An inter-humanitarian agency study of diabetes care and surveillance in humanitarian settings

Humanitarian crises and diabetes have been increasing at an unrelenting pace, especially in low-income and middle-income countries.[1] Over 80% of the global displaced population live in low-income and middle-income countries, which host 81% of the global diabetes population.[2] Furthermore, for 77% of refugees, the average duration of displacement is more than 20 years.[2]

Despite projections of further increases in the prevalence of diabetes and humanitarian crises, evidence on best practice interventions to guide feasibility and effectiveness of diabetes care delivery in humanitarian settings is lacking.[3–5] This was highlighted in the Boston Declaration, which outlined a priority agenda for addressing diabetes in humanitarian crises, including the need for improved data and surveillance.[3] Most data collected by humanitarian organisations, while providing humanitarian assistance, do not feature in academic literature. Diabetes prevalence, organisational practices, and barriers to care in these contexts are poorly understood.[4]

Therefore, as part of thee Humanitarian NCD Interagency Study in Emergencies and Disasters (UNITED), we convened a consortium of four humanitarian organisations (International Committee of the Red Cross, International Rescue Committee, Médecins Sans Frontières, and UN High Commissioner for Refugees) to assess current diabetes data collection practices, diabetes services, and key barriers to care in areas of humanitarian crisis. We surveyed 83 randomly selected sites across 27 countries in five global regions to assess diabetes care in humanitarian medical services provided in 2018 (appendix p 2).

Among the 83 sites, 65 (78%) collected diabetes care data and were included in the analysis; most of these sites were in the eastern Mediterranean (29 [45%] of 65) and Africa (23 [35%]; appendix p 5). Characteristics of the 18 sites that were not included in the analysis are in the appendix (pp 3, 12). Data from the Americas were limited to two sites in Mexico, despite Colombia hosting the highest number of internally displaced persons (IDPs) globally (appendix p 5).[2] Most sites were refugee camps (22 [34%] of 65) and rural non-camp sites (22 [34%]), with the remaining sites being urban non-camp sites (14 [22%]) and IDP camps (seven [11%]; appendix p 5). Populations were mostly a mix of refugees, IDPs, and the general population in protracted crises due to conflict. Diabetes data from during crises due to natural disasters, epidemics, and acute emergencies (crisis duration of <6 months) were lacking. This is an important data gap because natural disasters triggered three times more new internal displacements in 2020 than did conflict.[6]

Most sites (57 [88%] of 65) provided diabetes services (table; appendix p 6), including the clinical management of diabetes. 31 (48%) sites used Ministry of Health supported guidelines, while 16 (25%) used organisation-specific guidelines. Of 57 sites that offered diabetes services, patient diabetes education was available at 38 (67%) sites, mostly provided by health-care professionals. However, only 21 (37%) of these 57 sites provided diabetes training for health-care workers. Community outreach was not routinely available.

An absence of reliable access to diabetes medications was the most reported barrier to care (appendix p 11). 22 (34%) of 65 sites did not provide insulin (table). While most refugee camps provided insulin procured by the humanitarian organisation, only one (14%) of seven IDP camps provided insulin, which was obtained via patient out-of-pocket cost (appendix p 8). However, six (86%) IDP camps had referral programmes to diabetes specialists, who might have provided insulin (appendix p 6). Nonetheless, IDPs constitute most of the world's forcibly displaced populations and documenting and ensuring available insulin, provided by an humanitarian organisation, local providers, or national health programmes is critical.[2] Aspirin and Angiotensin-converting enzyme inhibitors were the most available cardioprotective medications at all sites; only 25 (38%) sites provided statins (table).

Diagnostic testing was the second most reported barrier to care (appendix p 11). Capillary glucose testing, the most basic diagnostic tool for diabetes management, was unavailable at 19 (29%) of sites. HbA_{1c} and home glucose monitoring were rarely available with only 12 sites (18%) having access to HbA_{1c} and 14 (22%) having access to home glucose monitoring (table). Without glucose monitoring, adequate diabetes management is practically impossible. Serum creatinine, potassium, and cholesterol measurements were uncommon, and dilated eye exams were only present at three (5%) of 65 sites. This paucity of available key diagnostic tests highlights the need for low-cost, field-adapted tools for diabetes management and monitoring. 29 (45%) sites screened for gestational diabetes (appendix p 6), although women constitute half the displaced population globally and 28% of maternal deaths are the due to non-obstetric causes, including diabetes.[7] However, some humanitarian programmes provide specialised perinatal care, which might not have been captured here. Only two (3%) sites provided a basic package of diabetes care that included diabetes management, medication provision, glucose testing, patient education, workforce training, and continuity of care (appendix p 3). High staff turnover, insufficient knowledge, and

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See Online for appendix

	All (n=65)	IDP camps (n=7)	Refugee camps (n=22)	Rural non-camps (n=22)	Urban non-camps (n=14)
Diabetes service provision	57 (88%)	7 (100%)	22 (100%)	17 (77%)	11 (79%)
Diabetes medication provision	47/57 (82%)	6/7 (86%)	21/22 (95%)	13/17 (76%)	7/11 (64%)
Clinical management of diabetes	46/57 (81%)	5/7 (71%)	21/22 (95%)	11/17 (65%)	9/11 (82%)
Diabetes patient education	38/57 (67%)	5/7 (71%)	20/22 (91%)	10/17 (59%)	3/11 (27%)
Referral to diabetes specialist	33/57 (58%)	6/7 (86%)	13/22 (59%)	8/17 (47%)	6/11 (55%)
Community outreach programmes	23/57 (40%)	6/7 (86%)	12/22 (55%)	2/17 (12%)	3/11 (27%)
Training of local staff in diabetes management	21/57 (37%)	2/7 (29%)	10/22 (45%)	5/17 (29%)	4/11 (36%)
Insulin provision	43 (66%)	1 (14%)	21 (95%)	12 (55%)	9 (64%)
Diagnostics availability					
Capillary glucose	46 (71%)	1 (14%)	18 (82%)	17 (77%)	10 (71%)
Urinary dipstick glucose	36 (55%)	2 (29%)	17 (77%)	11 (50%)	6 (43%)
Urinary microalbumin	26 (40%)	1 (14%)	18 (82%)	5 (23%)	2 (14%)
Serum creatinine	19 (29%)	0	10 (45%)	2 (9%)	7 (50%)
Serum glucose	18 (28%)	1 (14%)	5 (23%)	5 (23%)	7 (50%)
Home glucose monitoring	14 (22%)	1 (14%)	4 (18%)	3 (14%)	6 (43%)
HbA_{1c}	12 (18%)	0	4 (18%)	3 (14%)	5 (36%)
Lipid panel	11 (17%)	0	5 (23%)	2 (9%)	4 (29%)
Serum potassium	10 (15%)	0	5 (23%)	1 (5%)	4 (29%)
Dilated eye exams	3 (5%)	0	1 (5%)	0	2 (14%)
Cardiovascular medication availability					
Aspirin	59 (91%)	7 (100%)	22 (100%)	18 (82%)	12 (86%)
Angiotensin-converting enzyme inhibitors	50 (77%)	4 (57%)	22 (100%)	17 (77%)	7 (50%)
Statins	25 (38%)	3 (43%)	11 (50%)	8 (36%)	3 (21%)
Angiotensin-receptor blockers	17 (26%)	0	9 (41%)	4 (18%)	4 (29%)
Data collected					
Total number of diabetes consultations	51 (78%)	6 (86%)	19 (86%)	16 (73%)	10 (71%)
Number of follow-up diabetes visits	33 (51%)	4 (57%)	19 (86%)	5 (23%)	5 (36%)
Type 1 and type 2 diabetes as separate phenotypes	31 (48%)	2 (29%)	17 (77%)	5 (23%)	7 (50%)
Patients on diabetes medications*	38 (58%)	6 (86%)	17 (77%)	7 (32%)	8 (57%)
Patients on insulin	30 (46%)	1 (14%)	15 (68%)	7 (32%)	7 (50%)
Admissions for hyperglycaemic crises†	22 (34%)	2 (29%)	10 (45%)	6 (27%)	4 (29%)
Diabetic foot	15 (23%)	1 (14%)	4 (18%)	6 (27%)	4 (29%)
Diabetic retinopathy	8 (12%)	1 (14%)	4 (18%)	2 (9%)	1 (7%)
Diabetic nephropathy	9 (14%)	1 (14%)	4 (18%)	2 (9%)	2 (14%)
Diabetic neuropathy	11 (17%)	1 (14%)	3 (14%)	4 (18%)	3 (21%)
Diabetes and hypertension	21 (32%)	1 (14%)	10 (45%)	4 (18%)	6 (43%)
Diabetes and cardiovascular disease	14 (22%)	1 (14%)	6 (27%)	3 (14%)	4 (29%)

Data are n (%) or n/N (%), where n is number of sites. *Includes oral diabetes medications or insulin, or both. †Included diabetic ketoacidosis or hyperglycaemic hyperosmolar syndrome.

Table: **Humanitarian sites that reported routine diabetes data collection**

absence of standardised guidelines adapted to humanitarian contexts restrict the capacity of health-care workers to provide care.

Although most sites collected diabetes data, there was no standardised data collection system across or within organisations (appendix p 10). Most sites used organisation-specific data collection systems, although the type of data collected and method of collection was often inconsistent across sites within an organisation, and 12 (18%) of 65 sites used systems supported by the local Ministries of Health. Most sites collected aggregate data recording the total number of diabetes consultations (new and return visits), making it difficult to assess prevalence, and only 31 (48%) sites distinguished between type 1 and type 2 diabetes (appendix p 10). The number of patients on diabetes medications and with microvascular and microvascular complications and concomitant hypertension were not routinely reported, with 38 (59%) centres reporting numbers of patients on diabetes medication, and 18 (28%) sites reporting microvascular and microvascular complications (appendix p 10). Given that 43% of patients among sites that reported demographics (42 of 65 sites) were minors (ie, younger than 18 years; appendix p 3) and type 1 diabetes is immediately life-threatening without access to insulin and continuity of care, the paucity of data on type 1 diabetes is particularly concerning. Thus, standardised epidemiological tools and methods aligned with larger global efforts are needed to capture the burden of diabetes and its complications for decision-making, pharmaceutical forecasting, and programme evaluation.[8]

Representative quotes from the qualitative data were illustrative. When asked what three main barriers to diabetes care were, a site in Yemen answered: "1. Poor medical supplies and equipment alongside the weak infrastructure have made our practice very limited (no insulin was available at the site, so patients who needed it were left out), 2. Lack of financial resources have led to limited human resources available to provide medical care, 3. Lack of a systematic approach, like having a health information system, prevented us from providing [non-communicable disease] care as we don't have data collection processes [to] secure continuity

of care." One site in Bangladesh responded: "1. Continuation/timely insulin shot at the household level by the patient, 2. Storage of insulin at household by the patients considering hot and humid temperature, 3. Laboratory investigation at the clinic for monitoring the status of different biochemical markers."

Our study shows insufficient diabetes care delivery in a sample of humanitarian sites. These results likely underestimate how inadequate diabetes care is within these settings, given the over-representation of refugee camps in our sample; in our experience, refugee camps have more comprehensive health care than sites serving IDPs or the general community. Essential diabetes medicines, diagnostics, and trained health-care providers must be standard in any humanitarian response and integrated into routine care. Given the protracted nature of most crises, these data highlight the importance of expanding universal health coverage to populations affected by crises and strengthening the humanitarian-development nexus to support the most vulnerable populations and the health-care systems they rely on.

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