Chronic NCD care in crises: A qualitative study of global experts’ perspectives on models of care for hypertension and diabetes in humanitarian settings

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A B S T R A C T

Background: The high and rising global burden of non-communicable diseases (NCDs) is reflected among crisis-affected populations. People living with NCDs are especially vulnerable in humanitarian crises. Limited guidance exists to support humanitarian actors in designing effective models of NCD care for crisis-affected populations in low- and middle-income countries (LMICs). We aimed to synthesise expert opinion on current care models for hypertension and diabetes (HTN/DM) in humanitarian settings in LMICs, to examine the gaps in delivering good quality HTN/DM care and to propose solutions to address these gaps.

Methods: We interviewed twenty global experts, purposively selected based on their expertise in provision of NCD care in humanitarian settings. Data were analysed using a combination of inductive and deductive methods. We used a conceptual framework for primary care models for HTN/DM in humanitarian settings, guided by the WHO health systems model, patient-centred care models and literature on NCD care in LMICs.

Results: HTN/DM care model design was highly dependent on the type of humanitarian crisis, the implementing organisation, the target population, the underlying health system readiness to deal with NCDs and its resilience in the face of crisis. Current models were mainly based at primary-care level, in prolonged crisis settings. Participants focussed on the basic building blocks of care, including training the workforce, and strengthening supply chains and information systems. Intermediate health system goals (responsiveness, quality and safety) and final goals received less attention. There were notable gaps in standardisation and continuity of care, integration with host systems, and coordination with other actors. Participants recommended a health system strengthening approach and aspired to providing patient-centred care. However, more evidence on effective integration and on patients’ priorities and experience is needed. More funding is needed for NCD care and related research.

Conclusions: Comprehensive guidance would foster standardization, continuity, integration and, thus, better quality care. Future models should take a health system strengthening approach, use patient-centred design, and should be co-created with patients and providers. Those designing new models may draw on lessons learned from existing chronic care models in high- and low-income settings.
1. Background

Over 250 million people are estimated to be affected by humanitarian crises annually, including over 80 million people forcibly displaced from their homes as internally displaced persons (IDPs) or refugees (CRED, 2013; CRED, 2018; UNHCR, 2021). The high and rising global burden of non-communicable diseases (NCDs) is reflected among crisis-affected populations, and humanitarian crises increasingly occur in middle-income and urban settings where the NCD burden is significant (UNHCR, 2021; Guterres and Spiegel, 2012; Dewachi et al., 2014). People living with NCDs are especially vulnerable in humanitarian crises. Their access to essential NCD care and medicines may be limited by insecurity, population displacement, damaged health systems, interrupted supply chains and services, and irregular food supplies (Johanputra et al., 2016; Aebischer Perone et al., 2017; Slama et al., 2017). Thus, they are at increased risk of experiencing acute exacerbations or complications of their NCD condition(s) (Hayman et al., 2015).

In response, humanitarian actors have adapted humanitarian models of care, which traditionally provided acute care, focused largely on communicable diseases, to better address chronic NCDs.

The importance of models of care for NCDs has been highlighted in stable and high-income settings. Models of care may be broadly defined as the way health services are delivered to a person, population group or patient cohort (ACI, 2013). They describe how best practice health care is delivered through different stages of a condition, injury or event, ensuring that the right care is delivered at the right time, in the right place, to the right person or group (ACI, 2013). Care for chronic conditions in well-resourced settings has evolved from an acute, often hospital-based, physician-led, disease-focused care model to an increasingly primary care-based, multi-disciplinary, patient-centred approach, embracing multimorbidity (Coleman et al., 2009; Stokes et al., 2017; Low et al., 2011). By contrast, NCD care continues to be focused at hospital-level in many low and middle income country (LMIC) settings. Very limited guidance exists to support the design of effective models of NCD care for crisis-affected populations in LMICs (Ruby et al., 2015; Ebrahim et al., 2013; Jaung et al., 2021). Current NCD care models in crises are diverse, ranging from ad hoc responses to natural disasters to a de facto primary care system with electronic records in a stable refugee setting (Jaung et al., 2021).

The aim of this paper is to synthesise expert opinion describing current care models for hypertension and diabetes (HTN/DM) in humanitarian settings in LMICs, to examine the gaps in delivering good quality HTN/DM care and to propose solutions to address these gaps.

2. Methods

2.1. Study design

We conducted semi-structured interviews with experts in the delivery of care for HTN/DM in humanitarian settings. We focussed on HTN/DM as tracer conditions, since they are highly prevalent, have measurable outcomes and are amenable to management at primary care level. Humanitarian crises were defined as events stemming from armed conflicts, natural disasters, or food insecurity that threaten the health and safety of a community (Buttenheim, 2009; Blanchet et al., 2017).

2.2. Conceptual framework

To guide the overall study, a conceptual framework (Fig. 1) was developed, which drew on: (i) an adapted WHO model of health systems (including Penchansky and Thomas’ elements of access and coverage) (WHO, 2007; Penchansky and Thomas, 1981); (ii) a person-centred approach to healthcare (Stewart, 2001; Levesque et al., 2013; Cloninger, 2011; Nolte and Amell, 2020); and (iii) existing literature on models of NCD care in LMICs (Bradley et al., 2007). The function of the framework was to help operationalize the concept of a model of care to guide the development of study instruments, categorise data, shape the analysis and guide policy recommendations. For our purposes, the concept of a model of care served to illustrate the theoretical underpinning or motivations for organising care in a certain way and the specific elements necessary to deliver care (Stokes et al., 2017). It was not intended to identify or propose “off the shelf” or pre-defined packages or models of service delivery.

The WHO health systems framework includes overall goals or outcomes (responsiveness, improved health, improved efficiency and social and financial risk protection), which are achieved via intermediate goals (access, coverage, quality and safety) (WHO, 2007). We incorporated Penchansky and Thomas’ elements of access into our conceptual framework, which also included measures of coverage (Penchansky and Thomas, 1981). WHO defines responsiveness as the way in which individuals are treated and the environment in which they are treated, encompassing the individual’s experience of contact with the health system (WHO, 2007). We adapted our definition of responsiveness from Papanicolas & Smith and initially included it as an intermediate outcome, downstream of access, coverage, quality and safety (Fig. 1) (Papanicolas and Smith, 2013; Fuhr et al., 2020).

Since the WHO building blocks model does not capture the concept of patient-centeredness or the interaction between the formal health system and community-systems very well, we also included “demand side” and patient preference factors in the conceptual framework. These were drawn from economic models, social systems approaches to describing health systems and the burgeoning literature on quality of care in LMICs (Ensor and Cooper, 2004; Kruk et al., 2018). It was also informed by the “systems thinking” approach and on previous analyses of LMIC health systems and humanitarian responses to diabetes and hypertension. The individual components are defined in Supplementary File 1. The framework was further revised in light of our study findings.

2.3. Participant selection and recruitment

A list of potential participants (n = 48) was compiled based on their expertise in provision of NCD care in humanitarian settings, including people from United Nations (UN) agencies, academia, international and national non-governmental organisations (NGOs) and advocacy groups. They were identified through our academic and humanitarian partners’ networks and via a brief review of published and grey literature. Study participants were asked to rate participants for interview as high, medium or low in terms of both relevance and access. Greater weight was given to those who were directly involved in implementing NCD care in humanitarian setting(s) and/or who were not widely published, in order to document their experiences and opinions. A short list of thirty-one participants was invited via email.

2.4. Data collection

An interview topic guide (Supplementary File 2), informed by our conceptual framework, was developed and piloted by the lead researcher (EA – female, English-speaking, academic clinician). Semi-structured interviews were conducted in English via Skype and audio recorded by EA from February to April 2019. Written, informed consent was received from all participants.

2.5. Data management and analysis

Interviews were transcribed verbatim by EA and RI. Transcripts were de-identified and imported into QSR NVivo 10® for analysis. A thematic approach was used to analyse the data, following Braun and Clarke (Bradley et al., 2007), iteratively combining inductive and deductive methods.

Transcripts were read in their entirety. Analysis steps involved: (i) Deductive analysis coding to the key elements of the conceptual framework (Fig. 1) (EA, RI); (ii) Inductive analysis seeking to elicit new
themes or unexpected findings, which were then examined for robustness in relation to the research question and to existing literature, and incorporated into the coding framework if found to be robust (EA, RI, RW); (iii) Comparison of findings across sub-groups [participants from academia, UN agencies and NGOs] (EA, RI, RW). Throughout analysis, negative cases or exceptions were examined to test emerging themes and to explore why these cases were different. Core codes were developed applying constant comparative analyses toward categories. Finally, emerging findings were examined to ensure against the insertion of pre-conceived assumptions. The coding tree is provided in Supplementary File 3.

From among thirty one invitations, twenty interviews were conducted, four received no reply, four declined on the grounds that they felt inexpert in the area, two deferred to colleagues who were also invited, and one declined because of the project’s funding source. We conducted individual interviews until data saturation was achieved (i.e. our preliminary analysis indicated interviews were no longer uncovering new themes related to our research question). As we were interested in over-arching themes, or meta-themes, we were able to achieve saturation with a smaller sample size than would normally be needed for finer-grained themes (Guest et al., 2016). Information on the interviewees is given in Table 1. They all had experience of working on NCD programming or policy, with different geographic, emergency type, response phase and income level characteristics.

Table 1
Interviewee characteristics.

| Characteristic | Number |
|----------------|--------|
| Organisation Type |        |
| Academic | 5      |
| Advocacy | 2      |
| NGO - International | 8      |
| NGO - National | 1      |
| UN Agency | 4      |
| Gender |        |
| Female | 10     |
| Male | 10     |
| TOTAL | 20     |

3. Results

Participants described diverse and highly context-dependent models of NCD service delivery. Most implementing organisations took a primary or community care approach to NCD care, adapting to the underlying disease burden, the implementing organisation’s experience and strategy and, in many cases, to the host country health system’s existing NCD care infrastructure. Sustainable approaches, facilitating continuity of care and integration with existing health systems were mooted. Key needs included greater standardisation of care, supported by shared operational tools, guidance and indicators, more operational research and better funding for NCD research and operations.

Current care models were described with differing emphases depending on the category of participant. NGO implementers offered specific programme examples while managers offered an overview of their organisations’ approach to NCDs. Participants from UN agencies provided a global or regional overview of NCD responses and tended to focus on examining host countries’ health system structures, readiness and resilience, while academics offered examples of specific research study interventions and highlighted the challenges of performing research in humanitarian environments.

We present our findings based on our conceptual framework (Fig. 1). Most participants discussed adapting responses to the context and phase of the crisis. Most implementers focussed on the health system building blocks of care (facilities and services, medicines and equipment, health workforce, information, financing and governance). Participants also reported on the intermediate goals of access and coverage, with quality and safety featuring much less. Responsiveness to patient needs and patient or community factors were discussed in a limited or aspirational way, and were illustrated by limited practical experience. The final health system goals (improved health, social & financial risk protection and improved efficiency) received very limited attention.

3.1. Contextual factors and crisis phase

Respondents highlighted the fact that no single, unifying or ideal “model” of HTN/DM care was possible since the response to HTN/DM in humanitarian settings was so highly context dependent, with one noting:
“We cannot compare service delivery models without having a granular discussion on where we operate... (the) phase of an emergency (response),... (and) the health system context.”

3.1.1. Type of crisis and phase of response

Most participants agreed that the heterogeneity of humanitarian crises meant that HTN/DM responses have been adapted to: (a) the type of crisis (natural disaster, conflict or health crisis); (b) the phase of the crisis (acute vs. prolonged vs. protracted/cyclical); c) the phase of the response (Fig. 1). Most agreed, in theory, on the desired sequence of prioritisation for NCD interventions in response to an acute crisis. However, there was acknowledgement that the approach described was largely aspirational, that NCDs have often been “forgotten” in crises and that, in reality, responses may have been “ad hoc”, “disorganised” or delayed.

In the first stage of an early response to an acute emergency, such as the influx of a displaced population, all implementers suggested prioritising those at highest risk of death and significant acute morbidity; examples included people with Type 1 diabetes, epilepsy, severe asthma or psychotic mental illness.

During the second, early recovery response phase, in a more stable or prolonged crisis, most implementers agreed that further long-term morbidity (such as stroke and kidney failure) should be prevented by identifying people with existing NCD diagnoses, ensuring good disease control through prompt medical review, and maintaining their medication supply:

“We start with trying to ensure there’s facilities to manage life threatening complications of NCDs ... and ensure continuity of medication for people who are medication dependent”

Prompt intervention could help mitigate the stress experienced during an acute crisis, which could trigger exacerbations or complications. However, how to identify and respond to those needing intervention in the acute phase of a crisis was not well established. Several respondents described existing tools used in acute crises as lacking an NCD focus, while an NCD emergency health kit and guidelines (similar to that used in maternal and child health emergency response) were recent additions, still under evaluation.

In the third, late recovery response phase, as the situation stabilised into a more protracted crisis, most respondents proposed establishing an NCD care package to provide continuity of care for those with known diagnoses. Indeed, most programmes they described fit into this phase. The choice of target condition(s) for these care packages was influenced by WHO guidance, local NCD epidemiology, pre-existing services and feasibility to manage at primary care level. Thus, hypertension and diabetes care was almost universally included, cardiovascular disease and chronic respiratory disease were frequent additions, and, where relevant, other conditions such as epilepsy or thalassaemia were added. However, several respondents acknowledged that underlying epidemiological data to guide these decisions were “scant”.

Many suggested that community-level awareness raising, primary prevention activities, active case finding of symptomatic but undiagnosed people, or screening of asymptomatic people could be introduced during this third phase, for example:

“As the situation continues to normalise, ... you can now introduce the prevention aspects of promoting, healthy lifestyles, people doing exercise, but it’s very hard for you to promote that in the critical phase of an emergency.”

Asymptomatic screening was controversial, discussed further under “Facilities and services”, below.

3.1.2. Security, location and access to the affected populations

Service design was influenced by the target population’s location and access. Participants reported that providers were more likely to set up new, non-integrated services, for camp-based populations, whereas, for displaced populations living among the host population, most considered it more appropriate to integrate services within the pre-existing public health system. Several agencies introduced mobile clinics or outreach teams in insecure contexts, such as Yemen and Syria, or for hard to reach locations or populations, such as nomadic tribes in an insecure setting in Ethiopia.

3.1.3. Organisational approach and pre-existing services

An organisation’s underlying ethos regarding their role as strictly humanitarian versus development actor also reportedly influenced service design. Some international NGOs (iNGOs) collaborated closely with host country public health systems. Others worked through partner national NGOs or provided care directly, without engaging at the broader health system level:

“Until now we haven’t prioritised NCDs highly enough to want to start to engage with national programmes; we’ve confronted it on an individual facility or health zone level and felt very powerless at that level... this will continue to be a problem for [us] because we work at that level.”

Implementers reported that NCD care was often added to existing primary-level general outpatient, HIV/TB or maternal and child health programmes. Previous experience providing chronic HIV/TB care influenced service design in some cases, with existing task sharing, psychosocial support, patient recall and data collection systems adapted for HTN/DM care.

3.1.4. Underlying health system readiness, destruction and responsiveness

The host health system’s readiness, capacity and pre-existing model of NCD care delivery (particularly, the primary level capacity) also influenced the design of iNGOs’ NCD care models. In many crisis-affected countries, participants reported that NCD care was traditionally delivered by specialists, focussed at secondary or tertiary care level, with few having well developed NCD care at primary level. In some contexts, for example, in Jordan and Turkey, humanitarian actors adapted to well-established national health or humanitarian policies. In others, a lack of strong, coherent, national health policy and implementation led to a fragmented response, where humanitarian actors had intervened in a “piecemeal and uncoordinated” way. As one respondent explained:

“What exists before the crisis determines what you will get during the crisis. If NCD is not mainstream, be that the policies, strategy or healthcare at facility level, whatever you will get after will be determined by the actors that have jumped in during the emergency or were there before.’

Similarly, the degree of health system destruction, the system’s resilience and capacity to rebuild were interlinked with the severity, duration and the type of crisis (i.e. one-off crisis such as an earthquake or repeated crisis such as a protracted conflict).

3.2. Required health system inputs

3.2.1. Facilities and services

Most models described by participants were located in primary care facilities, and participants concurred that NCDs were best managed at primary care level, with practical justifications, for example:

“You’re geographically nearer, culturally nearer as the nurses, clinical officers and doctors know the local community…”

[GE13]

[GE3]

[GE19]

[GE12]
Table 2
NCD Service components.

1. Identification of established disease (requiring emergency assessment tools, targeted screening of specific populations)
2. Regular supply of good quality generic medications +/- equipment
3. Continuity of good quality care and follow up, which requires data collection and chronic care systems (patient files; appointment, recall and referral systems; monitoring & evaluation)
4. Medical assessment and management of cardiovascular risk (using basic tests, identifying and managing comorbid obesity and HTN/DM)
5. Prevention, screening and management of complications (involving patient education, promotion of healthy living, primary level complications management, and referral of more complex complications to higher levels of the health system, where possible)

Some respondents emphasised the benefits of "generalist training" to manage multimorbidity. Table 2 presents a synthesis of the key NCD service components identified by participants.

Healthy living counselling was seen as key by most respondents, but several felt the content should be improved, with greater involvement of patients. Rehabilitation and palliative care services were reportedly rarely available and all agreed this area required significantly more focus from the humanitarian sector. Palliative care was, "still in its infancy…very few people are trained in palliative care and…[there is poor] availability of medicines especially the controlled drugs (such as morphine)"

Screening, prevention and referral of NCD complications to specialist care was also viewed as important. The referral services participants identified as key (emergency care for acute exacerbations, cardiology, ophthalmology, endocrinology and renal medicine) were available to a limited degree in Middle East settings, in contrast to many other humanitarian settings, where, for example:

"We’re often encouraging people not to refer (to hospital) unless they really believe that referral is going to do the patient good (as)…when they arrive there, there’s no oxygen…there’s no opiate and they die in the hospital instead."

When referral services were unavailable, several respondents questioned the ethics of screening NCD patients for complications:

"…if you haven’t got free access to laser treatment for retinopathy, I don’t see the point of doing any retinal screening"

Instead, most participants emphasised the need for good quality, cost-effective secondary prevention at primary care level (screening and management of complications, such as routine foot exam and manufacture of adapted shoes). Few successful examples of this were offered, and it was seen as an area ripe for innovation, for example, by using retinal screening supported by artificial intelligence or telemedicine. For such innovations to be effective, participants emphasised that strengthening and up-skilling of the primary care team, along with good quality referral pathways to specialist centres were essential. A few participants noted that strengthening pre-hospital care, and ensuring adequate emergency care for acute complications, such as diabetic ketoacidosis, was needed in many LMICs. One commented that a separate international initiative had been launched to address this (Moresky et al., 2019).

Community-level screening and primary prevention (screening for undiagnosed disease) were favoured by those from community-oriented organisations, who often worked via community volunteers. Organisations functioning in protracted refugee situations, for example, the Palestinian refugee population in the Middle East, had introduced opportunistic, facility-based screening to target groups. However, several respondents felt it was not feasible or ethical to offer such screening in humanitarian settings due to capacity constraints:

"I think you’re going to overload a system that’s not adapted and then what do you do if you screen for something and discover something that you can’t treat in that context?"

Another respondent countered that there could still be value in screening despite a lack of treatment options, as:

"…you can offer (newly diagnosed people) lifestyle advice at a minimum and (they can) decide whether they want to go off and access treatment"

Several participants felt that community-based care and links between community and primary care, were under-utilised and needed strengthening. Only one model, a community hub providing holistic care for older people in Cox’s Bazaar, Bangladesh, illustrated a comprehensive continuum of care involving bidirectional referral between the community and primary care.

3.2.2. Medicines and equipment

The high cost and poor availability of medicines and equipment were discussed by all participants. Costs were reportedly high from both patient and provider perspectives. Some larger INGs provided free medications but other NGOs and public systems required patient co-payments. In many LMIC contexts, access to NCD medications was limited. They were often unavailable via the public system, either because they were not included in the public system’s basic package of care or because of national supply chain issues. Patients were forced to purchase their medications through the private sector or to go without. One respondent recounted that:

"most of the (health) centres (in low resource countries) I visit have the medication for 10 days and the rest the people have to purchase it out of pocket…so most of them neglect using the medicine and they end up with complication(s)."

High provider costs were discussed by some implementers, with diabetes and hypertension medicines accounting for 50% of one respondent’s programme budget [GE08]. To manage costs, most respondents reported that NGOs used older, generic medicines, including human insulins, in keeping with the WHO EML. This reportedly led to tensions with local health providers, who often had more experience using newer, branded medications, including insulin analogues.

Several implementers reported procuring NCD medicines via international tender to facilitate cost savings, quality control and consistent supply. An example was offered of a national NGO pooling procurement to cover a network of PHCs with diverse ownership in Lebanon, which enabled some consistency of supply for patients. Other implementing organisations directly supplied Ministries of Health or supported through advocacy, for example in negotiating reduced medication prices. However, many participants reported that supply of NCD medications was frequently interrupted in public facilities, despite ING support. Poor procurement and forecasting practices and long importation lag times were blamed for this.

Most participants specifically highlighted the problems around insulin access and supply. In some contexts, national policy limited insulin prescribing to specialists and the lack of cold chain infrastructure made it logistically challenging and expensive to import and distribute to lower health system levels. Participants offered solutions including building on existing vaccination cold chain infrastructure, changing national policy and training primary level health care workers (HCWs) in the management of insulin.

Several suggested that the innovations in HIV care around medicines manufacture, procurement and prescribing could be applied to NCD services and medications, especially insulin. Task sharing, decentralisation of antiretroviral prescribing; introduction of simplified treatment algo-
rhythms with fixed dose combination pills; and simplified pill formulation and packaging to allow for longer dispensing intervals were all seen as relevant to NCDs. One participant called for pre-qualification of NCD medicines by WHO and expediting the entry to market of biosimilar insulins to facilitate its procurement on the international market. WHO prepares a list of pre-qualified medicinal products, which reach acceptable standards of quality, safety and efficacy, that is used by international procurement agencies and countries to guide bulk purchasing of medicine. However, another participant cautioned applying lessons learned from the HIV epidemic in Sub-Saharan Africa to the Middle East, without first assessing and adapting to the contextual differences.

Participants described major disparity in the choice and availability of NCD equipment in primary care programmes (e.g. microfilaments, ECG machines), and the types and frequency of laboratory testing (e.g. use of HbA1c [a measure of blood glucose control over the previous 120 days] or fasting glucose for diabetes diagnosis/monitoring), even within the same organisation in different country contexts. One respondent noted the challenges, not unique to humanitarian settings, around the lack of evidence for HbA1c use in certain populations and the non-standardisation of glucose strips and glucometers. Some suggested that devices more appropriate to extreme climates and populations with low literacy were needed and one participant suggested the humanitarian community should present “target product profiles” to manufacturers [GE17]. The potential for continuous glucose monitors, a technology that is becoming more widely used in high-income countries, to minimise the burden of self-testing and to encourage self-management among patients in humanitarian settings, was highlighted by several respondents. Point-of-care biochemical testing, mobile laboratory units, use of dried blood spot (as in HIV care) or using drone-assisted delivery were innovations highlighted by other respondents.

3.2.3. Health workforce

Most respondents described models where non-specialist doctors and nurses provided HTN/DM care, sometimes supported by specialist doctors. Midwives, pharmacists, lab technicians and community health workers and volunteers were also involved, in various contexts. Respondents repeatedly highlighted the limited capacity most primary level health workforces had to manage HTN/DM in many LMIC settings. The complexity of care an organisation could provide was, therefore, linked to the skills of the available HCWs:

“The health workforces would be at the core of all this because this determines actually their ability to have much more complex management...”

[GE13].

Several participants described the development of training initiatives. Capacity strengthening with ongoing training and supervision, supported by clear guidelines, was called for by most, especially where staff turnover was high. By contrast, one-off training programmes, without supervision or follow-up support, were deemed inadequate for the provision of high quality chronic care.

Many participants described task sharing as an underutilised approach that could potentially address several key human resource challenges and opportunities including: (i) the lack of qualified medical or nursing personnel in many settings; (ii) the longer consultation times needed for chronic disease care, which stretched clinicians’ capacity, and (iii) the untapped potential of the nursing role, particularly in the Middle East:

“I think a lot of it can actually be done by qualified nurses measuring blood pressure, recording history, examining the foot, etc., providing counselling for diet”

[GE17]

While certain community-oriented organisations had successfully shared specific tasks to community volunteers or peer supporters, such as community education and screening, some respondents noted that an evaluation of their actual effectiveness was still required. Others’ attempts at task sharing had been limited by resistance from the local medical community or by national regulations, which prevented non-specialists acquiring specialists’ skills, and excluded nurses from prescribing.

3.2.4. Information

Strengthening primary level data collection systems to support good quality, continuous NCD care was essential, according to most participants. This should include the key elements necessary for clinical decision making and patient follow-up (patient level data) and for activity and quality monitoring (cohort level data) via “the individual clinical record... the register... the call and recall system ... and... the day (appointment) book.” [GE20]

By contrast, implementers described current patient level data collection as inconsistent and ad hoc, resulting in:

“...a waste of time and effort because diabetes and hypertension care that is disorganised and episodic means that you are investing money (and) you are not getting anything back.”

[GE02]

Similarly, many organisations’ current health information systems (HIS) were not geared to collect the “routine data from recurrent encounters”, necessary for cohort level monitoring or were inefficient [GE18]. In practice, parallel data collection systems were often in place to serve different audiences (funder, implementer, national system). Several participants, especially those with experience delivering HIV or TB care, emphasised the importance of keeping monitoring and evaluation (M&E) processes “extremely simple”, feasible for busy staff and useful [GE17]. This meant performing regular analysis of a small number of indicative feeding results back to frontline clinicians. Otherwise, data collection risked being ‘meaningless’ [GE02]. Standardised indicators and increased funding for M&E were identified as key gaps by implementers and academics, for example:

“There still remains huge frustration that we don’t have meaningful M&E in most programmes – it’s hard to do, expensive, there aren’t funds for it, and donors need to start paying for that.”

[GE08]

Continuity of information between different sites and levels of the health system was also considered essential by most respondents, but sorely lacking in many LMIC contexts.

To facilitate continuity, especially for mobile or displaced populations, many interviewees strongly advocated for paper or electronic patient-held clinical records. Some suggested this approach could also empower patient self-care. Examples included a patient passport used during outbreaks of conflict in the Democratic Republic of Congo and a pilot, cloud-based, patient file accessed via smart phone in Lebanon. While the potential of technology to support continuity of care and M&E indicators was recognised by most, its use was still limited and non-standardised. Some participants favoured the introduction of a comprehensive, integrated electronic medical record that could generate a patient file, cohort level reporting, reports/referral forms, and HCW prompts. However, it was acknowledged that:

“... (electronic medical records are) probably the future, but it’s not reality... and nobody has a good system that incorporates individual level medical data with a surveillance system”.

[GE18]

Several participants emphasised that any new HIS system should be standardised, yet “versatile”, interoperable with existing, national HIS, should not overburden staff and should be sustainable in terms of funding and maintenance.
3.2.5. Financing and governance

Participants all agreed that HTN/DM care, and NCD care in general, was underfunded. In contrast to the extensive funding for HIV, TB and Malaria, “there is no Global Fund for NCDs” [GE17] and a global fund specifically for insulin was mooted. Similarly, research funding for NCDs was extremely limited and all academics criticised available short-term funding, which necessitated short studies that could not demonstrate impact on hard clinical outcomes, such as mortality. Short-term, project-based funding cycles of one to two years, typical in the humanitarian sector, was seen as a poor fit for chronic disease care and led to certain innovative interventions not being sustained (see also Sustainability section, 4.6).

Many respondents reported that provider organisations perceived NCD care as costly. This influenced the extent to which implementers engaged in NCD care, and what they included in their package of primary level NCD care, including specialist referral services. For example, one iNGO participant ascribed their organisation’s low prioritisation of NCDs as relating to a fear of “overburden(ing)” the organisation, or committing it to engaging in costly “chronic care (and) NCD drugs” [GE17]. However, the high cost also focussed participants’ organisations on providing rationalised, evidence-based care.

International NGOs with independent financing models could fund and implement their own package of NCD care. Others directly funded public services at facility or central level, or funded partner national NGOs. Given the lack of alternative funding sources, some participants suggested that iNGOs themselves should fund innovations, including those around insulin delivery, accepting “higher up-front costs…to see how it can strengthen our model of care” [GE17], or, as one participant suggested, the pharmaceutical industry should invest:

“The industry has a certain level of responsibility in this and I think they cannot be part of this project without…, using their own research and development capacity and resourcing …to address these issues.”

[GE18]

Many participants called for strong advocacy by all stakeholders for increased, sustainable funding for NCD care in humanitarian crises.

Government public health policy and legislation around tobacco control, promoting exercise and health eating was reportedly lacking in many humanitarian settings and most felt strong national policy was essential to successful HTN/DM control.

3.3. Patient and community factors

3.3.1. Knowledge and education

Knowledge of diabetes, hypertension and their complications within communities varied depending on the context, according to our respondents. They perceived that knowledge was lower among populations in crisis-affected Sub-Saharan African countries compared to the Middle East. In response, one organisation had trained a Ministry of Health (MOH) community health worker network to teach households about NCDs, but acknowledged the need to cater for the resultant increased service demand. As discussed, many humanitarian actors called for tools, such as glucometers, to be adapted for use by populations with low literacy.

3.3.2. Preferences and trust

Few assessments of patients’ experience had been performed. Therefore, insight on patients’ needs was largely anecdotal:

“We don’t know much about patient priorities because there aren’t many patient surveys being done… So I can only surmise what the priorities are for patients.”

[GE20]

Respondents noted that accessing chronic disease care may feature low down on a displaced person’s hierarchy of needs, since shelter and protection concerns were likely more pressing:

“Human beings in such situations, their first priority is not to control blood pressure. Their first priority is to get back to normality.”

[GE16]

Notions about patient preferences were intertwined with the idea of trust in services. Respondents perceived that patients prioritised access to a continual supply of medications and experiencing interrupted or inconsistent supply diminished their trust in health services. In Middle Eastern settings, as noted above, patients reportedly preferred private providers and modern, branded medication, and had limited trust in public providers.

3.4. Intermediate goals

3.4.1. Access and coverage

Most interviewees focussed on access to NCD medicines (especially insulin) and referral services, and more specifically their availability and affordability. In general, participants noted a heavy reliance on out-of-pocket payments by patients to access medical consultation and investigations and this raised concerns about affordable access and coverage for patients:

“[if] they don’t find [the medication at the health centre], they don’t take it or they go elsewhere and they pay for more. They pay for consultation fee. They pay for transportation. They pay for the drug itself…when you add up those small contributions together for a household, it becomes something that might be quite substantial.”

[GE13]

Patients could rarely access referral services, because they were not available (especially in more resource-constrained settings) or were unsustainable (such as in the Middle East). UNHCR and UNRWA funded a limited package of specialist referral care for Syrian and Palestinian refugees, through the public system or via contracted private hospitals. Access was also mediated by national humanitarian policy. In Jordan and Turkey, for example, Syrian refugees were entitled to access the public primary care system but not higher levels of the health system. Where care was not subsidised by a national system, several participants noted that it could become “very costly for a diabetic patient to navigate the system” [GE13].

Limited access to NCD care by certain vulnerable groups was also highlighted by a number of participants. They noted that access to facilities may be difficult for older people, who may be “invisible” within their societies, and for marginalised groups, such as nomads and women, who may face safety or cultural issues [GE12].

3.4.2. Quality and safety

The quality of care delivered had rarely been focused on or measured, since organisations were still establishing the basic building blocks of care:

“So quantity first. If you haven’t got enough medicines, if you haven’t got enough time for people, if you haven’t got any care pathways in place, don’t start looking at the quality of the service.”

[GE20]

The degree of integration within host country systems influenced how much control an implementing organisation had over quality of care. One iNGO participant described their organisation’s strong medicines quality assurance policy and their variable capacity to implement this when working closely with MOH procurement. The lack of WHO prequalification, whereby pharmaceutical companies’ products were quality assured by WHO, exacerbated this issue, according to some participants.
Consistent M&E was linked to the idea of quality by most participants. However, formal quality assessment was rarely done in practice. One organisation recently commenced a quality assurance process for their contracted referral hospitals, while another had introduced a quality and safety framework, including critical incident reporting, and measures of patient-centredness.

“...we need to...start to think about patient autonomy or dignity or person centeredness and look at the experience of people as well as the sort of traditionally hard outcomes ... I think that the quality discourse has made us reflect more...”

[GE03]

There were contradictory opinions about how quality should be measured, with implementers favouring process outcomes and academics clinical outcomes, especially hard outcomes, such as incidence of complications and deaths.

Safety was rarely referred to and only in terms of setting conservative targets for glycaemic control to avoid dangerous hypoglycaemic episodes.

3.4.3. Responsiveness

Many participants raised the notion of “patient-centredness”, which was included in our definition of responsiveness. However, while their organisations aspired to provide “holistic”, responsive care, most felt that patient-centredness, including addressing patients’ psychosocial needs, was rarely achieved in practice and was often “forgotten”. The lack of holism was particularly noted in relation to the humanitarian response around nutrition for people living with NCDs. The nutrition sectors has traditionally focussed on “malnutrition and starvation [rather than] obesity and high fat and high salt.” [GE20], and therefore, food aid provided to people with NCDs living in camps was reportedly “inappropriate” [GE14].

Many participants proposed that, in theory, responsive, patient-centred care would involve having a geographically accessible clinic, flexible opening times (including emergency access), a choice of provider (including choice of genders), and friendly and welcoming staff. However, only limited examples were offered of patient-centeredness practice. These included efforts made to: (i) move care closer to patients using community volunteers, mobile health teams and home visit teams; and (ii) link different programmes, such as health, protection and finance, around a single patient or to include mental health and psychosocial support (MHPSS) with care for physical NCDs: and (iii) engage with communities in the design of context-relevant education materials.

Patient empowerment and peer support for HTN/DM patients were considered important by most respondents but were currently lacking in humanitarian settings. One pilot-based introduction of community cooking and exercise groups appeared successful:

“...honestly, that was the biggest hit I have ever seen, any campaign. They really like ... people are really interested in healthy life... But we fail to provide such opportunity.”

[GE11]

Several cited examples to learn from, including peer support interventions, which were well developed in chronic HIV/TB care globally and in NCD care in higher income countries, and HIV community support groups and community adherence groups.

Greater focus, funding and research for these programme components were recommended by most. One participant also suggested a family-centred approach, where the whole family benefits from healthy living education. As discussed, participants suggested that patient empowerment could be strengthened, for example, by patients holding their own data or being supported to self-manage their condition.

3.4.4. Standardisation

Most implementers looked to WHO for guidance but acknowledged that clear, standardised technical guidance, adapted to humanitarian contexts, was lacking. The majority of participants called for “guidelines for standardisation of care”, including clinical and operational guidance (e.g. medication and equipment lists, suggested patient monitoring intervals, and indicators) and data collection tools:

“what is the benchmark, what needs to be prioritised, what intervention(s) and...protocols.”

[GE13]

Some international NGOs and UNHCR had produced their own clinical guidelines, while other organisations used national guidelines. In settings where health workers were formally trained on UNHCR clinical guidelines, one respondent reported that local clinicians called for additional focus on mental health care, on epilepsy, musculoskeletal conditions and chronic kidney disease to complement training on the four major NCDs classes identified by WHO (WHO 2013). Telemedicine (connecting with remote specialists), was identified as a means to supplement written clinical guidance and support the management of patients with complex or poorly controlled disease by several respondents. One INGO had experience using telemedicine and its potential for wider use was discussed by several participants.

Standard operational guidance was also lacking within humanitarian and public health system sectors in LMICs. One respondent suggested, again, that the HIV model, where international guidance was published by WHO, could be adapted for NCDs:

“In the HIV world, we’ve always had the ‘what to do (clinical) guideline’, which is which drugs (and) when to start. It’s not until the last four to five years that we have had the ‘how to do it (operational) guideline’”

[GE17].

The absence of tools to assess NCDs in the acute emergency phase of a crisis was highlighted by many. Until recently, NCDs featured little in the Health Resources Availability Mapping System (HeRAMS) and there were no interagency standing committee (IASC) global health cluster guidelines for NCDs, meaning they were often an “afterthought” in emergency response:

“You know, you arrive with your interagency emergency health kit. It has got no insulin. It has got no first line drugs for NCDs. Then you realise ...we have diabetic patients and then you start running around to look for (those drugs).”

[GE19]

Similarly, existing health sector assessment tools for use in the post-acute phase of a crisis did not include NCDs.

Many participants suggested that standardisation of guidelines and tools would promote a “coordinated response ... (and) continuity of care” among humanitarian actors, as well as consistent and rational prescribing and continuity for mobile populations. Standardisation of care would also discourage patients from “shopping around” and would minimise duplication. One key challenge that emerged from several participant accounts was the potential fragmentation that occurred when multiple actors engaged in NCD care in an non-standardised way, for example:

“the response was (fragmented), both in terms of type of population, so IDPs versus refugees, people in the conflict zone versus non-conflict zone and then what different organisations provide. You know, some did provide NCD medicines, some didn’t. Some provided food, some didn’t.”

[GE14]

Finally, several proposed that standardisation would facilitate integration within host health systems and facilitate HCW training.
3.4.5. Integration and continuity

Integration and continuity were key overarching themes that emerged from the interviews. Integration was discussed by different participants in terms of patient level, across sites of care, and at a broader health system level. Participants focussed on six distinct elements when discussing the concept of integration. First, integration at the patient level within the consultation. This would ideally involve delivery of person-focussed care, catering for multimorbidity and managing cardiovascular risk, by a family medicine specialist or a well-trained generalist with good guidelines, training and ongoing supervision. Second, integration of NCD care within a primary care service (ideally within the existing health system), providing mental health and psychosocial support, healthy living counselling and adherence support, and managing complications, rehabilitation and end-of-life care within the same service. This could be done via a multidisciplinary team with nurses, podiatrists, physiotherapists, where these cadres were available, but simplified guidance should also be developed for contexts where basic care with appropriate training could be provided by less qualified health worker cadres. Third, integration with other facility services, including with HIV/TB care, antenatal care, and mental health care, to maximise efficiency and utilise existing infrastructure and processes:

“So if I’ve got HIV with diabetes, (I) should be able to pick up, within the same type of model, whether it’s a [Community Adherence Group] or club or fast track, I should be able to get my medicines for diabetes and ART, same day, same place, same model. That hasn’t been implemented unfortunately”.

[GE17]

Fourth, integration with other sites and levels within the health system to link primary care level services to community-based care and specialist referral care. Fifth, integration between humanitarian and the host country health system and host community, providing services accessible to both at a level equivalent to what is available to the host community. Lastly, integration with other humanitarian sectors, such as the protection sector, was also key but lacking to date.

Continuity was cited by the majority as a principle goal of an NCD care model. This was framed by many participants as continued attendance at a facility, continuity of medicines supply and consistent medical management, between facilities and locations.

Coordination between the various humanitarian actors and UN Clusters involved in humanitarian response, the “vertical areas, health, water and sanitation, nutrition, security” was needed, according to one participant [GE14]. In each setting this would, ideally, be facilitated by a “champion” who was familiar with humanitarian coordination mechanisms [GE18]. Standardisation, as mentioned above, and coordination were considered essential to integration and to continuity by many participants.

3.4.6. Sustainability

The need to move away from the traditional short-term, project-based humanitarian, emergency response in relation to NCDs was emphasised by many, and, although it may “allieve some suffering”, it is not sustainable, according to one participant [GE13]. The humanitarian response “has to be factored through the lens of health system, through the lens of what is possible when they leave.” [GE16]

Several participants criticised short-term humanitarian approaches, whereby NGOs demonstrated that a certain model could work and then departed the context. Instead, some suggested taking a “sustainability lens”, strengthening existing public health systems, analysing the “political context” and “health system readiness” [GE13], and planning for departure from the beginning:

“on the day after the humanitarian partner arrives, (they) need to be thinking about how they’re going to leave.”

[GE20]

Most implementers and UN agencies also recommended mapping a country’s existing NCD care at the start of an emergency, ideally using a universal healthcare framework. This would help humanitarian actors address gaps and potentially integrate into existing systems, with a long term view to sustainability. Without taking a health system approach, humanitarian actors were working “in a vacuum”, according to one participant [GE13]. Sustainability was also closely linked to the financing model, with many NGOs operating on the basis of short-term, project-based funding, which is a poor fit with chronic care models, as “chronic care requires sustainability of practice, but also of funding” [GE13].

3.5. Final goals

Participants focused mainly on health system inputs when describing current models, rather than on the final health system goals of improved health, social and financial risk protection and improved efficiency. While longer-term health goals of preventing complications and long-term disabilities ‘in five or 10 years’ time’ were mentioned by several, most implementing and academic participants acknowledged this was difficult to achieve and to measure. Intermediate clinical outcomes were suggested as more realistic indicators of programme effectiveness by several:

“So we’re not looking for fewer amputations, fewer strokes or heart attacks because that’s 10 or 15 years (from now). Are our proxy indicators being monitored? … we know that if we manage blood pressure, there’ll be fewer strokes and heart attacks. Are we controlling people’s blood sugar?”

[GE20]

Most participants also acknowledged that delivering effective NCD care and achieving these intermediate outcomes is challenging, even in high-income countries.

Several participants noted that protecting patients from financial precarity should also be a goal of NCD programmes themselves or of advocacy work with governments.

4. Discussion

We have applied the concept of a “model of care” to the area of HTN/DM care in humanitarian settings, exploring the modes of service delivering the right care, to the right people, by the right team, at the right time (Davidson et al., 2006). Using our conceptual framework, we categorised the essential elements, identified key gaps and priority needs and identified potential innovations to address these gaps. Our analysis highlighted the diversity of current models, whose design was highly dependent on the type of crisis, the implementing organisation, the target population, the underlying health system readiness to deal with NCDs and its resilience in the face of crisis.

Humanitarian crises have been stratified into phases requiring different speeds and types of response (Buttenheim, 2009). Our study participants offered few examples of acute emergency responses for people living with NCDs. The unfolding crisis in Ukraine illustrates the urgent need for countries to prepare for crises, which disrupt or destroy health systems and supply chains, and for tools to quickly map the needs once crises occur. The operational tools available to support this acute phase of crisis response are limited, but growing. While NCDs feature little in WHO’s Health Resources Availability Mapping System (HeRAMS) or in health system assessment tools, WHO regional offices and UNHCR have developed operational guidance to integration of NCD care in emergency response and preparedness (Slama et al., 2017; Integration of NCD, 2022; Bausch et al., 2021; WHO SEARO, 2018).

Despite some notable exceptions, participants’ experience has mainly been in delivering NCD care in stable, prolonged or protracted crises of displacement. The limited published literature on NCD models of care in humanitarian settings also reflects this reality (Jaung et al., 2021).
All of our participants advocated for focussing NCD care delivery at primary care level, in order to increase access and coverage and bring care closer to the patient. The existing models they described were mainly at primary level, developed in parallel or integrated with host country systems. While a few iNGO participants felt non-integrated approaches were necessary in some contexts (e.g. in some acute, emergency phases, when working within the public system was challenging or when refugee populations could not access public systems), they were not seen as desirable. The chronic nature of NCDs has pushed humanitarian actors to engage in health system assessment, planning and integration with host country health systems (Spiegel, 2017 Jun 7). In practice, this has often resulted in iNGOs supporting Ministries of Health to decentralise HTN/DAM care in countries where this has traditionally taken place at secondary or tertiary levels, and reorienting existing primary care to deliver longitudinal rather than the acute, episodic care typical of many LMIC health systems.

The lack of established primary level NCD services in most LMIC settings affected by humanitarian crises may explain participants’ focus on the basic building blocks of care, such as training the primary care workforce, and strengthening supply chains and information systems. The intermediate health system goals (responsiveness, quality and safety) and final goals, including improved health outcomes, featured much less in their accounts. Participants clearly aspired to providing patient-centred, holistic care, echoing both the evolution of chronic disease care and primary care in higher income settings and the increasing focus on quality of care in LMICs (Coleman et al., 2009; Kruk et al., 2018; Kruk et al., 2015). Some suggested using a primary care lens as well as level, advocating that care should be provided by generalists, taking a holistic, whole-person approach. This aligns with the well-established Chronic Care Model, person-centred model of care involving a proactive care team, combined with supported self-care and enhanced community resources, to improve quality of healthcare and health outcomes (Coleman et al., 2009; McNatt et al., 2019; Ansbro et al., 2021). In practice, however, few examples of patient-centred NCD care were described, patient-centredness is not currently measured, relevant indicators do not exist and patient experience has been explored in a very limited fashion (Ansbro et al., 2021).

Interviewees highlighted the lack of meaningful, shared NCD indicators and data collection tools, and gaps in humanitarian agency reporting systems for NCDs. These gaps were closely linked to the key themes of standardisation, coordination and integration that emerged from the interviews.

Several clinical and programmatic guidelines have been developed by individual humanitarian organisations, recently collated in a new online NCDs in Humanitarian Settings Knowledge Hub (Bausch et al., 2021; Martinez et al., 2015; Jobanputra, 2016; Mendis et al., 2020). WHO has recently taken on a greater leadership role in NCDs, such as designing the NCD inter-agency emergency kit in 2016, collaborating on the HEARTS technical package for cardiovascular care in 2016 and launching both a guideline on hypertension treatment and the Diabetes Global Compact in April 2021, an umbrella initiative to improve access to quality diabetes care, including to insulin and related products (Slaama et al., 2018;WHO, 2016, WHO, 2021; Hunt et al., 2021). However, participants almost universally called for NCD care delivery to be underpinned by standardised clinical, programmatic and monitoring guidance and tools, originating from WHO.

Greater coordination between agencies and better integration of NCD services, on multiple levels, were also called for. Humanitarian response often involves a multiplicity of actors working under the humanitarian cluster system, which was designed to foster greater coordination. Yet, to date, NCD responses have been fragmented, particularly in settings such as Lebanon (Blanchet et al., 2016; Akik et al., 2019). Study participants also emphasised that greater integration between the humanitarian health, nutrition and protection clusters was needed for people with NCDs (Jobanputra et al., 2016). Integration of NCD care with other humanitarian programming (delivered by single or multiple actors), e.g. primary health care, HIV/TB care, physical rehabilitation and MHPSS, was highlighted here and in previous studies (Ansbro et al., 2021). Similarly, the integration of displaced populations and, specifically, of NCD care programmes within existing national public health systems were also seen as key to sustainable, continuous chronic care for crisis-affected NCD patients.

Issues around medicines access and high costs for both patients and provider organisations also featured prominently. A regular supply of good quality medicines is an essential building block for chronic disease care but problems with supply, availability and cost in many LMIC settings has proven challenging, and these challenges are magnified in humanitarian crises (Hunt et al., 2021; Boule et al., 2019; Kehlenbrink et al., 2019; Devi, 2021). Participants’ call to learn from experience of delivering chronic HIV/TB care is also reflected in the NCD literature (Rabkin et al., 2018). Key lessons around anti-retroviral treatment and procurement simplification that could be applied to NCD treatment included the introduction of fixed dose combination drugs, simplification of treatment algorithms taking a public health approach, streamlining of procurement, including the introduction of WHO pre-qualification, and working with manufacturers to reduce costs (Caplan et al., 2018; UNAIDS and Médecins sans Frontières, 2015; Gilks et al., 2006). “Runaway packs” of medication and patient-held medical records have been introduced for patients living with HIV to mitigate service interruption in insecure settings, and have been recommended for NCD patients, but have yet to be implemented (Ansbro et al., 2019; Murphy et al., 2017).

The barriers to global insulin access have been well described. These include the global market dominance of the three major multinational insulin manufacturers, especially regarding the newer, more costly, analogue insulins (Boule et al., 2019; Beran et al., 2019; Beran et al., 2016). While manufacturers have facilitated access to low-cost human insulin for humanitarian actors and LMIC governments, participants reported that insulin was still one of the most costly elements of NCD care provision. There is a clear need for a cost-efficient insulin supply chain, potentially built around existing vaccination cold chains, and insulin delivery and glucose monitoring technology, adapted to the harsh physical conditions and potentially low literacy levels encountered in many humanitarian settings. The recently published study showing that insulin is heat stable when exposed to high storage temperatures may prove a game changer in contexts with limited or unreliable access to refrigeration (Kaufmann et al., 2021).

Important questions remain around the potential role of newer insulin-related tools, such as analogue insulins, pen devices and continuous glucose monitors to enable better glucose control and safety outcomes for people with diabetes, particularly in areas of food insecurity. Similarly, the role of fixed dose combination medications for hypertension was acknowledged in the WHO EML and 2021 hypertension guidance and in NGO guidelines but implementation experience in humanitarian settings is still limited (WHO, 2015).

WHO may consider working with stakeholders to produce a set of standardised operational guidelines on NCDs for member countries to prepare for, respond to, and recover from crises, possibly drawing on the existing South East Asia Regional Office guidance (WHO SEARO, 2018). A final set of shared indicators for good quality NCD care that have been piloted in humanitarian settings is highly desirable. A WHO pre-qualification mechanisms for insulin and glucometers would facilitate the entry of additional manufacturers to the market and aggregating demand of priority diabetes products with pooled procurement would facilitate cost savings and, thus, increase access. Supporting countries to strengthen primary level NCD care, through the lens of Universal Health Care, would mean that health systems are better equipped to deal with NCDs when affected by crisis. The informal Inter-agency Group on NCDs in Humanitarian Settings and key collaborators may use these findings to support their advocacy work around better tools, treatments and funding to support people living with NCDs in crises.
High quality research is needed to better define how to deliver effective and feasible integrated, patient-centred models of care for hypertension and diabetes in humanitarian settings. We need more evidence on patient and provider experiences and preferences; on peer support and patient empowerment approaches (including for nutrition and food aid), and on how best to adapt the HIV differentiated care model to cardiovascular disease and diabetes (Edwards et al., 2015; Some et al., 2016; Venables et al., 2016).

4.1. Strengths and limitations

This is the first paper to draw together the opinions and experiences of the key international stakeholders involved in NCDs in humanitarian settings. We interviewed participants from implementing, policy, advocacy and research organisations whose experiences spanned different continents, crises and responses over the past two decades. Our adapted conceptual framework highlighted the patient perspective and the importance of continuity, integration and sustainability in designing models of NCD care in crises. Limitations included the limited number of interviews, which were conducted in English by a single interviewer, although it was felt that theoretical saturation was reached. We purposefully selected respondents, which may have led to a reliance on those from our networks, most of whom were based in the global North, while the representation of local NGOs was more limited. Patient or provider perspectives were not included in this sample and, thus, their views on what should be included in a model of care and on prioritisation of interventions for NCDs in crisis response in humanitarian settings could not be included. We recommend that future research should include both patient and provider perspectives.

5. Conclusions

Models of care for hypertension and diabetes in humanitarian crises are diverse and highly context-dependent. The design of future models would be facilitated by more comprehensive clinical and operational guidance from WHO, which would foster standardisation, continuity, integration and, thus, better quality care. Future models should also take a health system strengthening approach, and use patient-centred design, ideally co-creating care models with patients and providers. Lessons may also be learned from the development of chronic care models in both high- and low-income settings.

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Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Supplementary materials

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