MoH facilities. Increasingly, NGOs use cohorts to provide more comprehensive services to patients with NCDs in Jordan which creates challenges for those who find themselves excluded from these systems.[8] Changing rules governing refugee access to Ministry of Health clinics have resulted in further confusion and barriers in accessing care.[11]

Studies have shown positive impact of community health workers on NCD management in emerging low- and middle-income settings.[13–17] However, limited evidence exists on the specific role CHVs might play in delivering care to refugees living with NCDs such as diabetes and hypertension in protracted displacement settings. Since 2011, the International Rescue Committee (IRC) has administered Jordan's largest community health volunteer (CHV) program, serving both Syrian refugees in non-camp settings as well as uninsured, vulnerable Jordanian patients. This program supports primary care functions for all household members, including monitoring, referral, and health education for child health, prenatal and antenatal care, and other health conditions. The specific role that CHVs might play in NCD care, from linkage to care, out-of-clinic monitoring, or support of medication adherence to early screening for complications or early disease required careful consideration from multiple stakeholder perspectives.

Causal loop analysis, drawn from systems dynamics theory, provides a means to understand complex systems and, when done in a participatory manner, suggest programming that is sensitive to the strengths and constraints of health systems.[18–20] Health care for refugees can be considered a complex adaptive system which results from the interactions of multiple actors (e.g., beneficiaries, NGOs, health workers) and processes (e.g., registration, diagnosis, adherence to care). Interactions between various components of this type of system are non-linear and difficult to predict. Causal loop analysis provides a means to qualitatively understand complex systems, and potential consequences of modifications and new programming within the system.[18,21]

A participatory causal loop analysis workshop was convened in June 2019 to explore the existing models for CHV programs in Jordan and the means by which these programs might be improved to fill in gaps for the provision of continuous health care to Syrian refugees with diabetes and hypertension.

Methods

Researchers and stakeholders co-developed and improved on a causal loop diagram via a multi-phase group model building exercise. In the first phase, a basic diagram was developed, after discussions with IRC health staff and document review, and authors PP and FR conducted 20 key informant interviews in May-June 2019 based on existing programming in Irbid and Mafraq governorates. This exercise focused on describing the ways in which a CHV program can potentially support Syrian refugees and uninsured, vulnerable Jordanian patients with diabetes and hypertension living in non-camp, urban and peri-urban settings where NGO-supported clinics are co-located.

Key informants were purposively selected to include experts in NCDs from the Ministry of Health, leadership of national and international health NGOs, and through IRC programs: CHVs, Syrian patients with diabetes and hypertension, and health care providers (MDs, RNs, and administrators). The initial list of key informants was created in collaboration with IRC staff, and this list was iteratively grown by asking interviewees to recommend relevant others (snowball sampling, **Box 1**). Community perspectives as well as the perspectives of CHVs who had practiced in target communities, often for years, were prioritized in order to fully consider the limitations of current programming and the ways in which future programming might meet identified gaps in care. Individuals were interviewed by the research team using a semi-structured interview guide **(Box 1)**. All interviews were carried out in the respondent's preferred language, English or Arabic.

Box 1

Individuals Interviewed

Community Health Professor from the Jordan University of Science and Technology (1)
Syrian refugee patients (1 male, 1 female)
IRC CHVs (1 male, 1 female)
IRC Health Staff (7)
Health INGOs/Donors, including Médecins Sans Frontières (MSF), Medair, Altkaful, Royal Health Awareness Society (RHAS), ABT Associates, International Medical Corps (6)
Jordanian Ministry of Health, Non-Communicable Disease Division, Public Health Department (2)
WHO, UNHCR

Domains of Semi-Structure Interviews

Components of the Jordanian health system accessed by Syrian refugees
Linkages between elements of the health system
Barriers and facilitators in accessing care for diabetes and hypertension
Current role of CHVs
Potential roles of CHVs in care of patients with diabetes and hypertension
Opportunities and constraints in realizing the potential of CHVs in managing diabetes and high blood pressure

Key themes were identified and then used to generate variables for inclusion in the causal loop diagram and the relationships between each of these variables using content analysis strategies. (**Box 3**).[22] The research team then generated a "seed" causal loop diagram. All causal loop diagrams were generated and edited using VensimPLE software.[23]

Stakeholders discussed this seed causal loop diagram and collaboratively refined it during a two-day workshop held in Amman in June of 2019. The objective of this exercise was to identify gaps and strengths in the current model of provision of NCD care for Syrian refugees and then identify CHV-led strategies that might fill key gaps, while building on strengths in the system whenever possible and incorporating mitigations strategies for anticipated barriers. Five male and female CHVs provided perspectives on current and potential roles for CHVs in Jordan, and the ways in which their roles might be expanded to address unmet needs. Similarly, Syrian refugee patients were invited to provide their perspectives on challenges faced. NGO, Ministry of Health, and UN/WHO representatives provided programmatic and funding context, and IRC leadership provided perspectives based on their management of the CHV program in Northern Jordan. Health practitioners and university professors/content experts provided additional academic and contextual expertise. Workshop facilitators presented data from a community-based survey of IRC catchment areas conducted during March/April of 2019 examining prevalence of disease, medication adherence, self-reported rates of complications and access to care among IRC beneficiaries.[3] Additionally, workshop facilitators presented a summary of relevant regional literature on the roles of CHVs in management of disease. Workshop participants then collaboratively edited the seed causal loop diagram which had been generated from key informant interviews. The final version of this collaboratively built, causal loop diagram was disseminated to participants in the workshop. During the fourth phase, key lessons from this final diagram were used to develop an improved CHV NCD program for implementation by IRC.

Ethics/Consent

This study was approved by the Institutional Review Boards of the University of Southern California, International Rescue Committee, and Jordan University of Science and Technology. Key informants gave written consent to participate, and workshop participants gave verbal consent. Individuals were asked to keep content of the discussions during the workshops confidential. Content of key informant interviews was summarized and shared in the workshop in a de-identified manner.

Patient and public involvement

Syrian patients and Syrian CHVs participated in the workshop to gather their perceptions and insight into the needs of NCD patients. They were not directly involved in the development of the research design.

Results

A final list of variables generated and their definitions are listed in **Box 2**. These variables and linkages are summarized in the final causal loop diagram below in **Box 3**, which, using positive and negative signs, considered how various components interact to ultimately affect health status.

Variables are described below and arranged in this causal loop diagram according to relevance at a *national/global policy level*, at the *health system level*, at the *level of community volunteers/community health*, and at the *level of the patients* themselves. Relationships between variables are described in the final causal loop diagram with arrows: two variables linked by an arrow and a + sign indicate that when one variable is influenced positively or negatively, the other variable also increases or decreases in importance. Similarly, variables linked by an arrow and a – sign indicate that when one variable varies, the linked variable goes in the opposite direction.

Box 2. Final list of variables

Patient/Community

Psychosocial State of Patient
Patient Capacity for Self/Care and Health Literacy
Out of Pocket Expenses
Mobility of Patients
Patients Receiving Care from Multiple Facilities
Unknown or Untreated Cases of DM/HTN
Use of Negative Coping Strategies

Health System
Capacity of Health System
Longitudinal Patient Access/Utilization to Primary Care
Patient Utilization of/Access to Secondary/Tertiary Care
Coordination of between health Actors
Provider Access to Health Information Across Systems
Perceived Quality of Health Services

Policy
Stable Financing for Health Programming
Duplication of Services by Health Actors
Policy Environment that facilitates Community Health Programming

Roles of Community Health Volunteers
CHV Program Utilization
Community Wide Morbidity/Impact Data

CHV Technical Skill and Motivation
CHV Capacity for Holistic Care
Community Trust in CHVs
Community Based Screening for DM/HTN
CHV Coordination of Care
CHV Referral to Care

[insert image, "Final Causal Loop Diagram]

Box 3. Final Causal Loop Diagram: Community Health Volunteer Program for Syrian Refugees and Vulnerable Jordanians with DM/HTN

Patient/Community Level

Out of pocket expenses were identified as the single most important factor affecting health seeking behavior at the patient level in this system **(Box 4; Quotes 1,2)**. The *patient's capacity for self-care and health literacy* was deemed central to appropriate management of diabetes and hypertension, including patient understanding of the chronic nature their of disease and treatment, the need for daily medication, routine dietary and exercise needs, and timely identification of complications. *Patients receiving care from multiple facilities* were seen as often suffering negative consequences as a result. It was recognized by stakeholders that patients may seek duplicate services as a relatively common coping mechanism, given limited and changing clinical services available to refugees. The *psychosocial state of the patient* was recognized as key in care-seeking behavior, as refugees are predisposed to suffer from serious mental illness and trauma, which may introduce feelings of hopelessness and impair the ability to prioritize continuous management of chronic health conditions. Finally, patients with impaired mobility, including women who must remain at home, the elderly and disabled, often have a challenging time traveling to health facilities **(Box 4; Quote 3)**.

At the community level, stakeholders identified *unknown/untreated cases* of diabetes and hypertension as a potentially large unmet need and knowledge gap. In the context of limited access to primary care, refugees face barriers to obtaining a diagnosis, including seeking care only when conditions become symptomatic, and a lack of exposure to information about NCDs. Finally, in an environment where services available to patients often change with shifting policy goals and funding priorities, patients often engage in *negative coping strategies* to fill gaps in care. These may involve seeking care from non-physician providers, including traditional healers who provide herbal remedies, seeking medications directly from pharmacies without the involvement of a physician, taking prescribed medications in lower doses or less frequently to make them last longer, or forgoing medications entirely despite a known diagnosis. Patient factors above, in particular *high out of pocket expenses, patient's* [most often sub-optimal] *capacity for self-care and health literacy,* and challenging *psychosocial state of the patient*, in combination with a potentially high burden of *unknown/untreated cases* of diabetes and among diagnosed persons, the perceived common use of *negative coping strategies,* could potentially result in poor health outcomes.

Health System

Stakeholders identified several factors at the level of the health system that affects the health of Syrian refugees. The *Capacity of the health system* was identified as suffering negatively from a lack of *coordination between health actors (NGOs, MoH).* Stakeholders, particularly medical providers, felt that a lack of *provider access to health information across multiple systems* was responsible, at least in part, for avoidable duplication of services. Stakeholders described unknowingly repeating testing or providing multiple prescriptions for either duplicate or potentially interacting medications to patients who receive care from multiple health centers **(Box 4; Quote 4)**. This was flagged as not only a danger to patients given challenges monitoring patients who seek care from multiple providers, it was seen as a strain on limited resources when services are duplicated. Generally, key informants and workshop participants agreed that MoH services were strained, and many patients, CHVs, and health actors perceived the quality of MoH services to have suffered as a result. Improved coordination between health NGOs had, per participants, mitigated many of these issues during the response; however, most felt coordination could be improved, particularly on improved access to medical records across health systems (via patient held records or better explicit mechanisms for sharing key pieces of information when needed). Stakeholders uniformly felt capacity of the health system was harmed by a lack of *stable financing for health programming*.

Barriers to longitudinal access to and utilization of primary care, largely resulting from the patient/community factors described above, were felt to substantially impact health outcomes among refugees with NCDs. Workshop participants highlighted that geographic and financial access might not always automatically result in medically required, longitudinal utilization by patients, with factors such as health literacy and competing household priorities playing an important role **(Box 4; Quote 2)**. *Access to and utilization of secondary and tertiary care*, when needed, was recognized as critical to the health of patients with diabetes and hypertension—particularly those who had experienced a complication of their disease. It was also recognized, both in key informant interviews and the workshop, that humanitarian agencies largely focus on primary care, with refugees facing very limited and typically expensive access to secondary or tertiary care **(Box 4; Quote 5)**. Stakeholders felt that increased utilization of primary care and preparedness for routine NCD management of some complications at the PHC level might decrease the reliance on scarce secondary and tertiary resources. However, participants noted that such an increase in primary care utilization would create a strain on the *capacity of the health system* as it risks inadequate resources and planning. Overall *capacity of the health system* was thought to be an essential component of high quality primary, secondary, and tertiary care.

In summary, when considering the health system, *coordination between health actors (NGOs, MoH)* and a lack of *provider access to health information across multiple systems*, in addition to policy factors outlined below, are major factors which decrease the *capacity of the health system*. Patient and community factors may serve as *barriers to longitudinal access to and utilization of primary care*, increasing rates of preventable complications as well as the needs for *access to and utilization of secondary and tertiary care*. Any strained *capacity of the health system* resulted in poor *perceived quality of health services*, which will, in turn, drive down longitudinal, appropriate utilization by patients and harm patient health.

Policy

Stakeholders identified key policy-level variables related to health status. Typical funding cycles for humanitarian programs are in the 1-2 year range, while NCD programming was felt to require a longer-term strategy. Donor funding of humanitarian NGO health programming has also decreased in the region per workshop participants, which has resulted in a lack of the type of *stable financing for health programming* that is critical for longitudinal care of diabetes and hypertension*.* **(Box 4; Quote 1)**. Workshop participants noted that the MoH was in the challenging position of having to provide for a large influx of refugees with limited funding, which has resulted in changing policies with regards to fees charged to Syrian refugees for health services. These changing policies have, in themselves, resulted in distrust and inaccessibility among refugees of MoH health services. *Duplication of services by health actors* in the domain of NCD care, with multiple providers present in some geographic areas with relatively fewer in others, was felt by participants to have resulted in inefficient use of limited funding. Many key informants during key informant interviews cited a perceived lack of adequate coordination of humanitarian programming nationally, resulting in overlapping programming in some locations and a relative lack of services in other geographic regions **(Box 4; Quote 6).**

In summary, when considering policies, a lack of *stable financing for health programming* and *duplication of services* between health actors was felt by workshop participants to have negatively impacted *capacity of the health system*, resulting in downstream effects of poor *perceived quality of health services* and *access/utilization of primary, secondary, and tertiary care*: all of which results harms the *health of Syrian refugees with diabetes and hypertension*.

Role of Community Health Volunteers

Stakeholders were asked to consider how a CHV program might, both positively and negatively, impact the health of Syrian refugees within the systems described above—and what factors might modify the impact of suggested programming. *CHV capacity*, including their technical skills, workload, appropriate remuneration, and motivation, were seen as central to the success of any CHV program. CHVs draw from the communities they serve—thus, their understanding of the social and cultural context was also seen as a tremendous asset to their work. Current policy in Jordan allows for limited payment of CHVs, which serves as a barrier. They have to been seen as highly skilled and reliable by the communities they serve, reflected in the variable *community trust in CHV programming. CHV Capacity for Holistic Care,* namely the ability to make accurate and timely referrals to resources not related to the central goals of their program (food aid, services for survivors of violence, psychosocial aid, cash transfers, etc) were considered central to securing patient engagement. Stakeholders, including CHVs themselves, agreed each time a CHV is unable to meet the need of a patient, that patient loses trust in their services and may not make the time for disease-specific messaging. However, CHVs stated that timely and meaningful referrals require improved coordination between humanitarian actors to ensure that services remain available when referrals are made and that CHVs do not make referrals to non-existent services. *CHV capacity*, *community trust in CHV programming* and *CHV capacity for holistic care* were thought to positively reinforce *CHV NCD program utilization* by the target beneficiaries.

Stakeholders identified multiple ways that a CHV NCD program might support the health of patients at multiple levels beyond the current system. CHVs were felt to be a critical conduit for increased patient knowledge on management of their disease, specifically increasing *patient's capacity for self-care and health literacy.* CHVs could strengthen health literacy and self-management by providing targeted health messaging (on foot checks, adherence to medication and clinic visits) **(Box 4; Quote 7)**. CHVs might also serve as a means of screening adults to identify undiagnosed cases of diabetes and hypertension, provide *communitywide, timely morbidity/impact data*, which might strengthen access to diagnoses and care as well as target particularly high-risk patients. CHVs could also provide basic psychosocial support and referrals to more advanced care for patients suffering from more acute mental health needs. CHVs were also felt to be an important means of combating negative coping strategies, both via education and referrals to services that might allow for more stable access to medications and allopathic primary care. Stakeholders identified patients with limited mobility as a key population that might greatly benefit from CHVs **(Box 4; Quote 3)**. CHVs could, with training, provide home-based blood glucose and blood pressure measurement and coordinate with clinics to provide disease management and health education, reducing the need for more frequent visits to a health facility.

Though CHV led, *community-based screening* might increase the burden on the health system, stakeholders felt that a robust CHV program might also decrease the burden on fixed clinics by reducing *duplication of services* (helping patients coordinate care within one health system as much as possible and aligning services between multiple health providers when needed), identifying poorly controlled disease early and thus preventing complications that require secondary and tertiary care. As well, taking on health education at the community level, freeing health facilities to focus more on medical disease management during appointments. Current national policies in Jordan prevent those who are not licensed nurses or physicians from measuring blood glucose and blood pressure as a part of the provision of health care, though measurement devices are available to households for purchase and private use. This, and the need for consistent funding sources, highlight the importance of a *policy environment that facilitates community health programming.*

Box 4. Quotes from Key Informant Interviews

1. *Previously there were many NGOs providing services, but now there are less; there are just a few that provide free services. [Humanitarian NGO] can provide some services, but they charge and even this subsidized rate is challenging. Only [different humanitarian NGO] is providing free services, and said [third humanitarian NGO] is not taking patients. If services or medications are not available in these places, I have to buy it externally.* –Syrian refugee, female

2. *Finances are the main barrier. Even if you give money to an old man with diabetes, if he has five children he will feed them and prioritize rent over his own health. Rental costs are very high and this is challenging. When we do our post-cash-transfer calls, we ask why are you still in debt? Recipients will often reply that they had to pay rent to avoid becoming homeless.*
   – NGO Health Program Administrator

3. *When we went to the field, some women had instructions from husbands that they could not go outside their home. They when they saw the CHVs, said, "thank God! If you can help me here in the home that is much better"* –IRC CHV, male

4. *The only link between different health providers is the patient. We try to get records of investigations from other NGOS, etc—but most patients come in with no records, no data, no labs, no access to files from MoH or other NGOs. Strict privacy policies prevent coordination. This gets in the way of patient care.* –NGO health provider

5. *NCDs need time-intensive care, at least 20-30 min per visit, but health providers don't have that time. Most providers focus on treatment and not prevention—and health messages need to be repeated many times. There aren't adequate human resources for this. Health providers focus on treatment, not prevention.* -NGO Health Program Administrator

6. *When I started, we were attending NCD working groups--health sector meetings. I noted that these are not run as efficiently as they should be. It was a parade of bragging. No one is collaborating and actually sorting out what they should be doing, NGOs fight to maximize funding. There seems to be no entity regulating/coordinating which organization should focus on what specific issues, etc.* –NGO Health Program Administrator

7. *If a CHV calls and states that there are 70 cases of diarrhea in one community, with dehydration in this informal tent settlement, then we can go there. If well trained, these CHVs can provide vital information in real time. They can do clinical assessments as well if trained well. You don't need health care professionals to measure blood pressure or blood glucose, CHVs can do this. CHVs can save time/cost and prevent complications. They can identify complication early. If there is a certain case that needs a referral, then they can refer. I tell my CHVs, "You are all soldiers". CHVs save people's lives.* -CHV Program Administrator

8. *Will there be real action, or just talking?* --Syrian Patient, Male

Discussion

This causal loop analysis workshop identified many issues borne out by previous studies among Syrian refugees in the region, highlighting costs, challenges with changing capacities and services of humanitarian actors, lack of coordination between humanitarian actors as well as the MoH, shifting national policies regarding provision of health care by state facilities to refugees, and very limited access to secondary and tertiary care as major barriers in assuring continuous care. [11,12,24] The final causal loop diagram and findings were used during a final, fourth phase by IRC program staff to contribute to the development of the CHV component of a primary care program for NCDs that more fully considered the needs and perspectives of all stakeholders in this complex system.[25] The identified strategies align with an evidence-based conceptual model of care for priority NCDs through primary care systems developed by Kane, et al.[26] These strategies are presented below using a version of the conceptual model above modified for the Jordanian context, along with a brief summary of available evidence relevant to each intervention and notes on feasibility in Jordan.

1. CHV-led community-based prevention via risk factor modification

A key strength of CHVs is their ability to provide targeted health education messaging to refugee communities on primary prevention, or the importance of addressing risk factors for NCDs, including diet and exercise, through tailored discussion of realistic goals given context-specific constraints. However, there are complex issues with regards to diet (e.g., food insecurity), smoking cessation (e.g., high prevalence, culture), and promoting exercise (e.g., few options for female heads of households) among Syrian refugees.[4,5] Additionally, evidence for the impact of broad community prevention by CHVs is non-existent or weak, and primary prevention is dependent on socio-political factors that are often difficult to change in the scope of a primary care, humanitarian health model.[12,27,28]

Given the limited resources and realities of the Jordanian context, it may be more efficient for CHVs to target secondary prevention through messaging on improved diet, exercise, and risk factor modification (smoking, etc.) to patients with diabetes and hypertension within the context of an NCD focused CHV program rather than broader community-wide education. Counseling given should be specifically tailored to the Syrian refugee context, taking into account resources and cultural acceptability. [29,30] For example, for Syrian refugees Lebanon, CHVs have targeted salt intake among known NCD patients.[29] CHVs should, however, should involve all members of the household in risk factor modification discussions. This will help to create crucial household support to support lower salt diets, lower fat meals, and potentially engage multiple family members in weight loss strategies.[4,9]

2. CHV screening of Syrian refugee communities for diabetes and hypertension

Many cases of diabetes and hypertension remain undiagnosed among Syrian refugees in Jordan.[3] Stakeholders felt that CHV-led, community-based screening might be a useful strategy to identify pre-symptomatic cases of diabetes and hypertension—and prevent morbidity and mortality via early linkage to care. Evidence suggests that screening in the community using random blood glucose and blood pressure has low specificity, and may yield excessive case numbers that when not appropriately discussed with a physician, result in limited linkage to care, and may result in low compliance with treatment and unclear impact on health.[31] In Saudi Arabia, only a limited proportion of those who screened positive for disease were ever appropriately linked to care.[32] Additionally, generating high levels of demand that cannot be appropriately met may not be ethical in humanitarian settings.[9]

Thus, CHV-led screening targeted to other members of the households of patients with diabetes and/or hypertension is likely to be the most reasonable strategy in this context, given accessibility. Household-level screening should focus on those ≥30 years, those with a history of gestational diabetes and hypertension, or those who report symptoms that might be consistent with complications of an NCD during the course of a CHV household visit.[15]

3. CHV support of adherence to medication, disease management, and clinical care.

CHVs were thought to have a potential role in helping coordinate care between multiple providers, including reduction in duplication of services, ensuring appropriate and timely referral to clinical care, encouraging adherence to medication, and providing early screening for complications of disease.

Evidence shows that among refugees, understanding of their disease and early signs of complications is limited and that patients have a limited understanding of how best to manage their disease.[4,5] Several studies of CHV interventions to improve disease control in rural Iran, Nepal, Mexico and Japan have shown that CHV programming designed to improve adherence to care and identify complications early can improve patient outcomes in non-refugee settings.[15,16] Those with the poorest control tend to benefit the most from this type of CHV intervention.[16] In light of the relatively high burden of NCDs in many humanitarian contexts and limited resources, interventions that focus on the most poorly compliant or sickest patients may be the highest yield and highest impact.[33]

An effective CHV intervention could target Syrian refugees with the highest needs (e.g., disabled or elderly) and/or most poorly controlled disease. CHVs can share simple tools designed to assist patients with self-management of disease, based on the Package of Essential

NCD Interventions designed for the humanitarian context as well as tools created for the Syrian context by the International Federation of the Red Cross and Red Crescent.[30,34] In addition, CHVs could engage in routine out-of-clinic biological monitoring of disease, including measurement of blood pressure and blood glucose, to better identify patients in need of urgent or emergent referrals to clinical care. Finally, CHVs could be trained to identify criteria for emergent and urgent referral of complications of disease through available community case definitions of diabetic foot ulcers, hyper- or hypoglycemia, myocardial infarction or unstable angina, etc.[34]

4. Mental health and psychosocial support

Conflict and displacement-affected patients may face significant hopelessness and mental illness barriers in dealing with NCDs. This may, in turn, affect compliance, adherence, motivation and result in increased reliance on negative coping mechanisms.[12,17] Stigma often prevents many Syrian refugees from seeking care for psychiatric needs, and clinic-based psychological services often do not have the capacity to meet the needs of these patients. There is some evidence of the effectiveness of psychosocial support for HIV adherence and better evidence for the application of mental health and psychosocial services in the context of a CHV program.[35]

CHVs can, in the context of a dedicated NCD program, provide basic psychosocial support to patients and referrals for individuals suffering from more acute mental health needs. Specifically, CHVs can use brief motivational interviewing strategies to problem-solve with NCD patients on optimizing diet, exercise, and managing substance use and smoking, and provide support to those who express hopelessness.[30,36] This would need to be administered in close collaboration with established mental health and psychosocial services in order to appropriately escalate any persons with mental illness or complaints, as counseling would be outside of the capacity of a CHV.[37]

5. Standardized referral pathway (from clinic) and follow-up (to clinic)

Patients face multiple challenges in engaging in primary care longitudinally, as described above.[12] With regards to secondary and tertiary care, referral pathways are complex, result in significant delays in care, and are most often unfunded.[38] Secondary care options are, in most humanitarian contexts, insufficient to meet needs. Additionally, limited coordination between clinical providers (NGOs, MoH, private) hinders referrals and data sharing.[5] Evidence suggests strategies that might support improved patient adherence to primary care. SMS-based reminders sent to Syrian refugees with NCDs in Lebanon improved patient attendance to clinic appointments.[39] A patient-held medical record trialed in Chiapas, Mexico contributed to a CHV intervention to improve patient adherence to care as well as patient understanding of their own health needs.[16]

Based on available evidence and the findings of this workshop, CHVs could be coordinators of care between facilities and organizations. A dedicated health information system designed for use by CHVs could provide them with a succinct record of clinic visits, medications, complications, and referral activities with a focus on high needs patients.[16,29]

Limitations

Workshop facilitators relied on Arabic translation during the exercise, as both Arabic and English speakers participated. A diverse set of stakeholders, including Syrian refugees, vulnerable Jordanians, CHVs, physicians, and health programs as well as national/UN leadership were invited. While every effort was made to encourage full participation, it is possible that in this environment, some community members and CHVs felt unable to fully participate. Interviews were conducted by an English-speaking researcher with the assistance of an Arabic speaking researcher as needed, which may have resulted in interviewee discomfort or subtle translation errors.

Conclusion

A participatory causal loop analysis allowed for the generation of an agreed-upon understanding of relevant context, barriers, and possibilities for a CHV-led primary care program for NCDs among Syrians. It involved stakeholders from across the humanitarian system and beneficiaries, who do not usually have opportunities to interact in this way. Our experience with this methodology was that the process was rapidly learned by the group and allowed for an open and honest discussion of a challenging situation.

References

1. Situation Syria Regional Refugee Response. https://data2.unhcr.org/en/situations/syria. Accessed February 26, 2020.
2. Rehr M, Shoaib M, Ellithy S, et al. Prevalence of non-communicable diseases and access to care among non-camp Syrian refugees in northern Jordan. *Confl Health*. 2018;12(1). doi:10.1186/s13031-018-0168-7
3. Ratnayake R, Rawashdeh F, Abu Al Rub R, et al. Access to care and prevalence of hypertension and diabetes among Syrian refugees in northern Jordan. *Jama Netw Open*.
4. Elliott JA, Das D, Cavailler P, et al. A cross-sectional assessment of diabetes self-management, education and support needs of Syrian refugee patients living with diabetes in Bekaa Valley Lebanon. doi:10.1186/s13031-018-0174-9
5. Boulle P, Kehlenbrink S, Smith J, Beran D, Jobanputra K. Challenges associated with providing diabetes care in humanitarian settings. *Lancet Diabetes Endocrinol*. 2019;8587(19). doi:10.1016/S2213-8587(19)30083-X
6. Spiegel PB, Checchi F, Colombo S, Paik E. Health-care needs of people affected by conflict: future trends and changing frameworks. *Lancet*. 2010;375(9711):341-345. doi:10.1016/S0140-6736(09)61873-0

7. Ansbro É, Maconick L, Ellithy S, Jobanputra K, Tarawneh M, Roberts B. “To die is better for me”, social suffering among Syrian refugees at a noncommunicable disease clinic in Jordan: a qualitative study. 2019:1-31. doi:10.21203/rs.2.19227/v1
8. Imhín Ansbro E´, Garry S, Karir V, et al. Delivering a primary-level non-communicable disease programme for Syrian refugees and the host population in Jordan: a descriptive costing study. *Health Policy Plan*. 2020:1-10. doi:10.1093/heapol/czaa050
9. Slama S, Kim H-J, Roglic G, et al. Care of non-communicable diseases in emergencies. *www.thelancet.com*. 2017;389. doi:10.1016/S0140-6736(16)31404-0
10. World Health Organization Eastern Mediterranean Region. *Health of Refugees and Migrants Practices in Addressing the Health Needs of Refugees and Migrants WHO Eastern Mediterranean Region 2018*.; 2018.
11. Doocy S, Lyles E, Akhu-Zaheya L, Oweis A, Al Ward N, Burton A. Health service utilization among syrian refugees with chronic health conditions in Jordan. *PLoS One*. 2016;11(4):1-12. doi:10.1371/journal.pone.0150088
12. Zahrah Mcnatt Z, Freels PE, Chandler H, et al. “What’s happening in Syria even affects the rocks”: a qualitative study of the Syrian refugee experience accessing noncommunicable disease services in Jordan. doi:10.1186/s13031-019-0209-x
13. Washington CH, Tyler FJ, Davis J, et al. Trauma training course: innovative teaching models and methods for training health workers in active conflict zones of Eastern Myanmar. 2014. doi:10.1186/s12245-014-0046-z
14. Musoke D, Ndejjo R, Kiracho EE. *Health for the People : National Community Health Worker Programs from Afghanistan to Zimbabwe*.; 2020.
15. Farzadfar F, Murray CJL, Gakidou E, et al. Effectiveness of diabetes and hypertension management by rural primary health-care workers (Behvarz workers) in Iran: A nationally representative observational study. *Lancet*. 2012;379(9810):47-54. doi:10.1016/S0140-6736(11)61349-4
16. Newman PM, Franke MF, Arrieta J, et al. Community health workers improve disease control and medication adherence among patients with diabetes and/or hypertension in Chiapas, Mexico: an observational stepped-wedge study. *BMJ Glob Heal*. 2018;3:566. doi:10.1136/bmjgh-2017-000566
17. Neupane D, McLachlan CS, Mishra SR, et al. Effectiveness of a lifestyle intervention led by female community health volunteers versus usual care in blood pressure reduction (COBIN): an open-label, cluster-randomised trial. *Lancet Glob Heal*. 2018;6(1):e66-e73. doi:10.1016/S2214-109X(17)30411-4
18. Varghese J, Kutty VR, Paina L, Adam T. Advancing the application of systems thinking in health: understanding the growing complexity governing immunization services in Kerala, India. *Heal Res policy Syst*. 2014;12(47). doi:10.1186/1478-4505-12-36
19. Li Q, Hyder AA, Peters DH, Paina L, Bishai D. Advancing the application of systems thinking in health: why cure crowds out prevention. *Heal Res Policy Syst*. 2014;12(1):1-5. doi:10.1186/1478-4505-12-28
20. Paina L, Bennett S, Ssengooba F, Peters DH. Advancing the application of systems thinking in health: Exploring dual practice and its management in Kampala, Uganda. *Heal Res Policy Syst*. 2014;12(1). doi:10.1186/1478-4505-12-41
21. Williams B, Hummelbrunner R. *Systems Concepts in Action. A Practical Toolkit.* Stanford,

California: Stanford University Press; 2011.

22. Elo S, Kyngä H. The qualitative content analysis process. *J Adv Nurs*. 62(1):107-115. doi:10.1111/j.1365-2648.2007.04569.x

23. Vensim PLE. https://vensim.com/vensim-personal-learning-edition/. Accessed July 15, 2020.

24. Akik C, Ghattas H, Mesmar S, Rabkin M, El-Sadr WM, Fouad FM. Host country responses to non-communicable diseases amongst Syrian refugees: A review. *Confl Health*. 2019;13(1). doi:10.1186/s13031-019-0192-2

25. Fawad M, Rawashdeh F, Parmar PK, Ratnayake R. Simple ideas to mitigate the impacts of the COVID-19 epidemic on refugees with chronic diseases Main text. doi:10.1186/s13031-020-00277-x

26. Kane J, Landes M, Carroll C, Nolen A, Sodhi S. A systematic review of primary care models for non-communicable disease interventions in Sub-Saharan Africa. *BMC Fam Pract*. 2017;18(1):1-12. doi:10.1186/s12875-017-0613-5

27. Collier J, Kienzler H. Barriers to cardiovascular disease secondary prevention care in the West Bank, Palestine-a health professional perspective. doi:10.1186/s13031-018-0165-x

28. Jeet G, Thakur JS, Prinja S, Singh M. Community health workers for non-communicable diseases prevention and control in developing countries: Evidence and implications. 2017. doi:10.1371/journal.pone.0180640

29. Sethi S, Jonsson R, Skaff R, Tyler F. *Community-Based Noncommunicable Disease Care for Syrian Refugees in Lebanon*. Vol 5.; 2017. www.ghspjournal.org. Accessed May 12, 2020.

30. International Federatin of the Red Cross. *Healthy Lifestyle Toolkit - IFRC*.; 2016. https://www.ifrc.org/en/what-we-do/health/diseases/noncommunicable-diseases/ncds-toolkit/. Accessed August 17, 2020.

31. American Diabetic Association. *Screening for Type 2 Diabetes*.; 2003. https://care.diabetesjournals.org/content/diacare/26/suppl_1/s21.full.pdf. Accessed August 17, 2020.

32. Al-Ghamdi A, Al-Turki K, El-Zubaier A. A COMMUNITY-BASED SCREENING CAMPAIGN FOR THE DETECTION OF DIABETES MELLITUS AND HYPERTENSION IN THE EASTERN PROVINCE, SAUDI ARABIA: METHODS AND PARTICIPATION RATES. *J Community Fam Med*. 2007;14(3):91-97. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3410157/. Accessed August 17, 2020.

33. Kehlenbrink S, Smith J, Ansbro É, et al. The burden of diabetes and use of diabetes care in humanitarian crises in low-income and middle-income countries. *Lancet Diabetes Endocrinol*. 2019;8587(19):1-10. doi:10.1016/S2213-8587(19)30082-8

34. Mendis S. *Package of Essential NCD Interventions for Primary Health Care in Humanitarian Emergencies (PEN-H)*.; 2019.

35. Han H-R, Kim K, Murphy J, et al. Community health worker interventions to promote psychosocial outcomes among people living with HIV-A systematic review. 2018. doi:10.1371/journal.pone.0194928

36. Van Ommeren M, Hanna F, Weissbecker I, Ventevogel P. *Mental Health and Psychosocial Support in Humanitarian Emergencies النفسية والدعم النفيس االجتامعي يف حاالت الطوارئ اإلنسانية الصحة*. Vol 21.; 2015. http://www.mhpss.net. Accessed August 17, 2020.

37. Kayali M, Moussally K, Lakis C, et al. Treating Syrian refugees with diabetes and

hypertension in Shatila refugee camp , Lebanon : Médecins Sans Frontières model of care and treatment outcomes. *Confl Health*. 2019;13(12):1-11.

38. Akik C, Ghattas H, Mesmar S, Rabkin M, El-Sadr WM, Fouad FM. Host country responses to non-communicable diseases amongst Syrian refugees: a review. *Confl Health*. 2019;13(1):8. doi:10.1186/s13031-019-0192-2

39. Doocy S, Paik KE, Lyles E, et al. Guidelines and mHealth to Improve Quality of Hypertension and Type 2 Diabetes Care for Vulnerable Populations in Lebanon: Longitudinal Cohort Study. *JMIR mHealth uHealth*. 2017;5(10):e158. doi:10.2196/mhealth.7745

Contributors

PKP and RR designed the study, NA, RAAR, MF, KAA and RAM provided critical support during the causal loop analysis workshop. PKP, RR, an FR analyzed and interpreted the data. PKP and RR wrote the article. All authors made critical revision to the article. All authors have read and approved the final version of the manuscript.

Data Availability Statement

The qualitative data from this study will not be made publicly available, due to the ease at which interviewees may be identified through the full transcripts, even if key sections are redacted. Furthermore, during the informed consent process, participants did not consent to make data publicly available.

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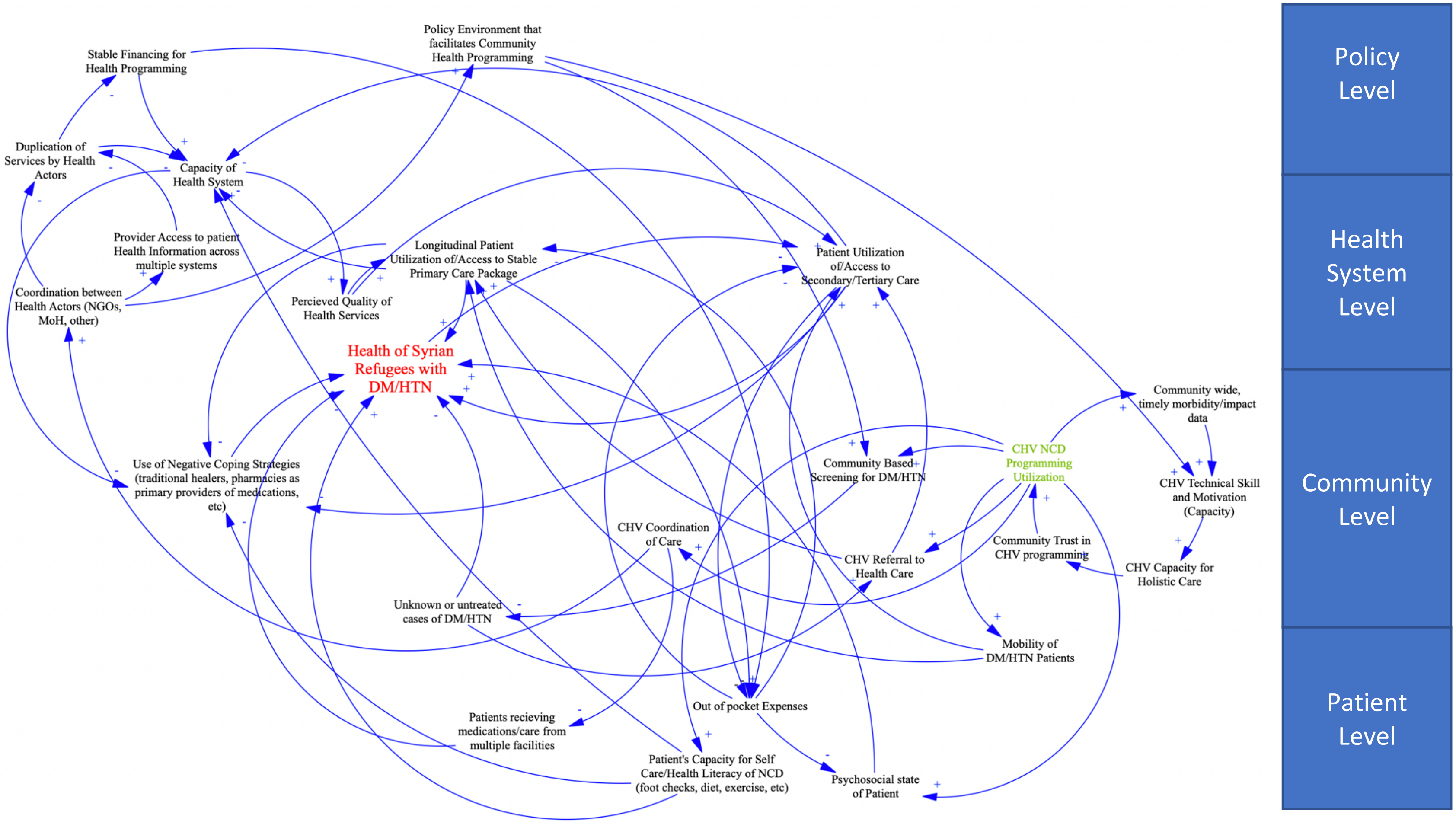
Stable Financing for Health Programming
Policy Environment that facilitates Community Health Programming
Duplication of Services by Health Actors
Capacity of Health System
Provider Access to patient Health Information across multiple systems
Coordination between Health Actors (NGOs, MoH, other)
Longitudinal Patient Utilization of/Access to Stable Primary Care Package
Percieved Quality of Health Services
Patient Utilization of/Access to Secondary/Tertiary Care
Health of Syrian Refugees with DM/HTN
Community wide, timely morbidity/impact data
CHV NCD Programming Utilization
Community Based Screening for DM/HTN
CHV Technical Skill and Motivation (Capacity)
Use of Negative Coping Strategies (traditional healers, pharmacies as primary providers of medications, etc)
CHV Coordination of Care
Community Trust in CHV programming
CHV Referral to Health Care
CHV Capacity for Holistic Care
Unknown or untreated cases of DM/HTN
Mobility of DM/HTN Patients
Out of pocket Expenses
Patients recieving medications/care from multiple facilities
Patient's Capacity for Self Care/Health Literacy of NCD (foot checks, diet, exercise, etc)
Psychosocial state of Patient
Policy Level
Health System Level
Community Level
Patient Level

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Integrating community health volunteers into non-communicable disease management among Syrian refugees in Jordan: a causal loop analysis.

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Title: Integrating community health volunteers into non-communicable disease management among Syrian refugees in Jordan: a causal loop analysis

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Abstract:

Objectives: Globally, there is emerging evidence on the use of community health workers and volunteers (CHVs) in low- and middle-income settings for the management of non-communicable diseases, provision of out-of-clinic screening, linkage with health services, promotion of adherence, and counseling on lifestyle and dietary changes. Little guidance exists on the role of this workforce in supporting non-communicable disease care for refugees who lack access to continuous care in their host country. The goal of this work was to evaluate the current roles of CHVs in the management of diabetes and hypertension among Syrian refugees and suggest improvements to the current primary care model utilizing community health strategies.

Setting and Participants: A participatory, multi-stakeholder causal loop analysis workshop with representatives from the Ministry of Health of Jordan, non-governmental organizations, and UN agencies, and community health volunteers and refugee patients was conducted in June 2019 in Amman, Jordan.

Primary Outcome: This causal loop analysis workshop was used to collaboratively develop a causal loop diagram (CLD) and CHV strategies designed to improve the health of Syrian refugees with diabetes and hypertension living in Jordan.

Results: During the causal loop analysis workshop, participants collaboratively identified and mapped how CHVs might improve care among diagnosed patients. Possibilities identified included the following: provide psychosocial support and foundational education on their conditions, strengthen self-management of complications (e.g., foot checks), and monitor patients for adherence to medications and collection of basic health monitoring data. Elderly refugees with restricted mobility and/or uncontrolled disease were identified as a key population where CHVs could provide home-based blood glucose and blood pressure measurement and targeted health education, to provide more precise monitoring.

Conclusions: CHV programs were cited as a key strategy to implement secondary prevention of morbidity and mortality among Syrian refugees, particularly those at high-risk of decompensation.

Strengths and Limitations of this Study

- The findings of this study resulted from convening of a group of diverse stakeholders related to diabetes and high blood pressure among Syrian refugees in Jordan.

- This study provides concrete ways in which a CHV program might support Syrian refugees in Jordan with diabetes and hypertension.

- The findings of this study may have been limited by translations errors, or a lack of ability to express views openly in a mixed-stakeholder setting.

Introduction

More than 5 million Syrian refugees are displaced throughout the Middle East as a result of the conflict in Syria, with 655,000 displaced in Jordan. [1] The majority of these refugees in Jordan live outside of camps.[2] Among non-camp Syrian refugees ≥18 years living in Ramtha and Mafraq governorates in Jordan, 9.8%, 17.2%, and 7.3% reported diagnoses of diabetes, hypertension, or both conditions.[3] Among Syrian refugees ≥30 years, 22.9% of those with above-threshold random blood sugar, and 39.1% with above-threshold blood pressure did not report a previous diagnosis.[3] Refugees have been displaced for many years, and may have developed these conditions after leaving Syria.[4]Prolonged displacement and a high burden of NCDs require that primary care predominantly delivered by non-governmental organizations (NGOs) be optimized to prevent severe morbidity and mortality. [5–9]

Syrian refugees in Jordan access health care in fragmented ways. In camp settings, non-governmental organizations (NGOs) typically provide clinical care through a primary care model that favors curative therapies over preventive care.[10] Syrian refugees in peri-urban and urban areas access care via a patchwork of multiple health providers. These include NGO facilities that usually provide primary care services and medications at low or no cost, Ministry of Health (MoH) clinics that provide services for low cost but often have limited resources, and private clinics which typically provide more expensive services. While NGO clinics often provide free services, referrals to secondary and specialist care, diagnostics, and laboratories typically require out of pocket payments.[11,12] Essential medications may have limited availability due to funding issues and stock-outs at both NGO and MoH facilities. Increasingly, NGOs use cohorts to provide more comprehensive services to patients with NCDs in Jordan which creates challenges for those who find themselves excluded from these systems.[8] Changing rules governing refugee access to MoH clinics have resulted in further confusion and barriers in accessing care.[11]

Studies have shown positive impact of community health workers on NCD management in low- and middle-income settings.[13–18] However, limited guidance exists on the specific role CHVs might play in delivering care to refugees living with NCDs in protracted displacement settings. Since 2011, the International Rescue Committee (IRC) has administered Jordan's largest community health volunteer (CHV) program, serving both Syrian refugees in non-camp settings as well as uninsured Jordanian patients. CHVs are refugees or Jordanians who may or may not have prior health experience. They receive an honorarium to volunteer a limited number of days per month. CHVs provide basic health education and referrals to primary care at IRC clinics when health issues are identified. This program historically supported primary care functions for all household members, including monitoring, referral, and health education for child health, prenatal and antenatal care, and other health conditions. The specific role that CHVs might play in NCD care, from linkage to care, out-of-clinic monitoring, or support of medication adherence to early screening for complications or early disease requires careful consideration from multiple stakeholders.

Causal loop analysis, drawn from systems dynamics theory, provides a means to understand complex systems and, when done in a participatory manner, suggest programming that is sensitive to the strengths and constraints of health systems.[19–21] Health care for refugees can be considered a complex adaptive system which results from the interactions of multiple actors (e.g., beneficiaries, NGOs, health workers) and processes (e.g., registration, diagnosis, adherence to care). Interactions between various components of this type of system are non-linear and difficult to predict. Causal loop analysis provides a means to qualitatively understand complex systems, and potential consequences of modifications and new programming within the system.[19,22,23]

A participatory causal loop analysis workshop was convened in June 2019 to explore the existing models for CHV programs in Jordan and the means by which these programs might be improved to fill in gaps for the provision of continuous health care to Syrian refugees with diabetes and hypertension.

Methods

The researchers co-developed the preliminary causal loop diagram in order to provide a platform for stakeholders to improve upon via a multi-phase group model building exercise. In the first phase, a preliminary causal loop diagram was developed by the research team, after discussions with IRC health staff and document review. PP (co-PI) and FR (research manager), both female, conducted 20 key informant interviews (KII) in May-June 2019 in Irbid and Mafraq governorates. PP is an experienced mixed-methods researcher and FR is Arabic-speaking and has expertise in community health, nursing, and research.

Key informants were purposively selected to include experts in NCDs from the MoH, focal points of national and international health NGOs, and through IRC programs: CHVs, Syrian patients with diabetes and hypertension, and health care providers (MDs, RNs, and administrators). The initial list of key informants was created in collaboration with IRC staff, and this list was iteratively grown by asking interviewees to recommend relevant others (**Box 1**). The majority of individuals interviewed and previously interacted with the researchers in the context of the broader research project on NCDs among Syrian refugees in Jordan, and were aware of the motivations and goals for this work. Community perspectives as well as the perspectives of CHVs who had practiced in target communities, often for years, were prioritized in order to fully consider the limitations of current programming and the ways in which future programming might meet identified gaps in care. Individuals were interviewed by the research team using a semi-structured interview guide **(Box 1)**. All interviews were carried out in the respondent's preferred language, English or Arabic in private locations outside of the home. Participants were contacted by a combination of phone, email, and in-person requests to participate. All approached agreed to participate, extensive notes were taken during each roughly one-hour interview. To ensure privacy of responses no interviews were recorded.

Box 1

Individuals Interviewed

Community Health Professor from the Jordan University of Science and Technology (1)
Syrian refugee patients (1 male, 1 female)

IRC Staff (7)
  - Including CHVs (1 male, 1 female)

Representatives from Médecins Sans Frontières (MSF), Medair, Altkaful, Royal Health Awareness Society (RHAS), ABT Associates, International Medical Corps (6)
Jordanian Ministry of Health (2)
UNHCR (1)

Domains of Semi-Structure Interviews

- Components of the Jordanian health system accessed by Syrian refugees
- Linkages between elements of the health system
- Barriers and facilitators in accessing care for diabetes and hypertension
- Current role of CHVs
- Potential roles of CHVs in care of patients with diabetes and hypertension
- Opportunities and constraints in realizing the potential of CHVs in managing diabetes and high blood pressure

PP and RR used content analysis strategies to identify key themes from these interviews.[24] These themes were used to generate variables for inclusion in a preliminary causal loop diagram, as well as relationships between each of these variables.[25] All causal loop diagrams were generated and edited using VensimPLE software.[26]

During a two-day workshop held in Amman in June, 2019, stakeholders discussed and refined this preliminary causal loop diagram, including all variables and definitions generated by the research team. A summary of workshop proceedings is included in Box 2. The objective was to identify gaps and strengths in the current model of provision of NCD care for Syrian refugees and then identify CHV-led strategies to fill key gaps, while building on strengths in the system and incorporating mitigation strategies for anticipated barriers. A broad group of stakeholders were invited to comment on all aspects of this complex system. Five male and female CHVs represented perspectives on current and potential roles for CHVs in Jordan, and the ways in which their roles might be expanded to address unmet needs. Similarly, Syrian refugee patients shared perspectives on challenges faced. NGO, MoH, and UN/WHO representatives provided programmatic and funding context, and IRC leadership provided perspectives based on their management of the current CHV program. Workshop facilitators presented data from a community-based survey of IRC catchment areas conducted during March/April of 2019 examining prevalence of disease, medication adherence, self-reported prevalence of complications and access to care among beneficiaries with diabetes and/or hypertension.[3] Additionally, workshop facilitators presented a summary of a global literature review on the roles of CHVs in management of NCDs. This was done in order to orient stakeholders less familiar with community health approaches, and more familiar with primary care for NCDs, programming orientation and context.

Workshop participants first met in small, mixed stakeholder groups to generate their own causal loop diagrams focusing on the outcome of the health of Syrian refugees with diabetes and high blood pressure. Each small group presented their work to the larger group for comparison and integration. The research team then presented the preliminary causal loop diagram to the group, who then collaboratively edited the preliminary diagram in small groups and later as a whole. This exercise led to the final, collaboratively built, causal loop diagram (**Figure 1**). Then, the group commented on barriers and opportunities within this system to achieving a CHV strategy with capacity to improve diabetes and high blood pressure outcomes.

Box 2. Stakeholder Workshop Proceedings

Day 1:
Review workshop objectives
Review regional data on NCDs, Community Health Volunteer programming
Stakeholder training on causal loop diagrams
Mixed stakeholder small groups generate their own causal loop diagrams
Present results of research team analyses--> preliminary causal loop diagram and discussion of all variables.

Day 2:
Mixed stakeholder small groups comment and edit preliminary causal loop diagram
Whole stakeholder group discussion on preliminary causal loop diagram, with real-time refinement
Final causal loop diagram and variables generated (**Box 2, 3**)
Stakeholder group identifies barriers and opportunities within the system to improve health utilizing Community Health Volunteer strategies

A final list of variables generated by the combination of research team content analysis of qualitative data and stakeholder feedback during the two-day workshop are listed in **Box 3**. These variables and linkages are summarized in the final causal loop diagram below in **Figure 1**, which, using positive and negative signs, considered how various components interact to ultimately affect health status. The central outcome of interest, "Health of Syrian Refugees with DM/HTN," has been highlighted in the CLD in red. Means by which CHVs might support the health of Syrian refugees in the Jordanian context as identified by this mixed stakeholder workshop are presented below, along with barriers that may limit opportunities.

Ethics/Consent

This study was approved by the Institutional Review Boards of the University of Southern California (#HS-18-00569, H 1.00.020), International Rescue Committee (IRB #: 00009752 FWA #: 00022773), and Jordan University of Science and Technology (83/117/2018, 57/28/2018). Key informants gave written consent to participate, and workshop participants gave verbal consent. Individuals were asked to keep content of the discussions during the workshops confidential. Content of key informant interviews was summarized and shared in the workshop in a de-identified manner.

Patient and public involvement

Syrian patients and Syrian CHVs participated in the workshop to gather their perceptions and insight into the needs of NCD patients. They were not directly involved in the development of the research design.

Results

Variables are described below and arranged in the causal loop diagram according to relevance at a *national/global policy level*, *health system level*, *community health level*, and *patient* level. Relationships between variables are described in the final causal loop diagram with arrows: two variables linked by an arrow and a (+) sign indicate that when one variable is influenced positively or negatively, the other variable also increases or decreases in importance. Similarly, variables linked by an arrow and a (–) sign indicate that when one variable varies, the linked variable goes in the opposite direction.

Box 3. Final list of variables

Patient/Community

Psychosocial State of Patient
Patient Capacity for Self/Care and Health Literacy
Out of Pocket Expenses
Mobility of Patients
Patients Receiving Care from Multiple Facilities
Unknown or Untreated Cases of DM/HTN
Use of Negative Coping Strategies

Health System
Capacity of Health System
Longitudinal Patient Access/Utilization to Primary Care
Patient Utilization of/Access to Secondary/Tertiary Care
Coordination of between health Actors
Provider Access to Health Information Across Systems
Perceived Quality of Health Services

Policy
Stable Financing for Health Programming
Duplication of Services by Health Actors
Policy Environment that facilitates Community Health Programming

Roles of Community Health Volunteers
CHV Program Utilization
Community-Based, Timely Morbidity/Impact Data
CHV Technical Skill and Motivation
CHV Capacity for Holistic Care
Community Trust in CHVs
Community Based Screening for DM/HTN
CHV Coordination of Care
CHV Referral to Care

[Insert "Final CLD March 2021"]

Figure 1. Final Causal Loop Diagram: Community Health Volunteer Program for Syrian Refugees and Vulnerable Jordanians with DM/HTN

Current Challenges in NCD Delivery and Utilization

The following section outlines current challenges in NCD Delivery and utilization at each level of the health system. Linkages describing the existing system are highlighted by thin dark blue arrows in the final CLD (**Figure 1**).

Patient/Community Level

Out of pocket expenses were identified as the single most important factor affecting health seeking behavior at the patient level **(Box 4; Quotes 1,2)**. The *patient's capacity for self-care and health literacy* was deemed central to appropriate management of diabetes and hypertension. This includes patient understanding of the chronic nature of their disease and treatment, the need for daily medication, routine dietary and exercise needs and avoidance of harmful behaviors such as smoking, and timely identification of complications. *Patients receiving care from multiple facilities* were seen as often suffering negative consequences as a result. It was recognized by stakeholders that patients may seek duplicate services as a relatively common coping mechanism, given limited and changing clinical services available to refugees. The *psychosocial state of the patient* was recognized as key in care-seeking behavior, as refugees are predisposed to suffer from serious mental illness and trauma, which may introduce feelings of hopelessness and impair the ability to prioritize management of chronic health conditions. Finally, patients with impaired mobility, including women who must remain at home, the elderly and disabled, often have a challenging time traveling to health facilities **(Box 4; Quote 3)**.

At the community level, stakeholders identified *unknown/untreated cases* of diabetes and hypertension as a potentially large unmet need and knowledge gap. In the context of limited access to primary care, refugees face barriers to obtaining a diagnosis, including seeking care only when conditions become symptomatic, and a lack of exposure to information about NCDs. Finally, in an environment where services available to patients often change with shifting policy goals and funding priorities, patients often engage in *negative coping strategies* to fill gaps in care. These may involve seeking care from non-physician providers, including traditional healers who provide herbal remedies, seeking medications directly from pharmacies without the involvement of a physician, taking prescribed medications in lower doses or less frequently to make them last longer, or forgoing medications entirely despite a known diagnosis. Patient factors above, in particular *high out of pocket expenses, patient's* [most often sub-optimal] *capacity for self-care and health literacy,* and challenging *psychosocial state of the patient*, in combination with a potentially high burden of *unknown/untreated cases* of diabetes and among diagnosed persons, the perceived common use of *negative coping strategies,* could potentially result in poor health outcomes.

Health System

Stakeholders identified several factors at the level of the health system that affects the health of Syrian refugees. The *capacity of the health system* was identified as suffering negatively from a lack of *coordination between health actors (NGOs, MoH).* Stakeholders, particularly medical providers, felt that a lack of *provider access to health information across multiple systems* was responsible, at least in part, for avoidable duplication of services. Stakeholders described unknowingly repeating testing or providing multiple prescriptions for either duplicate or potentially interacting medications to patients who receive care from multiple health centers **(Box 4; Quote 4)**. This was flagged as not only a danger to patients given challenges monitoring patients who seek care from multiple providers, it was seen as a strain on limited resources when services are duplicated. Generally, key informants and workshop participants agreed that MoH services were strained, and many patients, CHVs, and health actors perceived the quality of MoH services to have suffered as a result. Improved coordination between health NGOs had, per participants, mitigated many of these issues during the response; however, most felt coordination could be improved, particularly on improved access to medical records across health systems (via patient-held records or formal mechanisms for sharing information). Stakeholders uniformly felt capacity of the health system was harmed by a lack of *stable financing for health programming*.

Barriers to longitudinal access to and utilization of primary care, largely resulting from the patient/community factors described above, were felt to substantially impact health outcomes among refugees with NCDs. Participants highlighted that geographic and financial access might not always automatically result in medically-required, longitudinal utilization by patients, with factors such as health literacy and competing household priorities playing an important role **(Box 4; Quote 2)**. *Access to and utilization of secondary and tertiary care*, when needed, was recognized as critical to the health of patients with diabetes and hypertension—particularly those who had experienced a complication of their disease. It was also recognized, both in key informant interviews and the workshop, that humanitarian agencies largely focus on primary care, with refugees facing very limited and typically expensive access to secondary or tertiary care **(Box 4; Quote 5)**.

Policy

Stakeholders identified key policy-level variables related to health status. Typical funding cycles for humanitarian programs are in the 1-2 year range, while NCD programming was felt to require a longer-term strategy. Donor funding of humanitarian NGO health programming has also decreased in the region per workshop participants, which has resulted in a lack of the type of *stable financing for health programming* that is critical for longitudinal care of diabetes and hypertension. **(Box 4; Quote 1)**. Workshop participants noted that the MoH was in the challenging position of having to provide for a large influx of refugees with limited funding, which has resulted in changing policies with regards to fees charged to Syrian refugees for health services. These changing policies have, in themselves, resulted in distrust and inaccessibility among refugees of MoH health services. *Duplication of services by health actors* in the domain of NCD care, with multiple providers present in some geographic areas with relatively fewer in others, was felt by participants to have resulted in inefficient use of limited funding. Many key informants during KIIs cited a lack of coordination of humanitarian programming nationally, resulting in overlapping programming in some locations and a lack of services in other geographic regions **(Box 4; Quote 6).**

Potential for CHV Programming

Stakeholders were asked to consider how a CHV program might, both positively and negatively, impact the health of Syrian refugees within the systems described above. Linkages representing areas of potential impact are highlighted with thick light blue arrows in the CLD (**Figure 1**).

CHV capacity, including their technical skills, workload, appropriate remuneration, and motivation, were seen as central to the success of any CHV program. CHVs draw from the communities they serve—thus, their understanding of the social and cultural context was also seen as a tremendous asset to their work. Current policy in Jordan allows for limited payment of CHVs, which serves as a barrier. They have to been seen as highly skilled and reliable by the communities they serve, reflected in the variable *community trust in CHV programming. CHV capacity for holistic care,* namely the ability to make accurate and timely referrals to resources not related to the central goals of their program (food aid, services for survivors of violence, psychosocial aid, cash transfers, etc) were considered central to securing patient engagement. Stakeholders, including CHVs themselves, agreed that each time a CHV is unable to meet the need of a patient whether or not it is related to health care, that patient loses trust in CHV services. As a result, that patient may not engage with CHVs on health-related messaging and services in the future. However, CHVs stated that timely and meaningful referrals require improved coordination between humanitarian actors to ensure that CHVs do not make referrals to services that are no longer available. *CHV capacity*, *community trust in CHV programming* and *CHV capacity for holistic care* were thought to positively reinforce *CHV NCD program utilization* by the target beneficiaries.

Stakeholders identified multiple ways that a CHV NCD program might support the health of patients at multiple levels beyond the current system. CHVs were felt to be a critical conduit for increased patient knowledge on management of their disease, specifically increasing *patient's capacity for self-care and health literacy.* CHVs could strengthen health literacy and self-management by providing targeted health messaging (on foot checks, adherence to medication and clinic visits) **(Box 4; Quote 7)**. CHVs might also serve as a means of screening adults to identify undiagnosed cases of diabetes and hypertension, provide *community-based, timely morbidity/impact data*, which might strengthen access to diagnoses and care as well as target particularly high-risk patients. CHVs could also provide basic psychosocial support and referrals to more advanced care for patients suffering from more acute mental health needs. CHVs were also felt to be an important means of combating negative coping strategies, both via education and referrals to services that might allow for more stable access to medications and allopathic primary care. Stakeholders identified patients with limited mobility as a key population that might greatly benefit from CHVs **(Box 4; Quote 3)**. CHVs could, with training, provide home-based blood glucose and blood pressure measurement and coordinate with clinics to provide disease management and health education, reducing the need for more frequent visits to a health facility.

Though CHV led, *community-based screening* might increase the burden on the health system, stakeholders felt that a robust CHV program might also decrease the burden on fixed clinics by reducing *duplication of services* (helping patients coordinate care within one health system as much as possible and aligning services between multiple health providers when needed), identifying poorly controlled disease early and thus preventing complications that require secondary and tertiary care. As well, taking on health education at the community level, freeing health facilities to focus more on medical management during appointments. National policies prevent those who are not licensed nurses or physicians from measuring blood glucose and blood pressure as a part of the provision of health care, though measurement devices are available to households for purchase and private use. This, and the need for consistent funding sources, highlight the importance of a *policy environment that facilitates community health programming.*

Stakeholders felt that increased utilization of primary care and preparedness for routine NCD management of some complications at the PHC level might decrease the reliance on scarce secondary and tertiary resources. However, participants noted that such an increase in primary care utilization would create a strain on the *capacity of the health system* as it risks inadequate resources and planning. Overall *capacity of the health system* was thought to be an essential component of high-quality primary, secondary, and tertiary care.

Box 4. Quotes from Key Informant Interviews

1. *Previously there were many NGOs providing services, but now there are less; there are just a few that provide free services. [Humanitarian NGO] can provide some services, but they charge and even this subsidized rate is challenging. Only [different humanitarian NGO] is providing free services, and said [third humanitarian NGO] is not taking patients. If services or medications are not available in these places, I have to buy it externally.* –Syrian refugee

2. *Finances are the main barrier. Even if you give money to an old man with diabetes, if he has five children he will feed them and prioritize rent over his own health. Rental costs are very high and this is challenging. When we do our post-cash-transfer calls, we ask why are you still in debt? Recipients will often reply that they had to pay rent to avoid becoming homeless.*
   – NGO Health Program Administrator

3. *When we went to the field, some women had instructions from husbands that they could not go outside their home. They when they saw the CHVs, said, "thank God! If you can help me here in the home that is much better"* –IRC CHV

4. *The only link between different health providers is the patient. We try to get records of investigations from other NGOS, etc—but most patients come in with no records, no data, no labs, no access to files from MoH or other NGOs. Strict privacy policies prevent coordination. This gets in the way of patient care.* –NGO health provider

5. *NCDs need time-intensive care, at least 20-30 min per visit, but health providers don't have that time. Most providers focus on treatment and not prevention—and health messages need to be repeated many times. There aren't adequate human resources for this. Health providers focus on treatment, not prevention.* -NGO Health Program Administrator

6. *When I started, we were attending NCD working groups--health sector meetings. I noted that these are not run as efficiently as they should be. It was a parade of bragging. No one is collaborating and actually sorting out what they should be doing, NGOs fight to maximize funding. There seems to be no entity regulating/coordinating which organization should focus on what specific issues, etc.* –NGO Health Program Administrator

7. *If a CHV calls and states that there are 70 cases of diarrhea in one community, with dehydration in this informal tent settlement, then we can go there. If well trained, these CHVs can provide vital information in real time. They can do clinical assessments as well if trained well. You don't need health care professionals to measure blood pressure or blood glucose, CHVs can do this. CHVs can save time/cost and prevent complications. They can identify complication early. If there is a certain case that needs a referral, then they can refer. I tell my CHVs, "You are all soldiers". CHVs save people's lives.* -CHV Program Administrator

8. *Will there be real action, or just talking?* --Syrian Patient, Male

Discussion

This causal loop analysis workshop identified many issues borne out by previous studies among Syrian refugees in the region, highlighting costs, challenges with changing capacities and services of humanitarian actors, lack of coordination between humanitarian actors as well as the MoH, shifting national policies regarding provision of health care by state facilities to refugees, and very limited access to secondary and tertiary care as major barriers in assuring continuous care. [11,12,23,27] Based on the results of this causal loop analysis workshop, the research team and program staff identified multiple CHV strategies that align with an evidence-based conceptual model of care for priority NCDs through primary care systems developed by Kane, et al.[28] These strategies and relevant evidence are presented below.

1. CHV-led community-based prevention via risk factor modification

.A CHV-led community-based prevention program focusing on risk factor modification would enable CHVs to provide targeted health education messaging to refugee communities on primary prevention, including smoking, diet and exercise, through tailored discussion of realistic goals given context-specific constraints. CHVs should engage the entire household on risk factor modification.[4,9] There are, however, complex issues with regards to diet (e.g., food insecurity), smoking cessation (e.g., high prevalence, culture), and promoting exercise (e.g., few options for female heads of households) among Syrian refugees.[4,5,29,30]

2. CHV screening of Syrian refugee communities for diabetes and hypertension

Diabetes and hypertension may remain undiagnosed among Syrian refugees in Jordan.[3] However, evidence suggests that screening in the community using random blood glucose and blood pressure has low specificity, and may yield excessive case numbers that when not appropriately discussed with a physician, result in limited linkage to care, and may result in low compliance with treatment and unclear impact on health.[31,15] In a population-based screening in Saudi Arabia, only a limited proportion of those who screened positive for disease were appropriately linked to care.[32] Additionally, generating high levels of demand that cannot be appropriately met may not be ethical.[9] Thus, CHV-led screening might target patient household members ≥30 years, those with a history of gestational diabetes and hypertension, or those who report symptoms that might be consistent with complications of an NCD during the course of a CHV household visit.

3. CHV support of adherence to medication, disease management, and clinical care.

Refugees may have a limited understanding of how to best manage NCDs and avoid complications, given little interaction with health care.[4,5] Studies of CHV interventions in rural Iran, Nepal, and Mexico have shown that CHV programming designed to improve adherence to care and identify complications early can improve patient outcomes in non-refugee settings.[15,16,33] Those with the poorest control tend to benefit the most from this type of CHV intervention.[16] In light of the relatively high burden of NCDs in many humanitarian contexts and limited resources, CHV interventions that focus on the most poorly compliant or controlled patients may have the highest impact. Strategies outlined in the WHO's Package of Essential NCD Interventions and tools created by the International Federation of the Red Cross and Red Crescent can be carefully adapted for CHV interventions, including: out-of-clinic biological monitoring to better identify patients in need of urgent or emergent referrals to clinical care,identification criteria for emergent and urgent referral of complications via simple case definitions for presentations of diabetic foot ulcers, hyper- or hypoglycemia, myocardial infarction, unstable angina, etc; and modules for self-management counseling and psychosocial support[30,34,35] Importantly, the CHV would provide a patient a preliminary identification of a suspect condition or complications with a direct referral to primary or secondary care services.

4. CHV Provision of mental health and psychosocial support

Conflict and displacement-affected patients may face mental illness barriers in dealing with NCDs. This may, in turn, affect compliance, adherence, motivation and result in increased reliance on negative coping mechanisms.[12,17] Stigma often prevents many Syrian refugees from seeking care for psychiatric needs, and clinic-based psychological services often do not have the capacity to meet the needs of these patients. There is some evidence of the effectiveness of psychosocial support for HIV adherence and better evidence for the application of mental health and psychosocial services in the context of a CHV program.[36] Thus, a CHV NCD focused program should address the identification of psychosocial health needs in some form, with referral to mental health services. [30,37 38]

5. Standardized referral pathways (from clinic) and follow-up (to clinic)

Patients face multiple challenges in engaging in primary care longitudinally, as described above.[12] Evidence suggests strategies that might support improved patient adherence to primary care. SMS-based reminders sent to Syrian refugees with NCDs in Lebanon improved patient attendance to clinic appointments.[39] A patient-held medical record trialed in Chiapas, Mexico contributed to a CHV intervention to improve patient adherence to care and patient understanding of their own health needs.[16] With regards to secondary and tertiary care, referral pathways are complex, result in significant delays in care, and leftthe patient to fund.[40] Secondary care options are, in most humanitarian contexts, insufficient to meet needs. Additionally, limited coordination between clinical providers (NGOs, MoH, private) hinders referrals and data sharing.[5] CHVs may play an important role in coordinating care for Syrian refugees with NCDs in Jordan. [16,29]

Limitations

Workshop facilitators relied on Arabic translation during the exercise, as both Arabic and English speakers participated. A diverse set of stakeholders, including Syrian refugees, vulnerable Jordanians, CHVs, physicians, and health programs as well as national/UN leadership were invited. While every effort was made to encourage full participation, it is possible that in this environment, some community members and CHVs felt unable to fully participate. Interviews were conducted by an English-speaking researcher with the assistance of an Arabic speaking researcher as needed, which may have resulted in interviewee discomfort or subtle translation errors.

Conclusion

Syrian refugees with diabetes and hypertension face multiple barriers in accessing care, within a complex system. CHVs potentially provide an efficient means of helping this vulnerable population navigate this system. Further studies on the effectiveness of CHV interventions on NCDs among Syrian refugees in Jordan are needed.

References

1. Situation Syria Regional Refugee Response. https://data2.unhcr.org/en/situations/syria. Accessed February 26, 2020.
2. Rehr M, Shoaib M, Ellithy S, et al. Prevalence of non-communicable diseases and access to care among non-camp Syrian refugees in northern Jordan. *Confl Health*. 2018;12(1). doi:10.1186/s13031-018-0168-7
3. Ratnayake R, Rawashdeh F, Abu Al Rub R, et al. Access to care and prevalence of hypertension and diabetes among Syrian refugees in northern Jordan. *Jama Netw Open*.
4. Elliott JA, Das D, Cavailler P, et al. A cross-sectional assessment of diabetes self-management, education and support needs of Syrian refugee patients living with diabetes in Bekaa Valley Lebanon. doi:10.1186/s13031-018-0174-9
5. Boulle P, Kehlenbrink S, Smith J, Beran D, Jobanputra K. Challenges associated with providing diabetes care in humanitarian settings. *Lancet Diabetes Endocrinol*. 2019;8587(19). doi:10.1016/S2213-8587(19)30083-X
6. Spiegel PB, Checchi F, Colombo S, Paik E. Health-care needs of people affected by conflict: future trends and changing frameworks. *Lancet*. 2010;375(9711):341-345. doi:10.1016/S0140-6736(09)61873-0
7. Ansbro É, Maconick L, Ellithy S, Jobanputra K, Tarawneh M, Roberts B. “To die is better for me”, social suffering among Syrian refugees at a noncommunicable disease clinic in Jordan: a qualitative study. 2019:1-31. doi:10.21203/rs.2.19227/v1
8. Imhín Ansbro E´, Garry S, Karir V, et al. Delivering a primary-level non-communicable disease programme for Syrian refugees and the host population in Jordan: a descriptive costing study. *Health Policy Plan*. 2020:1-10. doi:10.1093/heapol/czaa050
9. Slama S, Kim H-J, Roglic G, et al. Care of non-communicable diseases in emergencies. *www.thelancet.com*. 2017;389. doi:10.1016/S0140-6736(16)31404-0
10. World Health Organization Eastern Mediterranean Region. *Health of Refugees and Migrants Practices in Addressing the Health Needs of Refugees and Migrants WHO*

Eastern Mediterranean Region 2018.; 2018.

11. Doocy S, Lyles E, Akhu-Zaheya L, Oweis A, Al Ward N, Burton A. Health service utilization among syrian refugees with chronic health conditions in Jordan. *PLoS One*. 2016;11(4):1-12. doi:10.1371/journal.pone.0150088
12. Zahrah Mcnatt Z, Freels PE, Chandler H, et al. "What's happening in Syria even affects the rocks": a qualitative study of the Syrian refugee experience accessing noncommunicable disease services in Jordan. doi:10.1186/s13031-019-0209-x
13. Washington CH, Tyler FJ, Davis J, et al. Trauma training course: innovative teaching models and methods for training health workers in active conflict zones of Eastern Myanmar. 2014. doi:10.1186/s12245-014-0046-z
14. Musoke D, Ndejjo R, Kiracho EE. *Health for the People : National Community Health Worker Programs from Afghanistan to Zimbabwe*.; 2020.
15. Farzadfar F, Murray CJL, Gakidou E, et al. Effectiveness of diabetes and hypertension management by rural primary health-care workers (Behvarz workers) in Iran: A nationally representative observational study. *Lancet*. 2012;379(9810):47-54. doi:10.1016/S0140-6736(11)61349-4
16. Newman PM, Franke MF, Arrieta J, et al. Community health workers improve disease control and medication adherence among patients with diabetes and/or hypertension in Chiapas, Mexico: an observational stepped-wedge study. *BMJ Glob Heal*. 2018;3:566. doi:10.1136/bmjgh-2017-000566
17. Neupane D, McLachlan CS, Mishra SR, et al. Effectiveness of a lifestyle intervention led by female community health volunteers versus usual care in blood pressure reduction (COBIN): an open-label, cluster-randomised trial. *Lancet Glob Heal*. 2018;6(1):e66-e73. doi:10.1016/S2214-109X(17)30411-4
18. Sub Centre H. *Module for Multi-Purpose Workers (MPW)-Female/Male on Prevention, Screening and Control of Common Non-Communicable Diseases*.
19. Varghese J, Kutty VR, Paina L, Adam T. Advancing the application of systems thinking in health: understanding the growing complexity governing immunization services in Kerala, India. *Heal Res policy Syst*. 2014;12(47). doi:10.1186/1478-4505-12-36
20. Li Q, Hyder AA, Peters DH, Paina L, Bishai D. Advancing the application of systems thinking in health: why cure crowds out prevention. *Heal Res Policy Syst*. 2014;12(1):1-5. doi:10.1186/1478-4505-12-28
21. Paina L, Bennett S, Ssengooba F, Peters DH. Advancing the application of systems thinking in health: Exploring dual practice and its management in Kampala, Uganda. *Heal Res Policy Syst*. 2014;12(1). doi:10.1186/1478-4505-12-41
22. Williams B, Hummelbrunner R. *Systems Concepts in Action. A Practical Toolkit.* Stanford, California: Stanford University Press; 2011.
23. Zablith N, Diaconu K, Naja F, et al. Dynamics of non-communicable disease prevention, diagnosis and control in Lebanon, a fragile setting. *Confl Health*. 2021;15(1):4. doi:10.1186/s13031-020-00337-2
24. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res*. 2005;15(9):1277-1288. doi:10.1177/1049732305276687
25. Elo S, Kyngä H. The qualitative content analysis process. *J Adv Nurs*. 62(1):107-115. doi:10.1111/j.1365-2648.2007.04569.x

26. Vensim PLE. https://vensim.com/vensim-personal-learning-edition/. Accessed July 15, 2020.
27. Akik C, Ghattas H, Mesmar S, Rabkin M, El-Sadr WM, Fouad FM. Host country responses to non-communicable diseases amongst Syrian refugees: A review. *Confl Health*. 2019;13(1). doi:10.1186/s13031-019-0192-2
28. Kane J, Landes M, Carroll C, Nolen A, Sodhi S. A systematic review of primary care models for non-communicable disease interventions in Sub-Saharan Africa. *BMC Fam Pract*. 2017;18(1):1-12. doi:10.1186/s12875-017-0613-5
29. Sethi S, Jonsson R, Skaff R, Tyler F. *Community-Based Noncommunicable Disease Care for Syrian Refugees in Lebanon*. Vol 5.; 2017. www.ghspjournal.org. Accessed May 12, 2020.
30. International Federatin of the Red Cross. *Healthy Lifestyle Toolkit - IFRC*.; 2016. https://www.ifrc.org/en/what-we-do/health/diseases/noncommunicable-diseases/ncds-toolkit/. Accessed August 17, 2020.
31. American Diabetic Association. *Screening for Type 2 Diabetes*.; 2003. https://care.diabetesjournals.org/content/diacare/26/suppl_1/s21.full.pdf. Accessed August 17, 2020.
32. Al-Ghamdi A, Al-Turki K, El-Zubaier A. A COMMUNITY-BASED SCREENING CAMPAIGN FOR THE DETECTION OF DIABETES MELLITUS AND HYPERTENSION IN THE EASTERN PROVINCE, SAUDI ARABIA: METHODS AND PARTICIPATION RATES. *J Community Fam Med*. 2007;14(3):91-97. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3410157/. Accessed August 17, 2020.
33. Abdel-All M, Thrift AG, Riddell M, et al. Evaluation of a training program of hypertension for accredited social health activists (ASHA) in rural India. *BMC Health Serv Res*. 2018;18(1):320. doi:10.1186/s12913-018-3140-8
34. Mendis S. *Package of Essential NCD Interventions for Primary Health Care in Humanitarian Emergencies (PEN-H)*.; 2019.
35. Kehlenbrink S, Smith J, Ansbro É, et al. The burden of diabetes and use of diabetes care in humanitarian crises in low-income and middle-income countries. *Lancet Diabetes Endocrinol*. 2019;8587(19):1-10. doi:10.1016/S2213-8587(19)30082-8
36. Han H-R, Kim K, Murphy J, et al. Community health worker interventions to promote psychosocial outcomes among people living with HIV-A systematic review. 2018. doi:10.1371/journal.pone.0194928
37. Van Ommeren M, Hanna F, Weissbecker I, Ventevogel P. *Mental Health and Psychosocial Support in Humanitarian Emergencies النفسية والدعم النفيس االجتامعي يف حاالت الطوارئ اإلنسانية الصحة*. Vol 21.; 2015. http://www.mhpss.net. Accessed August 17, 2020.
38. Kayali M, Moussally K, Lakis C, et al. Treating Syrian refugees with diabetes and hypertension in Shatila refugee camp , Lebanon : Médecins Sans Frontières model of care and treatment outcomes. *Confl Health*. 2019;13(12):1-11.
39. Doocy S, Paik KE, Lyles E, et al. Guidelines and mHealth to Improve Quality of Hypertension and Type 2 Diabetes Care for Vulnerable Populations in Lebanon: Longitudinal Cohort Study. *JMIR mHealth uHealth*. 2017;5(10):e158. doi:10.2196/mhealth.7745
40. Akik C, Ghattas H, Mesmar S, Rabkin M, El-Sadr WM, Fouad FM. Host country responses to non-communicable diseases amongst Syrian refugees: a review. *Confl Health*.

2019;13(1):8. doi:10.1186/s13031-019-0192-2

Contributorship Statement

PKP and RR designed the study, NA, RAAR, MF, KAA and RAM provided critical support during the causal loop analysis workshop. PKP, RR, an FR analyzed and interpreted the data. PKP and RR wrote the article. All authors made critical revision to the article. All authors have read and approved the final version of the manuscript.

The authors have no competing interests to declare.

Data Availability Statement

The qualitative data from this study will not be made publicly available, due to the ease at which interviewees may be identified through the full transcripts, even if key sections are redacted. Furthermore, during the informed consent process, participants did not consent to make data publicly available.

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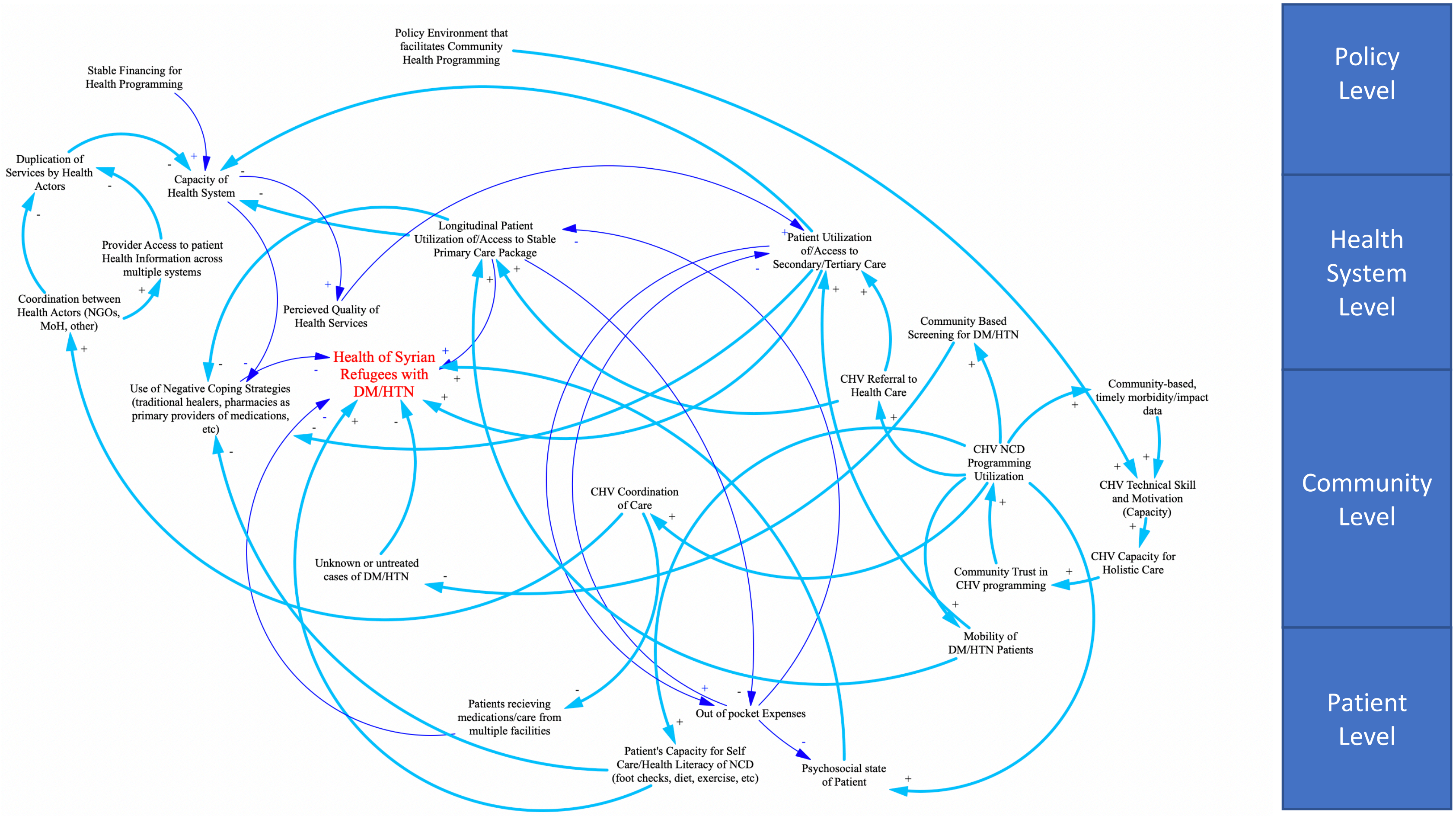
Policy Environment that facilitates Community Health Programming
Stable Financing for Health Programming
Duplication of Services by Health Actors
Capacity of Health System
Provider Access to patient Health Information across multiple systems
Coordination between Health Actors (NGOs, MoH, other)
Longitudinal Patient Utilization of/Access to Stable Primary Care Package
Patient Utilization of/Access to Secondary/Tertiary Care
Percieved Quality of Health Services
Health of Syrian Refugees with DM/HTN
Use of Negative Coping Strategies (traditional healers, pharmacies as primary providers of medications, etc)
Community Based Screening for DM/HTN
CHV Referral to Health Care
Community-based, timely morbidity/impact data
CHV NCD Programming Utilization
CHV Technical Skill and Motivation (Capacity)
CHV Coordination of Care
CHV Capacity for Holistic Care
Community Trust in CHV programming
Unknown or untreated cases of DM/HTN
Mobility of DM/HTN Patients
Patients recieving medications/care from multiple facilities
Out of pocket Expenses
Patient's Capacity for Self Care/Health Literacy of NCD (foot checks, diet, exercise, etc)
Psychosocial state of Patient
Policy Level
Health System Level
Community Level
Patient Level

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the inter view or focus group?	
Duration	21	What was the duration of the inter views or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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Title: Integrating community health volunteers into non-communicable disease management among Syrian refugees in Jordan: a causal loop analysis

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Abstract:

Objectives: Globally, there is emerging evidence on the use of community health workers and volunteers (CHVs) in low- and middle-income settings for the management of non-communicable diseases, provision of out-of-clinic screening, linkage with health services, promotion of adherence, and counseling on lifestyle and dietary changes. Little guidance exists on the role of this workforce in supporting non-communicable disease care for refugees who lack access to continuous care in their host country. The goal of this work was to evaluate the current roles of CHVs in the management of diabetes and hypertension among Syrian refugees and suggest improvements to the current primary care model utilizing community health strategies.

Setting and Participants: A participatory, multi-stakeholder causal loop analysis workshop with representatives from the Ministry of Health of Jordan, non-governmental organizations, UN agencies, community health volunteers and refugee patients was conducted in June 2019 in Amman, Jordan.

Primary Outcome: This causal loop analysis workshop was used to collaboratively develop a causal loop diagram (CLD) and CHV strategies designed to improve the health of Syrian refugees with diabetes and hypertension living in Jordan.

Results: During the causal loop analysis workshop, participants collaboratively identified and mapped how CHVs might improve care among diagnosed patients. Possibilities identified included the following: provide psychosocial support and foundational education on their conditions, strengthen self-management of complications (e.g., foot checks), and monitor patients for adherence to medications and collection of basic health monitoring data. Elderly refugees with restricted mobility and/or uncontrolled disease were identified as a key population where CHVs could provide home-based blood glucose and blood pressure measurement and targeted health education, to provide more precise monitoring.

Conclusions: CHV programs were cited as a key strategy to implement secondary prevention of morbidity and mortality among Syrian refugees, particularly those at high-risk of decompensation.

Strengths and Limitations of this Study

- The findings of this study resulted from convening of a group of diverse stakeholders related to diabetes and high blood pressure among Syrian refugees in Jordan.

- This study provides concrete ways in which a CHV program might support Syrian refugees in Jordan with diabetes and hypertension.

- The findings of this study may have been limited by translations errors, or a lack of ability to express views openly in a mixed-stakeholder setting.

Introduction

More than 5 million Syrian refugees are displaced throughout the Middle East as a result of the conflict in Syria, with 655,000 displaced in Jordan. [1] The majority of these refugees in Jordan live outside of camps.[2] Among non-camp Syrian refugees ≥18 years living in Ramtha and Mafraq governorates in Jordan, 9.8%, 17.2%, and 7.3% reported diagnoses of diabetes, hypertension, or both conditions.[3] Among Syrian refugees ≥30 years, 22.9% of those with above-threshold random blood sugar, and 39.1% with above-threshold blood pressure did not report a previous diagnosis.[3] Refugees have been displaced for many years, and may have developed these conditions after leaving Syria.[4] Prolonged displacement and a high burden of NCDs require that primary care predominantly delivered by non-governmental organizations (NGOs) be optimized to prevent severe morbidity and mortality. [5–9]

Syrian refugees in Jordan access health care in fragmented ways. In camp settings, non-governmental organizations (NGOs) typically provide clinical care through a primary care model that favors curative therapies over preventive care.[10] Syrian refugees in peri-urban and urban areas access care via a patchwork of multiple health providers. These include NGO facilities that usually provide primary care services and medications at low or no cost, Ministry of Health (MoH) clinics that provide services for low cost but often have limited resources, and private clinics which typically provide more expensive services. While NGO clinics often provide free services, referrals to secondary and specialist care, diagnostics, and laboratories typically require out of pocket payments.[11,12] Essential medications may have limited availability due to funding issues and stock-outs at both NGO and MoH facilities. Increasingly, NGOs use cohorts to provide more comprehensive services to patients with NCDs in Jordan which creates challenges for those who find themselves excluded from these systems.[8] Changing rules governing refugee access to MoH clinics have resulted in further confusion and barriers in accessing care.[11]

Studies have shown positive impact of community health workers on NCD management in low- and middle-income settings.[13–18] However, limited guidance exists on the specific role CHVs might play in delivering care to refugees living with NCDs in protracted displacement settings. Since 2011, the International Rescue Committee (IRC) has administered Jordan's largest community health volunteer (CHV) program, serving both Syrian refugees in non-camp settings as well as uninsured Jordanian patients. CHVs are refugees or Jordanians who may or may not have prior health experience. They receive an honorarium to volunteer a limited number of days per month. CHVs provide basic health education and referrals to primary care at IRC clinics when health issues are identified. This program historically supported primary care functions for all household members, including monitoring, referral, and health education for child health, prenatal and antenatal care, and other health conditions. The specific role that CHVs might play in NCD care, from linkage to care, out-of-clinic monitoring, or support of medication adherence to early screening for complications or early disease requires careful consideration from multiple stakeholders.

Causal loop analysis, drawn from system dynamics theory, provides a means to understand complex systems and, when done in a participatory manner, suggest programming that is sensitive to the strengths and constraints of health systems.[19–21] Health care for refugees can be considered a complex adaptive system which results from the interactions of multiple actors (e.g., beneficiaries, NGOs, health workers) and processes (e.g., registration, diagnosis, adherence to care). Interactions between various components of this type of system are non-linear and difficult to predict. Causal loop analysis provides a means to qualitatively understand complex systems, and potential consequences of modifications and new programming within the system.[19,22,23]

A participatory causal loop analysis workshop was convened in June 2019 to explore the existing models for CHV programs in Jordan and the means by which these programs might be improved to fill in gaps for the provision of continuous health care to Syrian refugees with diabetes and hypertension.

Methods

The researchers co-developed the preliminary causal loop diagram in order to provide a platform for stakeholders to improve upon via a multi-phase group model building exercise. In the first phase, a preliminary causal loop diagram was developed by the research team, after discussions with IRC health staff and document review. PP (co-PI) and FR (research manager), both female, conducted 20 key informant interviews (KII) in May-June 2019 in Irbid and Mafraq governorates. PP is an experienced mixed-methods researcher and FR is Arabic-speaking and has expertise in community health, nursing, and research.

Key informants were purposively selected to include experts in NCDs from the MoH, focal points of national and international health NGOs, and IRC programs. Additionally, CHVs, Syrian patients with diabetes and hypertension, and health care providers (MDs, RNs, and administrators) were included. The initial list of key informants was created in collaboration with IRC staff, and this list was iteratively grown by asking interviewees to recommend relevant others (**Box 1**). The majority of individuals interviewed had previously interacted with the researchers in the context of the broader research project on NCDs among Syrian refugees in Jordan and were aware of the motivations and goals for this work. Community perspectives as well as the perspectives of CHVs who had practiced in target communities, often for years, were prioritized in order to fully consider the limitations of current programming and the ways in which future programming might meet identified gaps in care. Individuals were interviewed by the research team using a semi-structured interview guide **(Box 1)**. All interviews were carried out in the respondent's preferred language, English or Arabic in private locations outside of the home. Participants were contacted by a combination of phone, email, and in-person requests to participate. All approached agreed to participate, extensive notes were taken during each roughly one-hour interview. To ensure privacy of responses no interviews were recorded.

Box 1

Individuals Interviewed

Community Health Professor from the Jordan University of Science and Technology (1)
Syrian refugee patients (1 male, 1 female)

IRC Staff (7)
  - Including CHVs (1 male, 1 female)

Representatives from Médecins Sans Frontières (MSF), Medair, Altkaful, Royal Health Awareness Society (RHAS), ABT Associates, International Medical Corps (6)
Jordanian Ministry of Health (2)
UNHCR (1)

Domains of Semi-Structure Interviews

- Components of the Jordanian health system accessed by Syrian refugees
- Linkages between elements of the health system
- Barriers and facilitators in accessing care for diabetes and hypertension
- Current role of CHVs
- Potential roles of CHVs in care of patients with diabetes and hypertension
- Opportunities and constraints in realizing the potential of CHVs in managing diabetes and high blood pressure

PP and RR used content analysis strategies to identify key themes from these interviews.[24] These themes were used to generate variables for inclusion in a preliminary causal loop diagram as well as relationships between each of these variables.[25] All causal loop diagrams were generated and edited using VensimPLE software.[26]

During a two-day workshop held in Amman in June, 2019, stakeholders discussed and refined this preliminary causal loop diagram, including all variables and definitions generated by the research team. A summary of workshop proceedings is included in Box 2. The objective was to identify gaps and strengths in the current model of provision of NCD care for Syrian refugees and then identify CHV-led strategies to fill key gaps, while building on strengths in the system and incorporating mitigation strategies for anticipated barriers. A broad group of stakeholders were invited to comment on all aspects of this complex system. Five male and female CHVs represented perspectives on current and potential roles for CHVs in Jordan, and the ways in which their roles might be expanded to address unmet needs. Similarly, Syrian refugee patients shared perspectives on challenges faced. NGO, MoH, and UN/WHO representatives provided programmatic and funding context, and IRC leadership provided perspectives based on their management of the current CHV program. Workshop facilitators presented data from a community-based survey of IRC catchment areas conducted during March/April of 2019 examining prevalence of disease, medication adherence, self-reported prevalence of complications and access to care among beneficiaries with diabetes and/or hypertension.[3] Additionally, workshop facilitators presented a summary of a global literature review on the roles of CHVs in management of NCDs. This was done in order to orient stakeholders less familiar with community health approaches, and more familiar with primary care for NCDs, programming orientation and context.

Workshop participants first met in small, mixed stakeholder groups to generate their own causal loop diagrams focusing on the outcome of the health of Syrian refugees with diabetes and hypertension. Each small group presented their work to the larger group for comparison and integration. The research team then presented the preliminary causal loop diagram to the group, who then collaboratively edited the preliminary diagram in small groups and later as a whole. This exercise led to the final collaboratively built causal loop diagram (Figure 1). Then, the group commented on barriers and opportunities within this system to achieving a CHV strategy with capacity to improve diabetes and high blood pressure outcomes.

Box 2. Stakeholder Workshop Proceedings

Day 1:
Review workshop objectives
Review regional data on NCDs, Community Health Volunteer programming
Stakeholder training on causal loop diagrams
Mixed stakeholder small groups generate their own causal loop diagrams
Present results of research team analyses--> preliminary causal loop diagram and discussion of all variables.

Day 2:
Mixed stakeholder small groups comment and edit preliminary causal loop diagram
Whole stakeholder group discussion on preliminary causal loop diagram, with real-time refinement
Final causal loop diagram and variables generated (**Box 2, 3**)
Stakeholder group identifies barriers and opportunities within the system to improve health utilizing Community Health Volunteer strategies

A final list of variables generated by the combination of research team content analysis of qualitative data and stakeholder feedback during the two-day workshop are listed in **Box 3**. These variables and linkages are summarized in the final causal loop diagram below in **Figure 1**, which, using positive and negative signs, considered how various components interact to ultimately affect health status. The central outcome of interest, "Health of Syrian Refugees with DM/HTN," has been highlighted in the CLD in red. Means by which CHVs might support the health of Syrian refugees in the Jordanian context as identified by this mixed stakeholder workshop are presented below, along with barriers that may limit opportunities.

Ethics/Consent

This study was approved by the Institutional Review Boards of the University of Southern California (#HS-18-00569, H 1.00.020), International Rescue Committee (IRB #: 00009752 FWA #: 00022773), and Jordan University of Science and Technology (83/117/2018, 57/28/2018). Key informants gave written consent to participate and workshop participants gave verbal consent. Individuals were asked to keep content of the discussions during the workshops confidential. Content of key informant interviews was summarized and shared in the workshop in a de-identified manner.

Patient and public involvement

Syrian patients and Syrian CHVs participated in the workshop to gather their perceptions and insight into the needs of NCD patients. They were not directly involved in the development of the research design.

Results

Variables are described below and arranged in the causal loop diagram according to relevance at a *national/global policy level*, *health system level*, *community health level*, and *patient level*. Relationships between variables are described in the final causal loop diagram with arrows: two variables linked by an arrow and a (+) sign indicate that when one variable is influenced positively or negatively, the other variable also increases or decreases in importance. Similarly, variables linked by an arrow and a (–) sign indicate that when one variable varies, the linked variable goes in the opposite direction.

Box 3. Final list of variables

Patient/Community

Psychosocial State of Patient
Patient Capacity for Self/Care and Health Literacy
Out of Pocket Expenses
Mobility of Patients
Patients Receiving Care from Multiple Facilities
Unknown or Untreated Cases of DM/HTN
Use of Negative Coping Strategies

Health System
Capacity of Health System
Longitudinal Patient Access/Utilization to Primary Care
Patient Utilization of/Access to Secondary/Tertiary Care
Coordination of between health Actors
Provider Access to Health Information Across Systems
Perceived Quality of Health Services

Policy
Stable Financing for Health Programming
Duplication of Services by Health Actors
Policy Environment that facilitates Community Health Programming

Roles of Community Health Volunteers
CHV Program Utilization
Community-Based, Timely Morbidity/Impact Data
CHV Technical Skill and Motivation
CHV Capacity for Holistic Care
Community Trust in CHVs
Community Based Screening for DM/HTN
CHV Coordination of Care
CHV Referral to Care

[Insert "Final CLD March 2021"]

Figure 1. Final Causal Loop Diagram: Community Health Volunteer Program for Syrian Refugees and Vulnerable Jordanians with DM/HTN

<u>Current Challenges in NCD Delivery and Utilization</u>

The following section outlines current challenges in NCD Delivery and utilization at each level of the health system. Linkages describing the existing system are highlighted by thin dark blue arrows in the final CLD (**Figure 1**).

Patient/Community Level

Out of pocket expenses were identified as the single most important factor affecting health seeking behavior at the patient level **(Box 4; Quotes 1,2)**. The *patient's capacity for self-care and health literacy* was deemed central to appropriate management of diabetes and hypertension. This includes patient understanding of the chronic nature of their disease and treatment, the need for daily medication, routine dietary and exercise needs, and avoidance of harmful behaviors such as smoking, as well as timely identification of complications. *Patients receiving care from multiple facilities* were seen as often suffering negative consequences as a result. It was recognized by stakeholders that patients may seek duplicate services as a relatively common coping mechanism, given limited and changing clinical services available to refugees. The *psychosocial state of the patient* was recognized as key in care-seeking behavior, as refugees are predisposed to suffer from serious mental illness and trauma, which may introduce feelings of hopelessness and impair the ability to prioritize management of chronic health conditions. Finally, patients with impaired mobility, including women who must remain at home, the elderly and disabled, often have a challenging time traveling to health facilities **(Box 4; Quote 3)**.

At the community level, stakeholders identified *unknown/untreated cases* of diabetes and hypertension as a potentially large unmet need and knowledge gap. In the context of limited access to primary care, refugees face barriers to obtaining a diagnosis (including seeking care only when conditions become symptomatic) and a lack of exposure to information about NCDs. Finally, in an environment where services available to patients often change with shifting policy goals and funding priorities, patients often engage in *negative coping strategies* to fill gaps in care. These may involve seeking care from non-physician providers, including traditional healers who provide herbal remedies, seeking medications directly from pharmacies without the involvement of a physician, taking prescribed medications in lower doses or less frequently to make them last longer, or forgoing medications entirely despite a known diagnosis. Patient factors above, in particular *high out of pocket expenses, patient's* (most often sub-optimal) *capacity for self-care and health literacy,* and impaired *psychosocial state of the patient*, as well as use of *negative coping strategies,* could potentially result in poor health outcomes.

Health System

Stakeholders identified several factors at the level of the health system that affect the health of Syrian refugees. The *capacity of the health system* was identified as suffering negatively from a lack of *coordination between health actors (NGOs, MoH).* Stakeholders, particularly medical providers, felt that a lack of *provider access to health information across multiple systems* was responsible, at least in part, for avoidable duplication of services. Stakeholders described unknowingly repeating testing or providing multiple prescriptions for either duplicate or potentially interacting medications to patients who receive care from multiple health centers **(Box 4; Quote 4)**. This was flagged as not only a danger to patients given challenges monitoring those who seek care from multiple providers, it was seen as a strain on limited resources when services are duplicated. Generally, key informants and workshop participants agreed that MoH services were strained, and many patients, CHVs, and health actors perceived the quality of MoH services to have suffered as a result. Improved coordination between health NGOs had, per participants, mitigated many of these issues during the response; however, most felt coordination could be improved, particularly with regard to access to medical records across health systems (via patient-held records or formal mechanisms for sharing information). Stakeholders uniformly felt capacity of the health system was harmed by a lack of *stable financing for health programming*.

Barriers to longitudinal access to and utilization of primary care, largely resulting from the patient/community factors described above, were felt to substantially impact health outcomes among refugees with NCDs. Participants highlighted that geographic and financial access might not always automatically result in medically necessary, longitudinal utilization by patients, with factors such as health literacy and competing household priorities playing an important role **(Box 4; Quote 2)**. *Access to and utilization of secondary and tertiary care*, when needed, was recognized as critical to the health of patients with diabetes and hypertension—particularly those who had experienced a complication of their disease. It was also recognized, both in key informant interviews and the workshop, that humanitarian agencies largely focus on primary care, with refugees facing very limited and typically expensive access to secondary or tertiary care **(Box 4; Quote 5)**.

Policy

Stakeholders identified key policy-level variables related to health status. Typical funding cycles for humanitarian programs are in the 1-2 year range, while NCD programming was felt to require a longer-term strategy. Donor funding of humanitarian NGO health programming has also decreased in the region per workshop participants, which has resulted in a lack of the type of *stable financing for health programming* that is critical for longitudinal care of diabetes and hypertension. **(Box 4; Quote 1)**. Workshop participants noted that the MoH was in the challenging position of having to provide for a large influx of refugees with limited funding, which has resulted in changing policies with regards to fees charged to Syrian refugees for health services. These changing policies have, in themselves, resulted in distrust and inaccessibility among refugees with regard to MoH health services. *Duplication of services by health actors* in the domain of NCD care, with multiple providers present in some geographic areas with relatively fewer in others, was felt by participants to have resulted in inefficient use of limited funding. Several key informants cited a lack of coordination of humanitarian programming nationally, resulting in overlapping programming in some locations and a lack of services in other geographic regions **(Box 4; Quote 6).**

Potential for CHV Programming

Stakeholders were asked to consider how a CHV program might, both positively and negatively, impact the health of Syrian refugees within the systems described above. Linkages representing areas of potential impact are highlighted with thick light blue arrows in the CLD (**Figure 1**).

CHV capacity, including their technical skills, workload, appropriate remuneration, and motivation, were seen as central to the success of any CHV program. CHVs draw from the communities they serve—thus, their understanding of the social and cultural context was also seen as a tremendous asset to their work. Current policy in Jordan allows for limited payment of CHVs, which serves as a barrier. They have to been seen as highly skilled and reliable by the communities they serve, reflected in the variable *community trust in CHV programming. CHV capacity for holistic care,* namely the ability to make accurate and timely referrals to resources not related to the central goals of their program (food aid, services for survivors of violence, psychosocial aid, cash transfers, etc.) were considered central to securing patient engagement. Stakeholders, including CHVs themselves, agreed that each time a CHV is unable to meet the need of a patient whether or not it is related to health care, that patient loses trust in CHV services. As a result, that patient may not engage with CHVs on health-related messaging and services in the future. However, CHVs stated that timely and meaningful referrals require improved coordination between humanitarian actors to ensure that CHVs do not make referrals to services that are no longer available. *CHV capacity*, *community trust in CHV programming* and *CHV capacity for holistic care* were thought to positively reinforce *CHV NCD program utilization* by the target beneficiaries.

Stakeholders identified multiple ways that a CHV NCD program might support the health of patients at multiple levels beyond the current system. CHVs were felt to be a critical conduit for increased patient knowledge on management of their disease, specifically increasing *patient's capacity for self-care and health literacy.* CHVs could strengthen health literacy and self-management by providing targeted health messaging (on foot checks, adherence to medication and clinic visits) **(Box 4; Quote 7)**. CHVs might also serve as a means of screening adults to identify undiagnosed cases of diabetes and hypertension, provide *community-based, timely morbidity/impact data*, which might strengthen access to diagnoses and care as well as target particularly high-risk patients. CHVs could also provide basic psychosocial support and referrals to more advanced care for patients suffering from more acute mental health needs. CHVs were also felt to be an important means of combating negative coping strategies, both via education and referrals to services that might allow for more stable access to medications and allopathic primary care. Stakeholders identified patients with limited mobility as a key population that might greatly benefit from CHVs **(Box 4; Quote 3)**. CHVs could, with training, provide home-based blood glucose and blood pressure measurement and coordinate with clinics to provide disease management and health education, reducing the need for more frequent visits to a health facility.

Though CHV led, *community-based screening* might increase the burden on the health system, stakeholders felt that a robust CHV program might also decrease the burden on fixed clinics by reducing *duplication of services*. CHVs could do this by helping patients coordinate care within one health system as much as possible and aligning services between multiple health providers when needed. CHVs might also allow health facilities to focus more on medical management during appointments by delivering health education in patient households. National policies prevent those who are not licensed nurses or physicians from measuring blood glucose and blood pressure as a part of the provision of health care, though measurement devices are available to households for purchase and private use. This, and the need for consistent funding sources, highlight the importance of a *policy environment that facilitates community health programming.*

Stakeholders felt that increased utilization of primary care and preparedness for routine NCD management of some complications at the PHC level might decrease the reliance on scarce secondary and tertiary resources. However, participants noted that such an increase in primary care utilization would create a strain on the *capacity of the health system* as it risks inadequate resources and planning. Overall *capacity of the health system* was thought to be an essential component of high-quality primary, secondary, and tertiary care.

Box 4. Quotes from Key Informant Interviews

1. *Previously there were many NGOs providing services, but now there are less; there are just a few that provide free services. [Humanitarian NGO] can provide some services, but they charge and even this subsidized rate is challenging. Only [different humanitarian NGO] is providing free services, and said [third humanitarian NGO] is not taking patients. If services or medications are not available in these places, I have to buy it externally.* –Syrian refugee

2. *Finances are the main barrier. Even if you give money to an old man with diabetes, if he has five children he will feed them and prioritize rent over his own health. Rental costs are very high and this is challenging. When we do our post-cash-transfer calls, we ask why are you still in debt? Recipients will often reply that they had to pay rent to avoid becoming homeless.*
   – NGO Health Program Administrator

3. *When we went to the field, some women had instructions from husbands that they could not go outside their home. They when they saw the CHVs, said, "thank God! If you can help me here in the home that is much better"* –IRC CHV

4. *The only link between different health providers is the patient. We try to get records of investigations from other NGOS, etc—but most patients come in with no records, no data, no labs, no access to files from MoH or other NGOs. Strict privacy policies prevent coordination. This gets in the way of patient care.* –NGO health provider

5. *NCDs need time-intensive care, at least 20-30 min per visit, but health providers don't have that time. Most providers focus on treatment and not prevention—and health messages need to be repeated many times. There aren't adequate human resources for this. Health providers focus on treatment, not prevention.* -NGO Health Program Administrator

6. *When I started, we were attending NCD working groups--health sector meetings. I noted that these are not run as efficiently as they should be. It was a parade of bragging. No one is collaborating and actually sorting out what they should be doing, NGOs fight to maximize funding. There seems to be no entity regulating/coordinating which organization should focus on what specific issues, etc.* –NGO Health Program Administrator

7. *If a CHV calls and states that there are 70 cases of diarrhea in one community, with dehydration in this informal tent settlement, then we can go there. If well trained, these CHVs can provide vital information in real time. They can do clinical assessments as well if trained well. You don't need health care professionals to measure blood pressure or blood glucose, CHVs can do this. CHVs can save time/cost and prevent complications. They can identify complication early. If there is a certain case that needs a referral, then they can refer. I tell my CHVs, "You are all soldiers". CHVs save people's lives.* -CHV Program Administrator

8. *Will there be real action, or just talking?* --Syrian Patient, Male

Discussion

This causal loop analysis workshop identified many issues borne out by previous studies among Syrian refugees in the region, highlighting costs, challenges with changing capacities and services of humanitarian actors, lack of coordination between humanitarian actors as well as the MoH, shifting national policies regarding provision of health care by state facilities to refugees, and very limited access to secondary and tertiary care as major barriers in assuring continuous care. [11,12,23,27] Based on the results of this causal loop analysis workshop, the research team and program staff identified multiple CHV strategies that align with an evidence-based conceptual model of care for priority NCDs through primary care systems developed by Kane, et al.[28] These strategies and relevant evidence are presented below.

1. CHV-led community-based prevention via risk factor modification

A CHV-led community-based prevention program focusing on risk factor modification would enable CHVs to provide targeted health education messaging to refugee communities on primary prevention, including smoking, diet and exercise, through tailored discussion of realistic goals given context-specific constraints. CHVs should engage the entire household on risk factor modification.[4,9] There are, however, complex issues with regards to diet (e.g., food insecurity), smoking cessation (e.g., high prevalence, culture), and promoting exercise (e.g., few options for female heads of households) among Syrian refugees.[4,5,29,30]

2. CHV screening of Syrian refugee communities for diabetes and hypertension

Diabetes and hypertension may remain undiagnosed among Syrian refugees in Jordan.[3] However, evidence suggests that screening in the community using random blood glucose and blood pressure has low specificity, and may yield excessive case numbers that when not appropriately discussed with a physician, result in limited linkage to care, and may result in low compliance with treatment and unclear impact on health.[31,15] In a population-based screening in Saudi Arabia, only a limited proportion of those who screened positive for disease were appropriately linked to care.[32] Additionally, generating high levels of demand that cannot be appropriately met may not be ethical.[9] Thus, CHV-led screening might target patient household members ≥30 years, those with a history of gestational diabetes and hypertension, or those who report symptoms that might be consistent with complications of an NCD during the course of a CHV household visit.

3. CHV support of adherence to medication, disease management, and clinical care.

Refugees may have limited understanding of how to best manage NCDs and avoid complications given little interaction with health care.[4,5] Studies of CHV interventions in rural Iran, Nepal, and Mexico have shown that CHV programming designed to improve adherence to care and identify complications early can improve patient outcomes in non-refugee settings.[15,16,33] Those with the poorest control tend to benefit the most from this type of CHV intervention.[16] In light of the relatively high burden of NCDs in many humanitarian contexts and limited resources, CHV interventions that focus on the most poorly compliant or controlled patients may have the highest impact. Strategies outlined in the WHO's Package of Essential NCD Interventions and tools created by the International Federation of the Red Cross and Red Crescent can be carefully adapted for CHV interventions, including: out-of-clinic biological monitoring to better identify patients in need of urgent or emergent referrals to clinical care; identification criteria for emergent and urgent referral of complications via simple case definitions for presentations of diabetic foot ulcers, hyper- or hypoglycemia, myocardial infarction, unstable angina, etc; and modules for self-management counseling and psychosocial support[30,34,35] Importantly, the CHV would provide patients with preliminary identification of a suspect condition or complications followed by a direct referral to primary or secondary care services.

4. CHV Provision of mental health and psychosocial support

Conflict and displacement-affected patients may face mental illness barriers in dealing with NCDs. This may, in turn, affect compliance, adherence, motivation and result in increased reliance on negative coping mechanisms.[12,17] Stigma often prevents many Syrian refugees from seeking care for psychiatric needs, and clinic-based psychological services often do not have the capacity to meet the needs of these patients. There is some evidence of the effectiveness of psychosocial support for HIV adherence and better evidence for the application of mental health and psychosocial services in the context of a CHV program.[36] Thus, a CHV NCD focused program should address the identification of psychosocial health needs in some form, with referral to mental health services. [30,37 38]

5. Standardized referral pathways (from clinic) and follow-up (to clinic)

Patients face multiple challenges in engaging in primary care longitudinally, as described above.[12] Evidence suggests strategies that might support improved patient adherence to primary care. SMS-based reminders sent to Syrian refugees with NCDs in Lebanon improved patient attendance to clinic appointments.[39] A patient-held medical record trialed in Chiapas, Mexico contributed to a CHV intervention to improve patient adherence to care and patient understanding of their own health needs.[16] With regards to secondary and tertiary care, referral pathways are complex, result in significant delays in care, and care itself is often expensive.[40] Secondary care options are, in most humanitarian contexts, insufficient to meet needs. Additionally, limited coordination between clinical providers (NGOs, MoH, private) hinders referrals and data sharing.[5] CHVs may play an important role in coordinating care for Syrian refugees with NCDs in Jordan. [16,29]

Limitations

Workshop facilitators relied on Arabic translation during the exercise, as both Arabic and English speakers participated. A diverse set of stakeholders, including Syrian refugees, vulnerable Jordanians, CHVs, physicians, and health programs as well as national/UN leadership were invited. While every effort was made to encourage full participation, it is possible that in this environment, some community members and CHVs felt unable to fully participate. Interviews were conducted by an English-speaking researcher with the assistance of an Arabic speaking researcher as needed, which may have resulted in interviewee discomfort or subtle translation errors.

Conclusion

Syrian refugees with diabetes and hypertension face multiple barriers in accessing care, within a complex system. CHVs potentially provide an efficient means of helping this vulnerable population navigate this system. Further studies on the effectiveness of CHV interventions on NCDs among Syrian refugees in Jordan are needed.

References

1. Situation Syria Regional Refugee Response. https://data2.unhcr.org/en/situations/syria. Accessed February 26, 2020.
2. Rehr M, Shoaib M, Ellithy S, et al. Prevalence of non-communicable diseases and access to care among non-camp Syrian refugees in northern Jordan. *Confl Health*. 2018;12(1). doi:10.1186/s13031-018-0168-7
3. Ratnayake R, Rawashdeh F, Abu Al Rub R, et al. Access to care and prevalence of hypertension and diabetes among Syrian refugees in northern Jordan. *Jama Netw Open*.
4. Elliott JA, Das D, Cavailler P, et al. A cross-sectional assessment of diabetes self-management, education and support needs of Syrian refugee patients living with diabetes in Bekaa Valley Lebanon. doi:10.1186/s13031-018-0174-9
5. Boulle P, Kehlenbrink S, Smith J, Beran D, Jobanputra K. Challenges associated with providing diabetes care in humanitarian settings. *Lancet Diabetes Endocrinol*. 2019;8587(19). doi:10.1016/S2213-8587(19)30083-X
6. Spiegel PB, Checchi F, Colombo S, Paik E. Health-care needs of people affected by conflict: future trends and changing frameworks. *Lancet*. 2010;375(9711):341-345. doi:10.1016/S0140-6736(09)61873-0
7. Ansbro É, Maconick L, Ellithy S, Jobanputra K, Tarawneh M, Roberts B. “To die is better for me”, social suffering among Syrian refugees at a noncommunicable disease clinic in Jordan: a qualitative study. 2019:1-31. doi:10.21203/rs.2.19227/v1
8. Imhín Ansbro E´, Garry S, Karir V, et al. Delivering a primary-level non-communicable disease programme for Syrian refugees and the host population in Jordan: a descriptive costing study. *Health Policy Plan*. 2020:1-10. doi:10.1093/heapol/czaa050
9. Slama S, Kim H-J, Roglic G, et al. Care of non-communicable diseases in emergencies. *www.thelancet.com*. 2017;389. doi:10.1016/S0140-6736(16)31404-0
10. World Health Organization Eastern Mediterranean Region. *Health of Refugees and*

Migrants Practices in Addressing the Health Needs of Refugees and Migrants WHO Eastern Mediterranean Region 2018.; 2018.

11. Doocy S, Lyles E, Akhu-Zaheya L, Oweis A, Al Ward N, Burton A. Health service utilization among syrian refugees with chronic health conditions in Jordan. *PLoS One*. 2016;11(4):1-12. doi:10.1371/journal.pone.0150088
12. Zahrah Mcnatt Z, Freels PE, Chandler H, et al. "What's happening in Syria even affects the rocks": a qualitative study of the Syrian refugee experience accessing noncommunicable disease services in Jordan. doi:10.1186/s13031-019-0209-x
13. Washington CH, Tyler FJ, Davis J, et al. Trauma training course: innovative teaching models and methods for training health workers in active conflict zones of Eastern Myanmar. 2014. doi:10.1186/s12245-014-0046-z
14. Musoke D, Ndejjo R, Kiracho EE. *Health for the People : National Community Health Worker Programs from Afghanistan to Zimbabwe*.; 2020.
15. Farzadfar F, Murray CJL, Gakidou E, et al. Effectiveness of diabetes and hypertension management by rural primary health-care workers (Behvarz workers) in Iran: A nationally representative observational study. *Lancet*. 2012;379(9810):47-54. doi:10.1016/S0140-6736(11)61349-4
16. Newman PM, Franke MF, Arrieta J, et al. Community health workers improve disease control and medication adherence among patients with diabetes and/or hypertension in Chiapas, Mexico: an observational stepped-wedge study. *BMJ Glob Heal*. 2018;3:566. doi:10.1136/bmjgh-2017-000566
17. Neupane D, McLachlan CS, Mishra SR, et al. Effectiveness of a lifestyle intervention led by female community health volunteers versus usual care in blood pressure reduction (COBIN): an open-label, cluster-randomised trial. *Lancet Glob Heal*. 2018;6(1):e66-e73. doi:10.1016/S2214-109X(17)30411-4
18. Sub Centre H. *Module for Multi-Purpose Workers (MPW)-Female/Male on Prevention, Screening and Control of Common Non-Communicable Diseases*.
19. Varghese J, Kutty VR, Paina L, Adam T. Advancing the application of systems thinking in health: understanding the growing complexity governing immunization services in Kerala, India. *Heal Res policy Syst*. 2014;12(47). doi:10.1186/1478-4505-12-36
20. Li Q, Hyder AA, Peters DH, Paina L, Bishai D. Advancing the application of systems thinking in health: why cure crowds out prevention. *Heal Res Policy Syst*. 2014;12(1):1-5. doi:10.1186/1478-4505-12-28
21. Paina L, Bennett S, Ssengooba F, Peters DH. Advancing the application of systems thinking in health: Exploring dual practice and its management in Kampala, Uganda. *Heal Res Policy Syst*. 2014;12(1). doi:10.1186/1478-4505-12-41
22. Williams B, Hummelbrunner R. *Systems Concepts in Action. A Practical Toolkit.* Stanford, California: Stanford University Press; 2011.
23. Zablith N, Diaconu K, Naja F, et al. Dynamics of non-communicable disease prevention, diagnosis and control in Lebanon, a fragile setting. *Confl Health*. 2021;15(1):4. doi:10.1186/s13031-020-00337-2
24. Hsieh HF, Shannon SE. Three approaches to qualitative content analysis. *Qual Health Res*. 2005;15(9):1277-1288. doi:10.1177/1049732305276687
25. Elo S, Kyngä H. The qualitative content analysis process. *J Adv Nurs*. 62(1):107-115.

doi:10.1111/j.1365-2648.2007.04569.x

26. Vensim PLE. https://vensim.com/vensim-personal-learning-edition/. Accessed July 15, 2020.
27. Akik C, Ghattas H, Mesmar S, Rabkin M, El-Sadr WM, Fouad FM. Host country responses to non-communicable diseases amongst Syrian refugees: A review. *Confl Health*. 2019;13(1). doi:10.1186/s13031-019-0192-2
28. Kane J, Landes M, Carroll C, Nolen A, Sodhi S. A systematic review of primary care models for non-communicable disease interventions in Sub-Saharan Africa. *BMC Fam Pract*. 2017;18(1):1-12. doi:10.1186/s12875-017-0613-5
29. Sethi S, Jonsson R, Skaff R, Tyler F. *Community-Based Noncommunicable Disease Care for Syrian Refugees in Lebanon*. Vol 5.; 2017. www.ghspjournal.org. Accessed May 12, 2020.
30. International Federatin of the Red Cross. *Healthy Lifestyle Toolkit - IFRC*.; 2016. https://www.ifrc.org/en/what-we-do/health/diseases/noncommunicable-diseases/ncds-toolkit/. Accessed August 17, 2020.
31. American Diabetic Association. *Screening for Type 2 Diabetes*.; 2003. https://care.diabetesjournals.org/content/diacare/26/suppl_1/s21.full.pdf. Accessed August 17, 2020.
32. Al-Ghamdi A, Al-Turki K, El-Zubaier A. A COMMUNITY-BASED SCREENING CAMPAIGN FOR THE DETECTION OF DIABETES MELLITUS AND HYPERTENSION IN THE EASTERN PROVINCE, SAUDI ARABIA: METHODS AND PARTICIPATION RATES. *J Community Fam Med*. 2007;14(3):91-97. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3410157/. Accessed August 17, 2020.
33. Abdel-All M, Thrift AG, Riddell M, et al. Evaluation of a training program of hypertension for accredited social health activists (ASHA) in rural India. *BMC Health Serv Res*. 2018;18(1):320. doi:10.1186/s12913-018-3140-8
34. Mendis S. *Package of Essential NCD Interventions for Primary Health Care in Humanitarian Emergencies (PEN-H)*.; 2019.
35. Kehlenbrink S, Smith J, Ansbro É, et al. The burden of diabetes and use of diabetes care in humanitarian crises in low-income and middle-income countries. *Lancet Diabetes Endocrinol*. 2019;8587(19):1-10. doi:10.1016/S2213-8587(19)30082-8
36. Han H-R, Kim K, Murphy J, et al. Community health worker interventions to promote psychosocial outcomes among people living with HIV-A systematic review. 2018. doi:10.1371/journal.pone.0194928
37. Van Ommeren M, Hanna F, Weissbecker I, Ventevogel P. *Mental Health and Psychosocial Support in Humanitarian Emergencies النفسية والدعم النفيس االجتامعي يف حاالت الطوارئ اإلنسانية الصحة*. Vol 21.; 2015. http://www.mhpss.net. Accessed August 17, 2020.
38. Kayali M, Moussally K, Lakis C, et al. Treating Syrian refugees with diabetes and hypertension in Shatila refugee camp , Lebanon : Médecins Sans Frontières model of care and treatment outcomes. *Confl Health*. 2019;13(12):1-11.
39. Doocy S, Paik KE, Lyles E, et al. Guidelines and mHealth to Improve Quality of Hypertension and Type 2 Diabetes Care for Vulnerable Populations in Lebanon: Longitudinal Cohort Study. *JMIR mHealth uHealth*. 2017;5(10):e158. doi:10.2196/mhealth.7745
40. Akik C, Ghattas H, Mesmar S, Rabkin M, El-Sadr WM, Fouad FM. Host country responses

to non-communicable diseases amongst Syrian refugees: a review. *Confl Health*. 2019;13(1):8. doi:10.1186/s13031-019-0192-2

Contributorship Statement

PKP and RR designed the study, NA, RAAR, MF, KAA and RAM provided critical support during the causal loop analysis workshop. PKP, RR, an FR analyzed and interpreted the data. PKP and RR wrote the article. All authors made critical revision to the article. All authors have read and approved the final version of the manuscript.

The authors have no competing interests to declare.

Data Availability Statement

The qualitative data from this study will not be made publicly available, due to the ease at which interviewees may be identified through the full transcripts, even if key sections are redacted. Furthermore, during the informed consent process, participants did not consent to make data publicly available.

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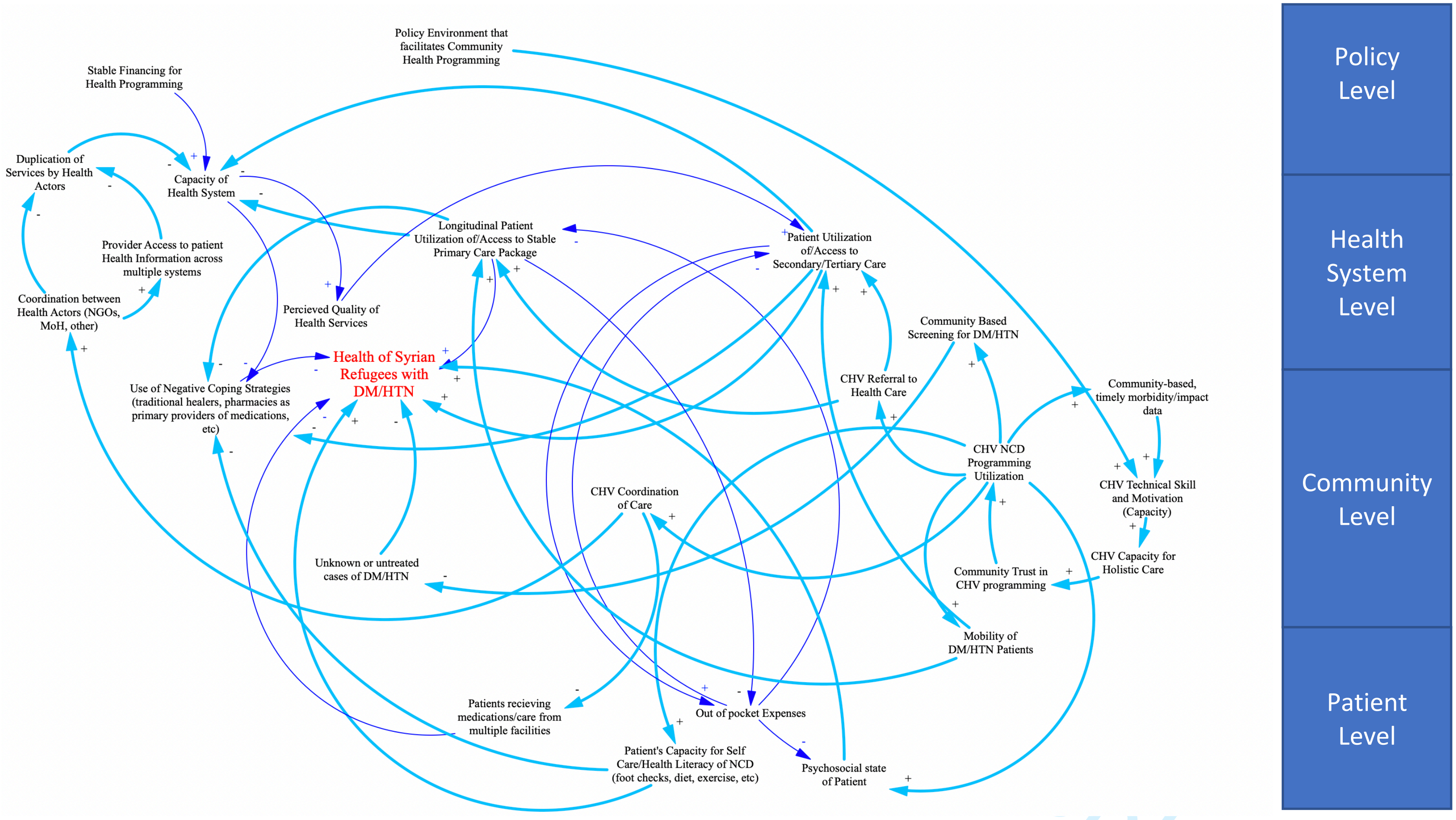
Policy Environment that facilitates Community Health Programming
Stable Financing for Health Programming
Duplication of Services by Health Actors
Capacity of Health System
Provider Access to patient Health Information across multiple systems
Coordination between Health Actors (NGOs, MoH, other)
Percieved Quality of Health Services
Longitudinal Patient Utilization of/Access to Stable Primary Care Package
Patient Utilization of/Access to Secondary/Tertiary Care
Use of Negative Coping Strategies (traditional healers, pharmacies as primary providers of medications, etc)
Health of Syrian Refugees with DM/HTN
Community Based Screening for DM/HTN
CHV Referral to Health Care
Community-based, timely morbidity/impact data
CHV NCD Programming Utilization
CHV Technical Skill and Motivation (Capacity)
CHV Coordination of Care
Unknown or untreated cases of DM/HTN
CHV Capacity for Holistic Care
Community Trust in CHV programming
Mobility of DM/HTN Patients
Patients recieving medications/care from multiple facilities
Out of pocket Expenses
Patient's Capacity for Self Care/Health Literacy of NCD (foot checks, diet, exercise, etc)
Psychosocial state of Patient
Policy Level
Health System Level
Community Level
Patient Level

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
Personal characteristics			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	
Occupation	3	What was their occupation at the time of the study?	
Gender	4	Was the researcher male or female?	
Experience and training	5	What experience or training did the researcher have?	
Relationship with participants			
Relationship established	6	Was a relationship established prior to study commencement?	
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	
Interviewer characteristics	8	What characteristics were reported about the inter viewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	
Domain 2: Study design			
Theoretical framework			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	
Participant selection			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	
Sample size	12	How many participants were in the study?	
Non-participation	13	How many people refused to participate or dropped out? Reasons?	
Setting			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	
Data collection			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	
Repeat interviews	18	Were repeat inter views carried out? If yes, how many?	
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	
Field notes	20	Were field notes made during and/or after the inter view or focus group?	
Duration	21	What was the duration of the inter views or focus group?	
Data saturation	22	Was data saturation discussed?	
Transcripts returned	23	Were transcripts returned to participants for comment and/or	

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
Data analysis			
Number of data coders	24	How many data coders coded the data?	
Description of the coding tree	25	Did authors provide a description of the coding tree?	
Derivation of themes	26	Were themes identified in advance or derived from the data?	
Software	27	What software, if applicable, was used to manage the data?	
Participant checking	28	Did participants provide feedback on the findings?	
Reporting			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	
Data and findings consistent	30	Was there consistency between the data presented and the findings?	
Clarity of major themes	31	Were major themes clearly presented in the findings?	
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

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