

# Patient experiences of diabetes and hypertension care during an evolving humanitarian crisis in Lebanon: a qualitative study

## WHAT IS THE ISSUE?

People living with non-communicable diseases (NCDs) are vulnerable in humanitarian settings where access to basic services is regularly interrupted. Monitoring and continuous treatment of NCDs are essential for preventing complications, preserving quality of life and saving lives. However, people with NCDs living in humanitarian settings face disrupted care pathways in the long-term management of their health conditions. Instead of investigating the patient's experience of the continuum of care for NCDs in humanitarian settings, literature has historically focused on service provision and access to care. As a result, research into patient and caregiver perspectives on obtaining care for chronic conditions in a fragmented or crisis-affected healthcare system is lacking.

## WHAT WE DID

We interviewed Syrian refugees and vulnerable Lebanese patients on their experiences receiving care for NCDs at health facilities supported by humanitarian organisations in Lebanon. We interviewed 18 patients living with diabetes, hypertension or with both conditions, and 10 caregivers. We systematically analysed interview data to examine the challenges for patients and caregivers.

## OVERALL FINDING

We found that people with NCDs and caregivers experienced disrupted, non-linear pathways in maintaining care for hypertension and diabetes. Family support networks were central to absorbing the treatment burden and sustaining long-term NCD management. We identified three typologies of patient experiences: (i) the patient is adequately managing their condition(s), (ii) the patient's management of their condition(s) is fragile, and (iii) the patient feels unable to manage their condition(s) adequately. Across the three typologies, the affordability and availability of medication and care, navigating the healthcare system, family support and mental health were identified as key factors in maintaining continuity of care.

## RECOMMENDATIONS FOR ACTION

Six recommendations were identified: 1) recognise and act to reduce the treatment burden for patients and caregivers, 2) determine and recognise the role of social support networks in assisting patients to maintain continuity of care, 3) consider where NCD prevention and early diagnosis can be incorporated into existing programmes, 4) integrate mental health support, 5) engage in efforts to develop and apply evidence-based clinical guidelines and 6) work with Ministries of Public Health to facilitate coordination and strengthen existing systems in the humanitarian sector.

## KEY MESSAGES

Although healthcare models for humanitarian settings are increasingly incorporating care for NCDs, more needs to be understood about patient and caregiver experiences of obtaining care for chronic conditions in humanitarian settings. We found that people with NCDs experience interrupted pathways to care, and family support networks are key to absorbing the treatment burden and sustaining long-term management of NCDs. More awareness of the role of social support networks in maintaining continuity of care is needed to reduce the burden on patients and caregivers required to sustain NCD management.



Scan the QR code or [click here](#) to access the full-text article.

## Authors

Ruth Willis<sup>\*</sup>, Chaza Akik<sup>~</sup>, Zeinab El-Dirani, Claudia Truppa, Carla Zmeter, Fabrizio Fleri, Sigiriya Aebischer Perone, Roberta Paci, Signe Frederiksen, Celine Abi Haidar, Randa S. Hamadeh, Fouad M. Fouad, Pablo Perel, Bayard Roberts, Éimhín Ansbro

<sup>~</sup>Joint first authors

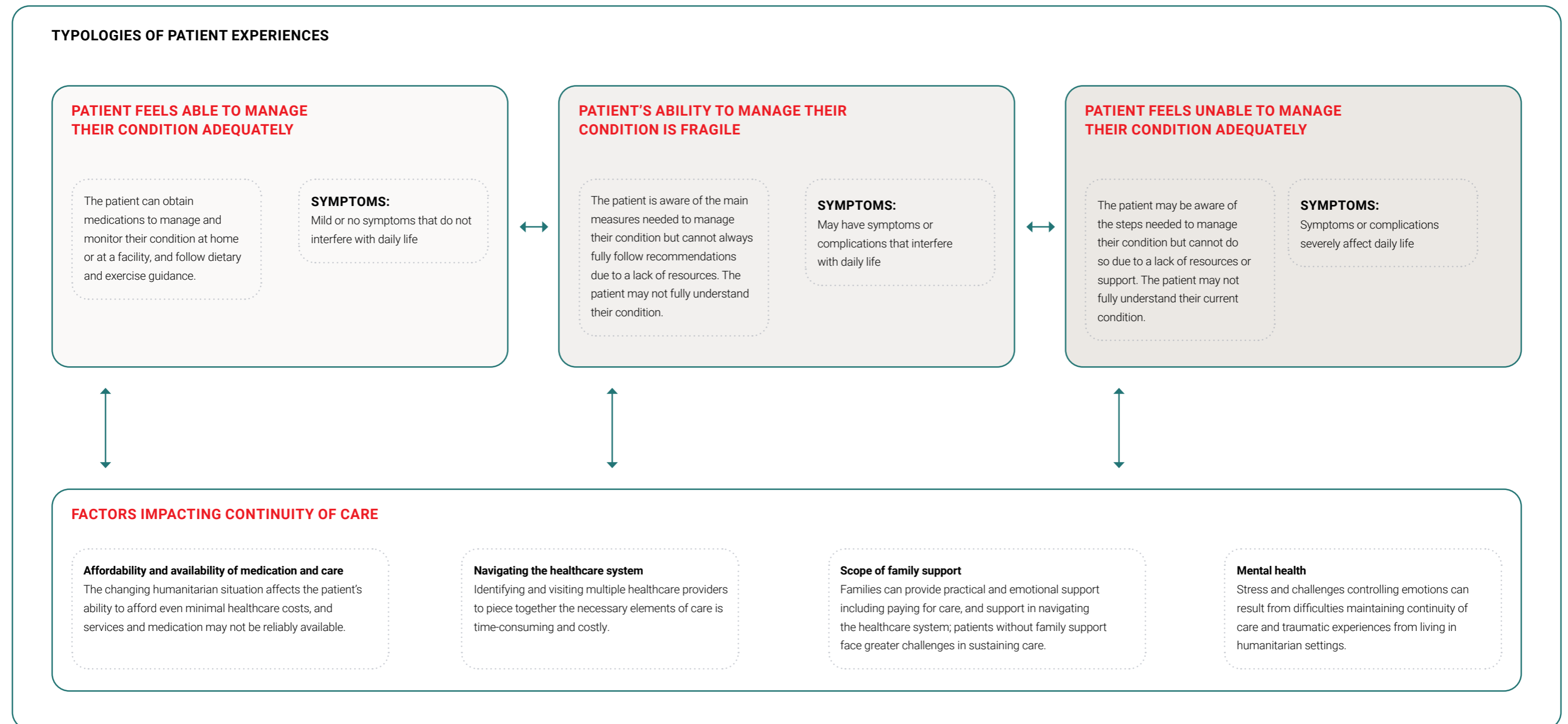
<sup>\*</sup>Corresponding author

Centre for Global Chronic Conditions, London School of Hygiene and Tropical Medicine, London, UK - [ruth.willis@lshtm.ac.uk](mailto:ruth.willis@lshtm.ac.uk)

# Framework for analysing patient experiences of NCD care in humanitarian settings

Patient experiences of living with an NCD in a humanitarian setting can be summarised across three key points in the healthcare pathway: at onset of symptoms and diagnosis, during daily management and during development and care of complications. Describing the patient experience as a care pathway suggests there is a defined route which the patient moves along over time, under the supervision of a consistent care provider. However, few patients described a continuous pattern of care with regular attendance at a single provider. Instead, most patients described seeking care from various sources, as related to the severity of symptoms, financial resources and competing priorities.

We suggest framing the patient experience managing NCD care in humanitarian settings through typologies highlighting how an individual's situation influences their capacity to engage with and navigate systems of care. Four key factors, present across all three typologies, impact the maintenance of continuous care.



# Non-communicable diseases in humanitarian crises

Worldwide, close to a billion people live in fragile and conflict-affected contexts, and this number is expected to grow.<sup>1</sup> Among those impacted globally, it is estimated that 274 million people need humanitarian assistance and protection.<sup>2</sup> Many of these individuals live with NCDs such as diabetes and hypertension.

## Partnering for Change

In 2018 the International Committee of the Red Cross, the Danish Red Cross and Novo Nordisk formed a partnership to tackle the growing issue of NCDs affecting millions of people in humanitarian crises worldwide. The collective vision of the partnership is that all people affected by humanitarian crises should have access to the NCD

care they need, no matter where they are. The research conducted by the partnership is supported by the London School of Hygiene & Tropical Medicine (LSHTM), the lead academic partner.

To realise the vision of the partnership, we conduct research and needs assessments, develop patient materials, and carry out field projects and joint advocacy initiatives. We are currently working in Lebanon and Iraq, implementing and adapting innovative models of care.

**For more information about Partnering for Change,** visit [www.humanitarianncdaction.org](http://www.humanitarianncdaction.org)

---

1. World Bank. Data: Population, total – Fragile and conflict affected situations. <https://data.worldbank.org> 2. UNOCHA. Global Humanitarian Overview 2022. UNOCHA. <https://gho.unocha.org>

## London School of Hygiene & Tropical Medicine (LSHTM)

The Centre for Global Chronic Conditions at the London School of Hygiene and Tropical Medicine (LSHTM) aims to improve the understanding of and responses to chronic conditions in order to improve the health and health equity of people worldwide. The Centre is made up of a group of researchers from multiple disciplines (including epidemiology, economics, social-political sciences and health systems). We work in low-, middle- and high-income country settings, including with vulnerable populations during humanitarian crises and with migrant populations. The Centre includes a **Special Interest Group on NCDs in Humanitarian Settings**, which hosts a knowledge hub on the topic.

More information about the hub can be found [here](#)

**This study was conducted through research collaboration between the London School of Hygiene and Tropical Medicine, American University of Beirut, Danish Red Cross, International Committee of the Red Cross, Lebanese Red Cross, and the Ministry of Public Health, Lebanon.**

## Authors

**Ruth Willis<sup>1,2,\*</sup>, Chaza Akik<sup>-3</sup>, Zeinab El-Dirani<sup>3</sup>, Claudia Truppa<sup>4,5</sup>, Carla Zmeter<sup>4</sup>, Fabrizio Fleri<sup>4</sup>, Sigiriya Aebischer Perone<sup>6,7</sup>, Roberta Paci<sup>8</sup>, Signe Frederiksen<sup>9</sup>, Celine Abi Haidar<sup>10</sup>, Randa S. Hamadeh<sup>11</sup>, Fouad M. Fouad<sup>12</sup>, Pablo Perel<sup>13,2</sup>, Bayard Roberts<sup>1,2</sup>, Éimhín Ansbro<sup>13,2</sup>**

~Joint first authors

\*Corresponding author

1. Department of Health Services Research and Policy, Faculty of Public Health and Policy, London School of Hygiene and Tropical Medicine, London, United Kingdom
2. Centre for Global Chronic Conditions, London School of Hygiene and Tropical Medicine, London, United Kingdom
3. Center for Research on Population and Health, Faculty of Health Sciences, American University of Beirut, Lebanon
4. International Committee of the Red Cross, Beirut, Lebanon
5. Current address: CRIMEDIM - Center for Research and Training in Disaster Medicine, Humanitarian Aid and Global Health, Novara, Italy
6. International Committee of the Red Cross, Geneva, Switzerland
7. Division of Tropical and Humanitarian Medicine, Hôpitaux Universitaires de Genève, Geneva, Switzerland
8. Danish Red Cross, Beirut, Lebanon
9. Danish Red Cross, Copenhagen, Denmark
10. Lebanese Red Cross, Beirut, Lebanon
11. Primary Healthcare and Social Health Department, Ministry of Public Health, Lebanon
12. Department of Epidemiology and Population Health, Faculty of Health Sciences, American University of Beirut, Lebanon
13. Department of Non-communicable Disease Epidemiology, Faculty of Epidemiology and Population Health, London School of Hygiene and Tropical Medicine, London, United Kingdom

PARTNERING FOR CHANGE PROGRAMME PARTNERS



ACADEMIC PARTNER

