# CARE UTILIZATION AND ADHERENCE TO MEDICATION FOR HYPERTENSION AND DIABETES AMONG SYRIAN REFUGEES AND HOST COMMUNITIES IN LEBANON

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#### Abstract

The influx of over one million Syrian refugees to Lebanon brought enormous demands on the country's health system. Despite some success in facilitating access to care for highly prevalent non-communicable diseases (NCDs), evidence is needed to tailor interventions to meet chronic health needs of Syrian refugees and host communities in Lebanon. To this end, this dissertation assesses healthcare utilization and medication adherence for hypertension and diabetes among Syrian refugees and host communities in Lebanon.

Paper 1 assesses care-seeking, spending, and medication adherence using data from a 2015 household survey of Syrian refugees and Lebanese host communities. Papers 2 and 3 explore care visit frequency and medication adherence, respectively, in greater depth using baseline data from a longitudinal cohort study of care-seekers at primary health facilities in Lebanon.

Descriptive analyses reveal material gaps between refugees and host communities in care utilization, out-of-pocket costs, and medication interruption. At the population level, care-seeking and uninterrupted medication adherence for hypertension and diabetes are high. Qualitative findings reveal potentially insufficient GP training and uncertainty about the NCD care quality at primary health facilities. Despite low rates of medication interruption for two weeks or longer in quantitative findings, non-adherence was widely reported during focus group discussions for shorter durations than captured quantitatively and suggest refinements to improve the quantitative measure's reliability in this context.

Few refugee household characteristics were associated with individuals' care-seeking and medication adherence. Individual level analyses among refugees indicate that for diabetes, older age and housing stability are associated with higher care-seeking and lower odds of medication interruption. For hypertension, housing stability was also associated with higher care-seeking rates and reduced odds of medication interruption.

Although care-seeking is high, there are opportunities to improve service utilization and medication adherence by these populations. Current programs may sustain high care-seeking rates; however, continued efforts are needed to inform refugees of available services. Expansion of alternative payment arrangements, increased use of community health workers and refugee outreach volunteers, and quality improvement via large-scale health provider training and collaborative care models could strengthen current initiatives to improve NCD management in Lebanon.

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# List of Terms and Abbreviations

ACC	American College of Cardiology
ACEi	angiotensin-converting-enzyme inhibitor
AHA	American Heart Association
AIC	Akaike Information Criterion
ARB	angiotensin II receptor blocker
ARMS	Adherence to Refills and Medications scale
BARS	Brief Adherence Rating Scale
BIC	Bayesian Information Criterion
BMI	body mass index
BMQ	Brief Medication Questionnaire
CCB	calcium channel blocker
CHW	community health worker
CI	95% confidence interval
DAI	Drug Attitudes Inventory
DALYs	Disability-Adjusted Life Years
DM	diabetes mellitus
ECHO	European Civil Protection and Humanitarian Aid Operations
EKG	electrocardiogram
EPHRP	Emergency Primary Healthcare Restoration Project
FGD	focus group discussion
GBD	Global Burden of Disease
GP	general practitioner
HAUS	Health Access and Utilization Survey
HB-HBP	Hill-Bone Compliance to High Blood Pressure Therapy Scale
HB-MAS	Hill-Bone Medication Adherence Scale
HbA1C	Glycated hemoglobin
HH	household
HT	hypertension
IMC	International Medical Corps
INGO	international non-governmental organization
IOM	International Organization for Migration
IRR	incidence rate ratio
JHSPH	Johns Hopkins Bloomberg School of Public Health
KII	key informant interview
LBP	Lebanese Pounds
LCRP	Lebanon Crisis Response Plan

MARS	Medication Adherence Rating Scale
MdM	Médecins du Monde
MMAS	Morisky Medication Adherence Scale
MMU	Mobile medical unit
MoPH	Ministry of Public Health
MoSA	Ministry of Social Affairs
MPR	Medication Possession Ratio
MSF	Médecins Sans Frontières
NB	negative binomial regression model
NBH	negative binomial hurdle regression
NCD	non-communicable disease
NCDP	Non-Communicable Disease Program
NGO	non-governmental organization
NSSF	National Social Security Fund
OR	odds ratio
PCHR	patient-controlled health record
PH	Poisson hurdle model
PHCC	primary healthcare center
PPS	probability proportional to size
REBAHS	Reducing Economic Barriers to Accessing Health Services project
ROV	refugee outreach volunteer
SD	Standard deviation
STEPS	World Health Organization STEPwise approach to surveillance
UNFPA	United Nations Population Fund
UNHCR	United Nations High Commissioner for Refugees
UNRWA	United Nations Relief and Works Agency for Palestine Refugees in the Near East
US\$	U.S. Dollars
VAS	visual analog scale
VASyR	Vulnerability Assessment of Syrian Refugees in Lebanon
VIF	variance inflation factor
WHO	World Health Organization
WHO PEN	WHO Package of Essential Noncommunicable Disease Interventions
YLDs	Years Lived with Disability
YLLs	Years of Life Lost
YMCA	Young Men's Christian Association
ZINB	zero-inflated negative binomial model
ZIP	zero-inflated Poisson model
ZTNB	zero-truncated negative binomial regression

# **Chapter 1. Introduction**

Since its start in March 2011, the Syrian conflict has generated widespread displacement. More than half of Syria's pre-conflict population has been displaced. By mid-2018, an estimated 6.2 million individuals were displaced within Syria and an additional 6.5 million refugees fled to other countries, accounting for one-third of the global refugee population.<sup>1</sup> The majority of these refugees are hosted in neighboring countries throughout the region. As of late 2018, an estimated 1.5 million Syrians were hosted in Lebanon, 950,000 of whom were registered with the United Nations High Commissioner for Refugees (UNHCR), making it host to the largest number of refugees per capita globally.<sup>2,3</sup> Given the substantial burden of non-communicable diseases among both Syrian refugees and the host communities within which they are settled, humanitarian actors and the Government of Lebanon face immense challenges in addressing health needs for chronic conditions, which are often difficult and expensive to manage and require continued monitoring and adherence to prescribed treatment over time to mitigate longterm complications.<sup>4-6</sup>

#### 1.1. Research Aims and Objectives

The objectives of this dissertation are to assess healthcare utilization and medication adherence for hypertension and type 2 diabetes among Syrian refugees and host communities in Lebanon, and to identify factors associated with care-seeking behaviors and medication adherence for these conditions among refugees. The specific research objectives are:

1. To compare health service utilization, out-of-pocket spending, and interrupted medication adherence between Syrian refugees and host communities at the

population level and assess whether refugee household characteristics are associated with care-seeking and interrupted medication adherence.

- 2. To characterize health service utilization patterns for hypertension and type 2 diabetes among Syrian refugees and host community patients receiving care at select primary health facilities in Lebanon, and to identify factors associated with refugees' utilization of general and specialist physician care.
- To compare the prevalence of interrupted medication adherence among Syrian refugees and host community patients receiving care at select primary health facilities in Lebanon, and to characterize determinants of interrupted adherence among Syrian refugees.

# **1.2. Organization of the Dissertation**

This dissertation is presented in eight chapters, organized as follows:

- Chapter 2 provides a background overview of the Syrian crisis, affected populations in Lebanon, and the organization of the Lebanese health system and provision of health services to Syrian refugees in Lebanon.
- Chapter 3 is a literature review of hypertension and type 2 diabetes treatment, care utilization, and the measurement, role, prevalence, and determinants of medication adherence.
- Chapter 4 details the conceptual framework, study design, and analytical methods utilized.
- Chapter 5 examines care-seeking, utilization of health services, out-of-pocket spending, and adherence to medication for hypertension and diabetes among Syrian refugees and

host communities in Lebanon at the population level, including analyses of household level determinants of care-seeking and medication adherence for Syrian refugees (Paper 1).

- Chapter 6 characterizes care utilization for hypertension and type 2 diabetes among Syrian refugees and Lebanese patients receiving care at select primary health facilities in Lebanon and explores clinical and demographic factors associated with utilization of health care provided by general practitioners and/or specialist physicians (Paper 2).
- Chapter 7 focuses on medication prescription and adherence for hypertension and type 2 diabetes among Syrian refugee and Lebanese primary care patients and examines individual and household level determinants of interrupted medication use by Syrian refugees (Paper 3).
- Chapter 8 summarizes key findings from chapters five through seven, outlines areas for further research, and provides recommendations for ongoing and future programming.

Additional information about parent study methods is provided in Appendices A and B. Supplemental analysis methods and results are included in Appendices C, D, E, F, and G.

# **Chapter 2. Background and Study Context**

#### 2.1. Syrian Crisis

The conflict in Syria, which began in March 2011, has produced widespread displacement with more than 6.5 million Syrians internally displaced and an exodus of refugees to countries throughout the region. In July 2015, over four million Syrian refugees were registered or awaiting registration with UNHCR, a figure that has grown to reach more than 5.5 million in July 2019, in addition to an unregistered population unknown in size.<sup>7,8</sup> The largest Syrian refugee populations are in Turkey, Lebanon, Jordan, and, to a lesser extent, Iraq and Egypt.

As of mid-2015 when data for this study were collected, there were over 1.17 million Syrian refugees registered with UNHCR in Lebanon. Though there is no reliable data on the number of unregistered refugees in Lebanon, 2014 estimates placed this figure between 2,000 and 4,000 individuals.<sup>9</sup> Lebanon kept its border open to Syrians fleeing the unrest through 2014; however, restrictions on the entry of Syrian refugees were tightened in early 2015. There are no formal Syrian refugee camps in Lebanon; rather, refugees reside in a variety of settings ranging from rented accommodations to informal settlements, other transitional housing, or staying with host families. As the Syrian refugee population has grown, Lebanon's absorption capacity has become increasingly strained. The impact of the refugee influx on Lebanon's economy, demographics, political stability, and security is pervasive since, with an estimated 183 refugees per 1,000 inhabitants at the end of 2015, the country is host to the largest number of refugees in relation to its host population worldwide.<sup>10</sup>

With direct and indirect effects of the Syria conflict on Lebanon's economy estimated at US\$7.5 billion at the end of 2014, the stability of Lebanon's economy and institutions continue to

face severe threats.<sup>11</sup> In addition to the Syrian refugee crisis unfolding, a second crisis has emerged with the tremendous effect on Lebanese host communities. An overwhelming 86% of Syrian refugees in Lebanon reside in communities already hosting 66% of the most vulnerable Lebanese populations.<sup>12</sup> In response, the 2015-16 Lebanon Crisis Response Plan (LCRP), an integrated humanitarian and stabilization guide to responding to the Syrian refugee crisis developed jointly by the humanitarian community and the Government of Lebanon, focuses on national and local capacities with two of its three objectives seeking to (i) "strengthen the capacity of national and local delivery systems to expand access to and quality of basic public services" and (ii) "reinforce Lebanon's economic, social, environmental, and institutional stability."<sup>13</sup> The US\$77.9 million applied to "support service delivery, institutional capacity building, and enhance societal resilience and stability" in public institutions through the LRCP in 2014 more than doubled to over US\$170 million in 2015.<sup>14</sup>

Despite priority setting and investment in local and national stability, numerous studies have noted a continued sense of dissatisfaction within Lebanese host communities.<sup>15,16</sup> This discontentment is driven by resource scarcity, perceived deterioration of living conditions, economic competition, and historical tensions between Syrians and Lebanese, among many other factors.<sup>15,16</sup> Perceptions of inequitable distribution of aid and access to basic services in favor of refugees only further these tensions, contributing to community instability and challenges to international assistance actors and the Lebanese government alike.

## 2.2. Population Overview

#### **Lebanese Population**

Due to the longstanding power struggle between Lebanon's 18 recognized religious sects and a multitude of other political reasons, most Lebanese demographic data is either outdated, extrapolated, or extensively modeled from outdated sources, rendering most figures unreliable.<sup>17</sup> The last official census conducted in Lebanon was in 1932; however, more recent estimates place the Lebanese population around or just above four million, exclusive of more than one million Syrian refugees, 450,000 Palestinian refugees, 7,000 Iraqi refugees, and an estimated, though not precisely known, foreign worker population between 300,000 and 400,000 also residing in Lebanon.<sup>18-22</sup> It should be noted that a sizeable population of Syrian migrant workers (estimated between 300,000 and 500,000 before the start of the crisis) have had a consistent seasonal presence in Lebanon for decades, just one example of the complex historical relationship between the two countries' populations.<sup>23,24</sup>

Among the most densely populated countries in the world, Lebanon has an average of 400 people per square kilometer.<sup>25</sup> Approximately 88% of Lebanon's population resides in urban areas, largely in the capital of Beirut, a figure not likely to decline in the near future given Lebanon's 3.2% annual increase in urbanization.<sup>26</sup> A middle-income country, Lebanon's economic growth has been inconsistent and unequal, and disparities in socioeconomics and access to social services throughout the country are great.<sup>27</sup> Despite these disparities, Lebanon ranked 67<sup>th</sup> out of 188 countries in the Human Development Index in 2014, placing it in the "high human development" category.<sup>28</sup>

Lebanon's population is representative of a mid-demographic transition, with sizeable young and aging populations (Figure 2-1). With a median age of 29.9 years and average life expectancy at birth of 77.6 years (76.3 years for males and 78.9 years for females), Lebanon's population growth rate is 0.85%, ranking 129<sup>th</sup> out of 235 countries on which data is reported in the U.S. Central Intelligence Agency's World Factbook.<sup>26</sup> Lebanon ranks similarly with regard to birth rate (14.4 births per 1,000 population/ranked 134<sup>th</sup>) and total fertility rate (1.73 children born per woman if she was to pass through child-bearing age/ranked 169<sup>th</sup>), though higher with

regard to death rate (4.90 deaths per 1,000 population per year/ranked 193<sup>rd</sup>).<sup>26</sup> The elderly (65 years and older) represent 6.6% of the Lebanese population and Lebanon's elderly dependency support ratio, a measure of individuals 65 years and older as a share of the working-age population (15 to 64 years), is estimated at 12%.<sup>26</sup>

#### **Syrian Population**

The most recent official estimates published prior to the start of the crisis in 2011 based on civil registration records estimated the Syrian population to be 24.5 million, approximately 21 million of whom were estimated to live in the country at the end of 2011.<sup>29,30</sup> Due to complex political motivations and access challenges, demographic data since 2011 varies widely and most figures reflect source biases and/or the inaccessibility of much of the country for proper data collection. July 2016 Syrian population figures estimated a decrease of 7.5 million people to just over 17 million, after accounting for deaths and the vast number of Syrians refugees that fled the country as a result of the conflict.<sup>31</sup> Substantially geographically larger than Lebanon, Syria's 2016 population density was 101.1 people per square kilometer.<sup>31</sup> More than half (57.7%) of Syria's population lives in urban areas, and the urban population reportedly grew by an average of 1.4% annually from 2010-2015. Catastrophic drought beginning in late 2006/early 2007 prompted urban migration of as many as 1.5 million people from herding and agriculturallydependent families from rural areas.<sup>31,32</sup>

Syria has an overall younger population than Lebanon, with a median age of 24.1 years, and is suggested to be in early mid-demographic transition owing to its growing aging population (Figure 2-2).<sup>31</sup> Both the total fertility rate (3.0 live births per woman) and birth rate (21.7 births per 1,000 population) are higher than in the Lebanese population and research among Syrian refugee populations in neighboring countries has shown that the conflict and challenges

associated with displacement are not leading to a decreased desire for more children. A 2015 report by the United Nations Population Fund (UNFPA) found that family planning is not a priority for Syrian refugee youth in Lebanon, rather, child-bearing is a "valued and necessary achievement" and 46% of married refugee couples reported intending to have children.<sup>33</sup> Rather than deterring families from having more children, the conflict is leading many to marry off young girls to reduce economic hardship or to protect girls from growing threats of sexual assault.<sup>34</sup> Moreover, half of the youths interviewed by UNFPA agreed with the statement, "it is important to have children under these circumstances since we are losing many people in wars."<sup>33</sup> Of the 13.5 million people in Syria estimated to be affected by the crisis, 4.1 million are women and girls of reproductive age, 360,000 (or eight percent) of whom are estimated to be pregnant, indicating a likelihood for the continued growth of the young Syrian population.<sup>33</sup> Among the more than one million Syrian refugees in Lebanon, 265,272 are women and girls of reproductive age, 7.2% of whom are estimated to be pregnant.<sup>33,35</sup> The elderly (65 years and older) represented an estimated 4.1% of the population in Syria in 2016 for an elderly dependence ratio (6.9%), almost half that of the Lebanese population.<sup>31</sup> Life expectancy at birth in Syria in 2016 was 74.9 years (77.4 for females and 72.5 for males), and the death rate was four deaths per 1,000 population per year; little evidence has been published on changes to this since the start of the current conflict.<sup>31</sup> While concrete evidence is lacking, many posit that death rates among Syrian refugees are higher than among local populations due to poor living conditions and access to health services.<sup>36</sup>

Trends from the period of 1950-1955 through 2005-2010 indicated that Syria was progressing through mid-demographic transition. In this period, Syria's total fertility rates fell from 7.2 to 3.2 children per woman and the crude birth rate declined substantially from 50.8 births per 1,000 population to 26.3.<sup>37</sup> Accompanying a decreased crude death rate from 19.2 to

3.5 deaths per 1,000 population, Syria's life expectancy at birth rose from 70.8 to 74.4.<sup>37</sup> Despite clear evidence of Syria's demographic transition pre-crisis, demographic changes since 2011 likely serve to offset the population's movement through the full transition model, though there is little recent evidence of such trends in either direction.

#### 2.3. Non-Communicable Diseases Among Syrian Refugees and Host Lebanese

With increased urbanization, population growth, aging populations, and rises in behavioral risk factors, hypertension and diabetes have grown as worldwide public health crises in recent decades. Global prevalence of hypertension rose from 600 million (13.5% of the global population) in 1980 to 1 billion (14.9% of the global population) in 2008.<sup>38,39</sup> Over 17 million deaths each year are attributable to cardiovascular disease and over 9 million of these deaths are the result of complications of hypertension.<sup>40</sup> Not only is hypertension prevalence higher in lowand middle-income countries, but it goes undiagnosed or untreated more often in these countries than in high-income nations.<sup>41</sup>

Diabetes prevalence has also risen in recent decades from 108 million (2.4% of the global population) in 1980 to over 400 million adults (5.6% of the global population) in 2014.<sup>39,42</sup> In 2012, 1.5 million deaths were attributed to diabetes and an additional 2.2 million deaths were attributed to cardiovascular diseases, chronic kidney disease, and tuberculosis related to higher-than-optimal blood glucose.<sup>42</sup> Diabetes is a notable cause of many long-term health complications, including kidney failure, lower limb amputation, and blindness, among others.<sup>42</sup> From 2005 to 2015, diabetes rose from the eighth leading cause of years lived with disability (YLD) to the sixth. Similarly, diabetes climbed from the 24<sup>th</sup> leading cause of disability-adjusted life years (DALY) worldwide in 1990 to the 11<sup>th</sup> in 2015. In many countries, the number of observed DALYs caused by diabetes in 2015 exceeded the expected number based on the Global

Burden of Disease Study's (GBD) Socio-demographic Index, a composite indicator based on countries' income per capita, average years of schooling, and total fertility rate.<sup>43</sup>

Like many countries in the region, Lebanese and Syrian populations are in the mid to late stages of the epidemiologic transition from communicable, maternal, neonatal, and nutritional conditions to non-communicable diseases (NCDs).44-48 Diabetes prevalence has been estimated at 7.4% in Syria and 14.4% in Lebanon; in other studies of the Lebanese population, it ranges from 7% to 15.8%, and according to World Health Organization (WHO) 2018 NCD country profiles, it was 13% in both countries in 2014.<sup>40,49-56</sup> Data from the WHO STEPwise approach to Surveillance (STEPS) survey conducted in Lebanon in 2009 showed raised blood glucose (defined as either plasma venous value:  $\geq 7.0 \text{ mmol/L}$  or capillary whole blood value  $\geq 6.1$ mmol/L) in 11.2% of adults age 25-64, an overall average fasting blood glucose result of 104.0 mg/dl, and 5.9% of adults reporting known diabetes diagnoses.<sup>57</sup> Neither plasma venous nor capillary whole blood values were reported in an earlier (2003) STEPS survey in Syria, but blood sugar measures of 110 or higher were reported for 19.8% of the population with an overall average fasting blood glucose result of 98.2 mg/dl and 4.8% of adults reporting known diabetes diagnoses.<sup>58</sup> In the 2016-2017 Lebanon STEPS survey, a smaller proportion (10.5%) of Lebanese respondents had raised fasting blood glucose or were currently on medication for raised blood glucose as compared to the 2009 survey, with an average fasting blood glucose of 99.7 mg/dl, and 6.3% reporting known diabetes diagnoses in 2016-2017.59

Variations in prevalence reporting are likely a result of different methodologies and demographic characteristics of study samples, but the overwhelming majority of published estimates remain higher than the 2013 estimated global prevalence of diabetes (8.3%).<sup>60</sup> From 1990 to 2010, the number of DALYs caused by diabetes more than doubled based on the GBD estimates.<sup>61</sup> According to the 2015 GBD, diabetes was the third leading cause of DALYs and

YLDs, and the fifth leading cause of Years of Life Lost (YLL) in Lebanon.<sup>43,62,63</sup> The number of DALYs caused by diabetes similarly increased in Syria from 1990 to 2010 and though it was not among Syria's leading ten causes of DALYs or YLLs during the same year, diabetes was the eighth leading cause of YLD in 2015.<sup>61,62</sup>

Though evidence of the burden of hypertension in Syria and Lebanon is not as widely available as diabetes estimates, previous literature has estimated regional prevalence of hypertension at 29.5%, prevalence in Syria at 24.9%, and 28.8% in Lebanon.<sup>64-67</sup> The prevalence of raised blood pressure in adults 18 years and older reported in the WHO's 2018 NCD country profiles were 20% in Lebanon and 19% in Syria.<sup>55,56</sup> High blood pressure was reported in 12.7% of adults in the 2008 STEPS survey in Lebanon and 28.8% in Syria in 2003; mean systolic and diastolic blood pressure, respectively, were 124.3 mmHg and 77.3 mmHg in Lebanon and 126.0 mmHg and 77.1 mmHg in Syria.<sup>57,58</sup> Among STEPS respondents in Lebanon, 13.8% reported a known high blood pressure or hypertension diagnosis; comparable figures were not provided in 2003 Syria STEPS results.<sup>57,58</sup> According to the 2016-2017 STEPS survey in Lebanon, 35.3% of Lebanese respondents had high blood pressure (systolic blood pressure ≥140 and/or diastolic blood pressure ≥90 mmHg).<sup>59</sup> Mean systolic and diastolic blood pressure, respectively, were 127.1 mmHg and 76.1 mmHg among Lebanese respondents, of whom 17.1% reported a previous high blood pressure or hypertension diagnosis.<sup>59</sup>

In 2001, an estimated 115 deaths and 1,389 DALYs per 100,000 population per year were attributable to hypertensive disease in the Middle East and North Africa.<sup>68</sup> In Lebanon specifically, the GBD estimated number of DALYs caused by hypertensive heart disease increased by 24% from 1990 to 2010 and just under 11% of the country's 2010 estimated DALYs were attributable to high blood pressure, making it the fourth leading disease burden risk factor.<sup>69</sup> Hypertensive heart disease also accounted for 28% more YLL in Lebanon in 2010 as compared to

1990, rising from the country's 16<sup>th</sup> leading cause of YLL in 1990 to the 14<sup>th</sup> in 2010.<sup>69</sup> In Syria, the proportion of all YLL due to hypertensive heart disease rose 41% between 1990 and 2010 from the 22<sup>nd</sup> to the 12<sup>th</sup> leading cause of YLLs; high blood pressure was the country's second highest disease burden risk factor in 2010, attributed with 11% of the country's estimated DALYs, largely for cardiovascular and circulatory diseases.<sup>70</sup>

Syrian refugees are no exception to the Middle East's high NCD burden. UNHCR estimates that 14.6% of adult Syrian refugees in Lebanon have a chronic disease and two similar surveys found that 39.8% and 43.4% of Syrian refugee households in Jordan had at least one household member with a chronic health condition (including hypertension, cardiovascular disease, diabetes, chronic respiratory disease, and arthritis).<sup>67,71,72</sup> While estimates of chronic disease prevalence specifically among Syrian refugees in the region are sparse, the most recently published rates among adult Syrian refugees in Jordan (2015) estimated 9.7% prevalence for hypertension and 5.3% for diabetes. Comparable figures for Lebanon (published in 2016) are similar at 7.4% for hypertension and 3.3% for diabetes.<sup>67,73</sup>

The STEPS survey conducted in 2016-2017 in Lebanon included Syrian refugees (both registered and non-registered), of whom 9.4% had raised fasting blood glucose or were currently on medication for raised blood glucose.<sup>59</sup> The average fasting blood glucose among Syrian refugees was 97.5 mg/dl, and 4.8% reported diabetes diagnoses.<sup>59</sup> High blood pressure prevalence reported among Syrian refugees in the 2016-2017 STEPS survey was 32.8%; mean systolic and diastolic blood pressure, respectively, were 127.4 mmHg and 76.8 mmHg, and 10.9% of refugees reported high blood pressure or hypertension diagnoses.<sup>59</sup>

The demographic transition, longer life expectancies, and changes in lifestyle patterns portend an increasing burden of NCDs in the Middle East consistent with pre-crisis patterns.<sup>67,74</sup>

Previous studies in Syria found cigarette smoking was common across all age groups, and in particular among men age 18 – 35 years.<sup>75</sup> Low levels of physical activity were common in urban populations, particularly in women, and body mass index (BMI) was shown to increase with age.<sup>76</sup> Dietary risks ranked highest in the 2010 GBD ranking of DALYs attributable to primary risk factors in Lebanon, followed by high BMI, high blood pressure, smoking, high fasting plasma glucose, and physical inactivity, all of which are central risk factors for hypertension and diabetes.<sup>61</sup> DALYs attributable to leading risk factors in Syria were similar as follows: dietary risks, high blood pressure, high BMI, smoking, high fasting plasma glucose, and physical inactivity. all of which are central risk factors for hypertension and diabetes.<sup>61</sup> Consequently, both host and refugee populations in Lebanon suffer from a large burden of NCDs that are often difficult and expensive to manage and require continuous care and monitoring to mitigate long-term complications.<sup>4-6</sup> The international community, as well as national actors, face immense challenges addressing the needs of affected populations in both refugee and host communities due to the high NCD burden, the complexity of managing these conditions, limited resources available for health care, and concerns about crowding Lebanese out of public services.<sup>6,44,77.79</sup>

#### 2.4. The Lebanese Health System

The Lebanese health system, often described as "fragmented and pluralistic," is marked by strong involvement of the private sector and outside actors, particularly for primary health care and pharmacy services.<sup>80</sup> While the private sector is decentralized at the level of providers with little oversight, the public health system is centralized with links to health insurance organizations, though the state plays a large role in funding part of the care provided by the private sector. Health spending accounted for 5.9% of Lebanon's gross domestic product in 2010, though health financing contributions varied widely with public sector contribution at 28.98%, private sector at 70.99%, and international donor contributions at 0.03% (which have since increased due to the refugee influx).<sup>80</sup> Health financing in Lebanon is a complex assortment of public funding, private insurance, mutual funds, and the Ministry of Public Health (MoPH).<sup>81</sup> Less than half (44.9%) of Lebanon's population benefits from some type of insurance.<sup>82</sup> The National Social Security Fund (NSSF), a public insurance institution providing mandatory coverage for formal sector employees (excluding civil servants and uniformed forces) funded largely by employers and employee contributions, covers 23.4% of all residents in Lebanon, followed by the Army and Internal Security Forces schemes, which cover another 9.0% of residents.<sup>82</sup> The remaining 53.3% of Lebanese reporting no formal health coverage are considered MoPH beneficiaries entitled to coverage of "what would be considered a catastrophic payment for households."<sup>81</sup> Though perhaps the most frequently cited and readily available, these figures on insured populations in Lebanon have been challenged as underestimates compared to MoPH records.<sup>81</sup> Nevertheless, household spending on health (largely for insurance premiums, private clinic services, and medication) accounted for 44% of total health spending in Lebanon in 2009.<sup>80</sup>

With 31.3 physicians per 10,000 population, Lebanon has the highest number of physicians per capita in the Eastern Mediterranean Region.<sup>83-86</sup> The per capita density of nurses, previously among the lowest in the region, has increased in recent years substantially to 36.4 nurses per 10,000 population in 2017.<sup>83,86,87</sup> In 2010, 70% of physicians registered in the country's two Orders of Physicians were specialists, and an estimated 10-15% of registered physicians did not practice in Lebanon.<sup>80</sup> It must be noted that the cited average rates of health providers are potentially misleading as provider concentrations vary throughout the country and are predominantly focused in the capital of Beirut and specialist physicians are concentrated in private facilities or hospitals.<sup>80</sup>

Efforts were made to reform the health system in Lebanon's 1990's post-civil war period with a focus on primary health care and strengthening public hospitals. Of the more than 900 health centers operated by both public and private bodies including the MoPH, the Ministry of Social Affairs (MoSA), local municipalities, non-governmental organizations (NGOs), civil society organizations, and religious/political groups, almost one-quarter are regulated and supported by the MoPH. MoPH network primary healthcare centers (PHCCs) receive financial and logistical support from the Ministry as well as frequent training activities and commodities.<sup>81</sup> An increasing number of PHCCs (nearly 200 as of August 2015 and 229 as of early 2019) are part of the country's MoPH network, providing reduced cost care for vulnerable Lebanese nationals.<sup>88,89</sup> In 2012, it was estimated that, at most, 20% of the population utilizes PHCCs in Lebanon, a figure that, though low, is more than twice that estimated in 2002.<sup>80</sup> Through the joint Non-Communicable Disease Program (NCDP) with the WHO and the associated National Program on Controlling Diabetes, facilities in the MoPH network are also mandated to offer a spectrum of services for NCDs including, but not limited to prevention education/counseling, screening, regular follow-up monitoring care, and essential medicines. In addition to primary health care services, the NCDP "aims at establishing a link with the MoPH coverage of needed episodic hospitalization of the chronically ill that include diabetic complications, heart attacks, strokes, dialysis, and others, in order to ensure a continuum of care."81 How this specifically translates to coverage of such hospital care or more complex secondary/tertiary care is less clearly outlined.

In 2014, the MoPH published the most recent edition of Lebanon's National List of Essential Medicines. An update from the 2002 version, this edition is similarly based upon the WHO's Model List of Essential Medicines, outlining medicines believed to "satisfy the priority health care needs of the population."<sup>90</sup> The WHO's definition of essential medicines explains that they "are intended to be available within the context of functioning health systems at all times in adequate amounts, in the appropriate dosage forms, with assured quality, and at a price the individual and the community can afford."<sup>90</sup> The list of essential medicines is meant to be "flexible and adaptable" in implementation and is not innately a required formulary for individual dispensaries or health facilities. In Lebanon's 2014 List of Essential Medicines, Dr. Walid Ammar, then Director General of the MoPH in Lebanon, expressed the intention for the list's publication: "that all health providers would embrace this document as important tool for management of medicines and rationalizing prescription in the country."<sup>91</sup>

Chronic disease medications are available at a nominal fee to enrolled beneficiaries, including Syrian refugees and host Lebanese, in select dispensaries through a joint program between the MoPH and Young Men's Christian Association (YMCA); however, the process necessary for receiving medicines through the YMCA program is illusively documented and lengthy. Based on information from key informants and health working group meeting notes, to receive YMCA medication for a nominal fee, patients are required to submit an application that includes legal identity documents and a copy of the relevant prescription(s) from a physician.<sup>92</sup> After applications are submitted, patients wait approximately three months before receiving approval for entry into the program. Once accepted to the program, patients generally receive the medication from a participating center every three months. Patients only receive medications included in their initial application and can only do so at the health facility listed on the application. Additional challenges are faced when facilities attempt to contact patients to pick up prescriptions once orders are received. Expiration of phone lines is frequent among all populations in Lebanon, and facilities are often unable to reach patients to inform them that their medications are available. For refugee patients experiencing frequent relocation, obtaining medication from the same facility every three months is extremely difficult, if not impossible.

#### 2.5. Assistance for Syrian Refugees in Lebanon

With refugees under the responsibility of UNHCR now accounting for one in six people in Lebanon, the country's highly fragmented and privatized health system is immensely burdened by additional financial demands and increased infrastructure, capacity, and resource allocation needs.<sup>80,93,94</sup> The Lebanese health system has incurred tremendous costs for delivering services, strengthening capacity, and maintaining infrastructure to meet the growing demand brought on by the influx of Syrian refugees.<sup>95</sup> Unlike other countries hosting large numbers of Syrian refugees, Lebanon has not established formal camps for Syrian refugees nor health facilities dedicated to providing services only to refugees. In response to the Syrian crisis, UNHCR established an interagency mechanism with the Lebanese government to coordinate the humanitarian response across all sectors. Delivery of health services for Syrian refugees in Lebanon is based on a primary health care strategy. As of mid-2015 when data for this study was collected, Syrian refugees could utilize primary healthcare services for subsidized rates at approximately 116 of more than 1,200 existing PHCCs/dispensaries across the country, including existing MoPH PHCCs (Figure 2-3).<sup>13,79,88,96-99</sup>

Subsidized care at participating primary level health facilities is offered to Syrian refugees for a fee of 3,000 to 5,000 LBP (approximately US\$2 to US\$3) per visit. Additional primary health facilities not supported by UNHCR or NGOs may also offer care at reduced rates, though these costs are not guaranteed, vary widely, and it is often difficult to identify PHCCs or private facilities providing reduced cost care.<sup>100</sup> UNHCR covers 85% of diagnostic costs for select vulnerable refugee groups (children under five years, adults 60 years and older, the disabled, and pregnant or nursing women).<sup>37</sup> Medication for chronic conditions are provided to refugees for a dispensing fee of 1,000 LBP (approximately US\$0.66) through the ongoing

medication support program run by the YMCA; however, stocks are not always sufficient, and enrolling in the program can be a lengthy process requiring extensive formal documentation.<sup>96,101</sup>

A third-party private administrator manages referrals for secondary and tertiary services for Syrian refugees.<sup>13,88,93,97,98</sup> Though each case is evaluated individually, most coverage for secondary and tertiary care is provided for life-saving emergencies, deliveries, and care for newborns. Coverage for secondary or tertiary services for NCDs and associated complications are rarely referenced, suggesting that few if any of these cases are covered. Hospital care is provided to Syrian refugees in Lebanon by referral from a primary level health facility or self-presentation in the case of a life-threatening emergency. Eligibility is limited to cases fitting one of two categories: (1) emergencies (obstetric, medical, and surgical), and (2) elective cases for "complementary investigations" and/or specific treatment. Refugees not meeting eligibility criteria or otherwise seeking care at hospitals for non-life-threatening emergencies can be considered by the UNHCR Exceptional Care Committee to determine whether the case may be covered. If the Exceptional Care Committee does not approve the case, refugees must directly pay the full cost of care.<sup>37</sup> Lebanon's highly privatized health system often makes care for refugees similarly as expensive for vulnerable Lebanese.<sup>80,93</sup>

Despite some subsidized primary care, many refugees are not able to access needed secondary and tertiary care because of resource and funding constraints; many cases that could have received early intervention do not receive care until their condition is advanced enough to be considered a health emergency if care is received at all. The cost of care and demand for secondary and tertiary services are notably high due to the sizable burden of NCDs among both Syrian refugees and Lebanese. The complexity of managing these conditions and the limited resources available for refugee health care are apparent given the current coverage gap for secondary and tertiary care. For both those that receive subsidized care and those where treatment costs are not covered, the burden of even a small out-of-pocket payment can serve as a barrier to care, especially given the tenuous financial situation and increasing debt of many refugee households.<sup>102</sup> Although health consultations are provided at participating primary level health facilities for a nominal fee, an estimated 39% of Syrian refugees in Lebanon are reportedly not receiving needed medical care because of the costs of treatment and medication, the long-term results of which are increased morbidity, mortality, and costs incurred for more specialized care for later complications.<sup>103</sup>



Figure 2-1. Lebanon's Population Pyramid, 2016

Central Intelligence Agency. The World Factbook: Lebanon. 2016. https://www.cia.gov/library/publications/the-world-factbook/geos/le.html (accessed October 29, 2016).



Figure 2-2. Syria's Population Pyramid, 2016

Central Intelligence Agency. The World Factbook: Syria. 2016. https://www.cia.gov/library/publications/the-world-factbook/geos/sy.html (accessed October 29, 2016).



Figure 2-3. Primary Health Care Centers in Lebanon as of August 2015

Data Source: United Nations High Commissioner for Refugees (UNHCR), Inter-Agency Coordination Lebanon. Lebanon information hub.

https://www.dropbox.com/sh/4wqtdgihu566i9m/AABZcfPATVWNsmf6xMkLqUAWa?dl=0 (accessed January 8, 2016).

#### **Chapter 3. Literature Review**

#### 3.1. Hypertension and Type 2 Diabetes Treatment

Treatment of both hypertension and type 2 diabetes require close, continued follow-up over time with standard treatments involving both pharmacological and lifestyle interventions.

#### Hypertension

Hypertension, also characterized as high blood pressure, is a major global health challenge. As outward symptoms are rare in early stages, patients are often not diagnosed until the condition has progressed, complicating treatment and management. As with many chronic NCDs, prevention strategies and screening to identify cases earlier in their progression can greatly improve health outcomes. Uncontrolled hypertension has been linked to heart disease, stroke, and kidney failure in addition to associated premature disability and mortality.<sup>41</sup>

Standard treatment protocols for hypertension advise providers to begin treatment for elevated blood pressure by encouraging lifestyle modifications. If blood pressure levels cannot be controlled through lifestyle modifications alone, pharmacological treatment is advised in accordance with *The Eighth Joint National Committee on the Prevention, Detection, Evaluation, and Treatment of High Blood Pressure's 2014 Hypertension Guideline Management Algorithm* and more recently revised 2017 American College of Cardiology/American Heart Association (ACC/AHA) Guideline for the Prevention, Detection, Evaluation, and Management of High Blood Pressure in Adults to achieve optimal blood pressure.<sup>104,105</sup> Failure to intervene pharmacologically when systolic blood pressure is consistently above 130 mmHg or diastolic blood pressure is consistently above 80 mmHg, whether due to providers' or patients' decisions,

is often associated with greater risk of atherosclerotic cardiovascular disease and worse hypertensive health outcomes overall.<sup>104-106</sup>

#### **Type 2 Diabetes**

Type 2 diabetes is marked by insulin resistance and is often diagnosed at older ages. Uncontrolled long-term diabetes mellitus can result in retinopathy (with potential blindness), nephropathy (possibly leading to renal failure), and neuropathy (possibly leading to foot amputation), as well as increased risk of cardiovascular, peripheral vascular, and cerebrovascular diseases.<sup>107</sup>

Type 2 diabetes treatment and management, much like hypertension, requires a combination of pharmacological intervention along with dietary and lifestyle modifications to maintain controlled blood glucose levels (defined as HbA1C<sup>\*</sup> level of 7% or lower) and, in turn, prevent potentially severe cardiovascular, ocular, renal, and neurological complications.<sup>108,109</sup>

# 3.2. Care Utilization for Hypertension and Type 2 Diabetes

#### The Role of Care Utilization in Hypertension and Type 2 Diabetes Management

Regular monitoring and continuous care visits are essential for controlling both hypertension and type 2 diabetes. Hypertensive patients not attending regular visits with health providers (specifically follow-up care received within a six-month period) have been found to have higher blood pressure. Early studies showed a higher prevalence of diastolic blood pressure above 90 mmHg among patients not seeing a physician for a period of more than six months (67%) compared to those who received physician care in the same period (30%).<sup>110</sup> In addition to general hypertensive populations, this association between frequency of care and improved blood

<sup>\*</sup> Glycated hemoglobin (HbA1C) is a standard test used to determine average blood sugar levels over extended periods (weeks or months)

pressure has been reported in elderly sub-populations.<sup>111</sup> Evidence also suggests a reduced risk of hospitalization among hypertensive patients with greater continuity of care, both in the United States and abroad.<sup>112,113</sup> Similarly, regular care for type 2 diabetes has been shown to improve control of both blood glucose and blood pressure as well as lower the risk of hospitalization.<sup>114,115</sup>

#### Estimates of Syrian Refugee and Lebanese Care Utilization

# Syrian Refugee Care Utilization

A recent survey (2014) of Syrian refugees in Lebanon found that among households with at least one member with an NCD, 56.1% were unable to access necessary medicine or other health services.<sup>71</sup> Results such as this suggest that condition management for Syrian refugees with NCDs may be more complicated, particularly with respect to medicines. For refugee populations living in non-camp settings, such as those in Lebanon, a high burden of NCDs translates to an immense burden on host countries' health systems. Given the protracted nature of the crisis, the high costs of providing NCD care, and the large caseload of Syrian refugees with NCDs, implications for Lebanon's health system are vast. The burden of out-of-pocket expenses on persons with NCDs is also substantial, especially given the tenuous economic status of many refugees. The extensive implications and unnecessary complications resulting from inadequate access to or use of health care by Syrian refugees in Lebanon has been reported previously, though no comprehensive quantitative assessments provide evidence of the extent of these impacts.<sup>100</sup>

The Lebanese health system's public sector is over-burdened, and its quality of care is perceived to be much lower than private sector care.<sup>80</sup> This is particularly troublesome as cost was the primary barrier to care-seeking reported in numerous surveys, despite subsidized care provided by the MoPH and humanitarian organizations to Syrian refugees.<sup>71,116</sup> In addition to

cost, inadequate equipment or medicines, long wait times, transportation difficulties, and absence of family permission have been commonly reported barriers to care-seeking in recent studies of Syrian refugees in Lebanon.<sup>71,117</sup> Despite relatively high UNHCR registration figures, average costs reported by refugees often indicate that the standard subsidized cost of US\$2-US\$3 for primary care at participating primary level health facilities is most often exceeded, likely an indication that refugees are receiving care at non-UNHCR or NGO supported centers.<sup>116</sup> While the costs of clinical services for refugees carried by the MoPH, UNHCR, and NGOs is greater in Lebanon than in other settings where NCDs account for a smaller portion of the burden of disease among refugees, increased capacity and targeted services for refugees with chronic conditions including hypertension, diabetes, and cardiovascular disease have also helped improve disease control and health outcomes among Palestinian refugees in the region.<sup>118</sup>

#### Lebanese Care Utilization

Research on care utilization and treatment rates for NCDs among the Lebanese population shows varying results. A 2015 study of prevalence, awareness, treatment, and control of hypertension in Lebanon found that only 53.0% of study participants were aware of their condition and the overall treatment rate (defined as current use of antihypertensive medications) was 48.9%.<sup>50</sup> These figures are higher than estimates from neighboring countries (namely Turkey, Egypt, and Palestine) where treatment rate estimates range from 23.9% to 40.0% and overall hypertension control rates range from 8.0% to 9.0%. Despite higher treatment rates in Lebanon than elsewhere in the region, that more than half of hypertensive patients remain untreated raises concern for the overall health of individuals and the costs incurred by governmental, nongovernmental, and international organizations subsidizing health care in Lebanon.<sup>119-121</sup>
Differences in treatment and control rates favoring the Lebanese population may be attributable to their overall higher socioeconomic status and a higher ratio of physicians to the general population, among other factors. "Treatment and control" as typically defined miss an essential component of care for chronic conditions like hypertension and diabetes in that reported use of medication does not inherently indicate receipt of care from a health provider, nor does reported care-seeking speak to the quality of care received.<sup>122</sup> Lebanese hypertension and diabetes patients report having medication prescribed largely by cardiologists and endocrinologists, with a minority prescribed medication for their condition from a general practitioner, likely a reflection of the Lebanese health system's emphasis on specialist care.<sup>123</sup> A small, though a noteworthy minority of these patients report multiple prescribers, most often two specialist prescribers. Such fragmentation has implications for continuity of care. Furthermore, the ability for patients in Lebanon to obtain medications directly from pharmacies without a proper prescription (whether new medication or refill of a previously prescribed medication) although illegal, has been previously observed and reported elsewhere.<sup>124-127</sup> Owing to the illegal nature of the topic and political sensitivities, the extent and implications of this practice have been reported and interpreted various ways, though infrequently focused on medication for chronic diseases. A 2014 study of completion of therapeutic and safety monitoring test among Lebanese outpatients on chronic disease medications found that only 3.0% of sampled patients had medication dispensed by pharmacists without physician consultation.<sup>123</sup> Conversely, a qualitative study conducted by Integrity Research and Consultancy in 2014 reported the more frequent tendency for men to seek care directly at pharmacies, a finding supported by numerous studies and reports in other media of the practice of obtaining medication (particularly antibiotics) in Lebanon pharmacies without prescription.124,125,127-134

Numerous international guidelines reinforce the importance of safety monitoring tests for patients taking chronic medications; however, the extent of such monitoring varies widely. In the Lebanese population, previous studies reported nearly three-quarters of patients receiving incomplete therapeutic and safety monitoring tests recommended by standard treatment guidelines for patients on chronic medications.<sup>123</sup> Specifically, only 27.0% of Lebanese community pharmacy outpatients screened in 2011 were considered completely monitored, 65.0% partially monitored, and 8.0% unmonitored.<sup>123</sup> The same study reported that only 35.0% of studied diabetic patients prescribed oral medications were receiving the frequency of HbA1C monitoring tests advised by the American Diabetes Association (at least two times per year for glycemically controlled patients and quarterly in patients for whom a treatment regimen has recently changed or who are not meeting targeted glycemic control).<sup>135</sup> Among diabetic patients with incomplete monitoring (either partial or no monitoring tests), more than half (62.0%) of patients reported visiting a physician once per year or less. Similar results were observed for patients on statin therapy with 64.0% completing baseline liver function tests and 25.0% completing baseline creatine phosphokinase tests; in other words, 65.0% of patients on statin therapy had periodic liver function tests measured at least once during follow-up.<sup>123</sup>

There is a noted gap between clinical practice in Lebanon and international guidelines.<sup>136</sup> While the MoPH has worked in recent years to train providers on standard treatment guidelines for several chronic NCDs (including hypertension and diabetes), results from the 2013 Initiative for Cardiovascular Service in the MoPH-PHCC network indicate persistent deficiencies in physician compliance with treatment protocols and an overarching culture of reliance on specialist, secondary, and tertiary care, even among general practitioners.<sup>137</sup> A 2014 study of predictors of blood pressure control in the Lebanese population purported that poor provider adherence to guidelines may largely be attributed to lack of access to treatment guidelines, but also noted the influence of physicians' attitudes regarding existing practices.<sup>136,138</sup> Limited flexibility in most guidelines is also a likely source of poor adherence as many guidelines cannot meet the complexity of the context in which they are practiced.<sup>136,138</sup> Thorough adherence to guidelines in complex settings is particularly necessary for counseling patients about how to manage their conditions, possible complications, necessary lifestyle changes, and the importance of continuous monitoring and adherence to treatments.

### Facilitators and Barriers to Care Utilization for Hypertension and Type 2 Diabetes

Numerous factors are associated with care-seeking and treatment of both hypertension and diabetes, though much of this research is from developed countries in relatively stable populations. Although extensive research on health behaviors, including care-seeking and health service utilization, exists for vulnerable populations and in low resource settings, there is limited evidence in contexts analogous to the protracted Syrian refugee response in Lebanon.<sup>139-148</sup> Some factors associated with care utilization occur in multiple contexts, suggesting relevance regardless of the setting. These can broadly be categorized as patient characteristics, provider-related factors, and structural/environmental features.<sup>149-157</sup>

#### Patient Characteristics

Four types of patient-related factors are associated with health care-seeking behavior for hypertension and diabetes: (i) sociodemographic characteristics; (ii) condition-related factors; (iii) patient attitudes and beliefs; and (iv) psychosocial characteristics. Among the sociodemographic factors, care-seeking has mixed associations with marital status and general educational attainment; the evidence for age, sex, ethnicity, and minority status are more consistent.<sup>140,155,158-</sup> <sup>161</sup> A 1997 review of health care utilization predictors for individuals with chronic illness reported ambiguous results for the relationship between patient age and care utilization, but this information is dated and the majority of more recent studies report increased utilization with older age, ostensibly reflecting an increased actual need for assorted health services with age.<sup>140,158,162-</sup> <sup>164</sup> Current studies also indicate that women utilize services more than men.<sup>140,152,158,159,161,164,165</sup> Cultural and religious norms in Arab countries strongly influence the function of sex in individual health behaviors, in some cases altering the magnitude of the association.<sup>159</sup> Disparities exist in minority care-seeking, specifically ethnic and racial minorities, although higher use of care relative to non-minority populations has been consistently reported, particularly for diabetes.<sup>166-169</sup> In this case, increased minority utilization is postulated to result from increased disease severity and complications resulting from inadequate routine preventive care.

The role of financial factors in care utilization is well-established. Financial resources can transform medical need into effective demand for care. Higher income and having health insurance are associated with increased health service utilization overall and for chronic health conditions such as hypertension and diabetes.<sup>140,159-162,170-174</sup> Low socioeconomic status (education, employment, and income, among others) has also been assessed as a mediator on the causal pathway from socioeconomic position to care-seeking to health outcomes.<sup>155,172,175</sup> Competing demands for patients' limited resources (primarily financial, but also time) also hinder health care utilization.<sup>142,146,161,172,174,176,177</sup> In their 2014 study of barriers and enablers to health among homeless persons with diabetes in the U.S., Elder et al. noted that "urgent, daily needs have priority for time, money and emotional energy…" and that "chronic disease care, without acute symptoms, is low priority."<sup>174</sup>

Clinical or condition-related characteristics also influence individuals' health behaviors, largely from the perspective of an individual's need for care. Care for hypertension and diabetes increases with longer disease duration, greater disease and symptom severity, and the presence of complications and co- or multi-morbidities.<sup>77,140,155,158,162,164,167,177-182</sup>

In addition to sociodemographic and condition factors, individuals' knowledge, perceptions, and beliefs about their condition and its management strongly influence care-seeking behaviors. While knowledge alone may not motivate seeking health services, increased knowledge and beliefs concerning the consequences of hypertension and diabetes, as well as individuals' access to information about diagnosed conditions and available services are associated with increased care utilization.<sup>77,155,159,174,177</sup> Beyond knowledge of the diagnosed condition for which care is needed, there is a relationship between overall health literacy and increased healthcare visits.<sup>159,172,183,184</sup>

A patient's first clinical encounter is motivated by their attitudes and beliefs, and continuity of care-seeking beyond the first visit is also influenced by their perception(s) about the quality of care they receive: did health providers devote sufficient time to consultations, were services culturally sensitive, and did patients trust their provider's abilities.<sup>159,185-187</sup> Moreover, self-efficacy, an individual's confidence that they can perform necessary tasks, is associated with increased adherence to treatment and regular follow-up appointments.<sup>139,186,188</sup> Additional psychosocial barriers and supports influence health care behaviors: psychological distress and fears, clinical depression and anxiety, and supportive factors such as social support and social networks.<sup>146,152,158,162,172,174,176,177,189,190</sup>

### **Provider Characteristics**

Factors related to health providers also influence care-seeking and health service utilization: the patient-provider interaction/relationship, provider adherence to clinical guidelines, workload, provider type (i.e., generalist or specialist physician, nurse, pharmacist, etc.) and provider sex.<sup>144,146,147,149,151,156,185,191</sup> Evidence supports increased care-seeking when there is a valued patient/provider relationship, but care-seeking delays and avoidance in the absence of such relationships.<sup>146,155,165,173,177,186,188</sup> In individuals with chronic conditions, patient trust in their health providers' technical abilities facilitates increased follow-up care.<sup>144,146,178</sup> Conversely, patients tend to have lower overall care utilization when their providers have high workloads and limited time available for them, and when their physicians have poor adherence to standard treatment guidelines.<sup>165,178,185,192</sup> The type of health care provider also influences patients' use of services, but the direction of association is inconsistent, depending upon the study context.<sup>149,151,172,191</sup>

# Structural and Environmental Factors

Beyond individual patient and provider factors, the structure of the health system in which care for chronic conditions is sought has a role in care-seeking. Structural factors that influence health care use include the acceptability, availability, accessibility, and affordability of available services.<sup>144-146,149,151,156,176,177,185,191,193</sup> Availability of health care providers, services, medication, and testing equipment is central to initial care-seeking and continuity of follow-up care.<sup>146,149,165,176-178,194</sup> Facility operating hours and appointment systems are core resources for accessible health services, and in some contexts, these can pose insurmountable barriers to accessing care.<sup>146,159,173,185,194,195</sup> The provider network's complexity can facilitate or hinder patients' access to care.<sup>176,185,196</sup> This is especially true in refugee and migrant populations where patients are new to a country, and lack a basic understanding of the health system, and may not know where and how to access available services.<sup>196</sup> Research on the relationship between provider mix and care utilization is limited; however, a 2008 study indicated an inverse relationship between the ratio of primary care physicians to specialists within concentrated geographic areas and hospital admissions, emergency department visits, and surgeries.<sup>197</sup>

Other health system factors that decrease future care utilization beyond the first contact include long wait time and poor care quality during visits.<sup>159,165,177,178,185,194,195,198</sup> There is an inverse relationship between cost and the use of health services both for care generally and for hypertension and diabetes.<sup>146,165,178,194</sup>

Environmental factors, principally the distance to a health facility and transportation access and affordability are prominent determinants of individuals' health care behaviors.<sup>146,165,172,177,178,194,195,199,200</sup> Lower care utilization is associated with longer distances to health facilities, reflecting the burden on patients' limited time and resources. There is substantial evidence that transportation access and its associated costs are critical but underappreciated components of care-seeking decisions.<sup>145,146,159,160,165,176,185,194-196,199,200</sup>

### **Refugee-Specific Factors**

There is a growing body of research on refugees' access to and use of healthcare, mainly in the U.S., Europe, and Australia and not focused on NCDs such as hypertension and diabetes.<sup>201-208</sup> A 2001 Australian study on the effect of immigrant status on health insurance, health care access, and service utilization found decreased access to care among noncitizens and their children, regardless of health insurance coverage.<sup>209</sup> Later research has tended to show higher rates of healthcare utilization among refugees relative to host country nationals, particularly in the first year of displacement.<sup>210,211</sup> For example, in their 2015 study of health care utilization by Arab immigrants and Iraqi refugees in the U.S., Elsouhag et al. reported both increased refugee care utilization and health needs; however, unlike refugees, immigrants utilized care significantly less than the U.S. national rate.<sup>160</sup> The comparison of refugees and immigrants in Elsouhag et al.'s research offers unique insight into the dissimilarities in health-seeking behaviors of refugees compared to immigrants and host country populations, each of whom is afforded differential access to services in most countries. Refugees' healthcare barriers include language impediments and navigating a healthcare system which likely has different policies, procedures, and norms from those of their country of origin. Specific reported challenges include not knowing where to seek care, accessing specialty care, unclear referral procedures. Health providers treating refugee patients also raise concerns about language barriers and ambiguity regarding available services and referrals for refugees requiring additional care.<sup>196,202-208,212</sup>

# 3.3. Medication Adherence: Measurement, Role, and Determinants

The WHO has identified medication nonadherence as one of the major causes of avoidable health care costs, morbidity, and mortality worldwide.<sup>213</sup> It is estimated that between 30 to 50% of all prescribed medication and 17 to 80% of prescribed long-term medication is not taken as directed.<sup>214-217</sup>

A key challenge in studying medication adherence is the lack of agreement on terminology and how to define adherence. Various terms, such as adherence, compliance, persistence, and concordance, among others, have historically been applied to describe medication usage. These terms are used inconsistently across studies, hindering comparison of results, and potentially leading to misinterpretation in employing intervention strategies.<sup>218,219</sup> Medication *compliance* and *adherence* are frequently used interchangeably, though their technical distinction reflects the inherent complexity in medication usage itself.<sup>220</sup> Medication *compliance* is traditionally understood to be "the extent to which the patient's behavior matches the prescriber's recommendations"; however, the term is now out of favor as it indicates an asymmetric power relationship rather than a therapeutic partnership.<sup>218,220,221</sup> Definitions of medication *adherence* vary more widely. Historically, adherence concerned whether medication is filled, but over time it has come to include initiation, implementation, and discontinuation and thus, may also include the extent to which medication is taken once it is filled.<sup>222-225</sup> The term *adherence* often indicates a general adherence to overall treatment recommendations, as is the case in the WHO's 2013 "Adherence to Long-Term Therapies: Evidence for Action" report in which adherence is defined as "the extent to which a person's behavior—taking medication, following a diet, and/or executing lifestyle changes—corresponds with agreed recommendations from a health care provider."<sup>225</sup> While many studies define adherence broadly to include all aspects of treatment adherence (including diet, lifestyle, and care-seeking recommendations), the issues with medication use can be quite different from those concerning adherence to diet, lifestyle behaviors, or follow-up care and testing.<sup>226</sup> For the purpose of this dissertation, the term adherence is used both because of the broader scope of its definition and its widespread use in the relevant literature.

Medication adherence can broadly be organized into three components or types. The first type of nonadherence is *nonfulfillment*, or primary nonadherence, which occurs when patients do not fill prescriptions from health providers. This also includes patients who fill the prescription but never actually take the medication. *Non-persistence*, a second type of nonadherence, occurs when patients start a prescribed medication but choose to stop taking it without being instructed to do so by a medical professional. While non-persistence may be unintentional (i.e., when patients misunderstand or are not provided with proper instructions on how to take the medication), it is often intentional, and most patients who stop taking medication do so within six months of initiating.<sup>227</sup> Medication persistence is often studied independently of adherence and is defined as "the duration of time from initiation to discontinuation of therapy."<sup>218</sup> A third type of nonadherence, *nonconforming*, occurs when medications are taken, but not according to the prescribed regimen. This may include timing, dosage, or skipping doses altogether. Patients are considered fully adherent to a medication regimen only when all three of these components are

achieved, meaning that to be fully adherent, pursuant to being prescribed a medication, patients must fill the medication, initiate taking it, and continue taking it as instructed. The varied consequences of nonadherence depend on the specific medication and the condition being treated. For example, an isolated incident of missing a cholesterol medication will not have substantial clinical significance in the way that occasionally missing a cardiac medication would.

#### **Measuring Medication Adherence**

One of the central challenges to researching medication adherence is the difficulty associated with reliably measuring it.<sup>228,229</sup> Many methods have been tested and validated in various settings. Methods for measuring medication adherence fall into two categories: direct and indirect methods. Direct methods include testing blood samples and clinical observation (e.g., direct observed treatment or clinically observed therapy). Such methods are not as widely used outside of clinical settings as they provide data only on a limited period and are costly to implement and sustain. Conversely, indirect methods are more practical as they tend to be less labor and cost intensive than direct methods of measurement. The most commonly used indirect methods for measuring adherence include patient self-report, pill counts, prescription fill records, and, primarily in more developed settings, electronic medication monitors.

Despite the advantages of indirect measurement methods, each method carries its own disadvantages as well. Patient self-report is arguably the least expensive and easiest method to implement, but results are often less reliable and tend to overestimate adherence, particularly when compared to alternative direct methods.<sup>228</sup> Another commonly used method, pharmacy fill records, is also among the easiest ways of obtaining adherence information; however, the accuracy of the data included in databases varies and is often difficult to assess. This method is particularly troublesome in areas with inadequate record-keeping systems, as is often the case in

many low- and middle-income countries. Moreover, the use of database information relies on several assumptions about adherence that may not hold and, in fact, may substantially bias analytic results. For example, adherence measures based on pharmacy records assume that patients take the filled prescription as advised. If this assumption does not hold, results may be highly inaccurate and may misinform recommendations or future interventions. Additionally, assuming that patients are not filling their prescriptions at a pharmacy other than that from which data are collected may be inaccurate, particularly in areas with a large number of dispensing outlets accessible to patients.<sup>230-239</sup> Further along the spectrum of indirect measurement methods are electronic medication monitors. These monitors are built into the prescription bottle and track the time and date for each time a patient opens the bottle. Electronic medication monitors are widely considered to be the gold standard for measuring medication adherence and, although they can be beneficial for tracking how and when patients are taking prescribed medication, monitors are expensive and often impractical to implement, especially in less developed settings with limited resources.<sup>240 230</sup> In the absence of a single "gold standard" method for measuring medication adherence, use of multiple adherence measures is considered one of the most accurate methods.241

Given its superior feasibility, self-reported adherence measurement is often preferred over more direct measures of adherence in low resource settings where record keeping and the possibility of using electronic monitors are not feasible. Many validated tools for self-report of medication adherence are available and commonly used. While there is no firmly established gold standard for adherence measurement, the Morisky Medication Adherence Scale (MMAS) is perhaps the most widely validated and referenced self-reported measure. First published in 1986 to assess adherence to antihypertensive medication, the MMAS-4 consists of four yes/no questions focused on forgetfulness, carelessness, stopping medication use because the patient feels better, and stopping because the patient feels worse. Widely used for its length and relative ease of implementation, the MMAS-4 nonetheless initially showed fair psychometric properties with 81% sensitivity, 44% specificity, and a Cronbach's alpha reliability of 0.61. An eight-item version of the MMAS, consists of a total of seven yes/no questions and a five-point Likert scale question. The MMAS-8 has improved psychometric properties as compared to the MMAS-4 (93% sensitivity, 53% specificity, and a Cronbach's alpha reliability of 0.83), has been found to maintain a high degree of concurrent and predictive validity with pharmacy fill rates in a number of studies, and has been adapted for use in a many countries and contexts.<sup>242,243 244-251</sup>

In addition to the MMAS, the Hill-Bone Compliance to High Blood Pressure Therapy Scale (HB-HBP) and the Hill-Bone Medication Adherence Scale (HB-MAS), developed specifically for measuring compliance with hypertension treatment, are also frequently used and have been validated in numerous settings and populations.<sup>252-256</sup> The 14-item HB-HBP assesses patient behaviors related to appointment keeping, diet, and medication adherence, while the 9item HB-MAS focuses exclusively on medication adherence and can also be applied to various chronic conditions aside from hypertension.

Another commonly used adherence measure, The Brief Medication Questionnaire (BMQ), consists of nine main items with three additional subscales to be used based on the type of nonadherence identified.<sup>257</sup> The three subscales (consisting of the regimen screen, belief screen, and recall screen) can be used to better adapt use of the tool to each patient; however, original validation of the BMQ did not include a sufficient sample to evaluate its psychometric properties, and limited evidence of the tool's validity is available.<sup>252</sup>

Numerous instruments developed to measure adherence to medication for psychiatric conditions have also been applied to other chronic conditions. The Drug Attitudes Inventory

(DAI) is widely used to evaluate adherence among psychiatric patients.<sup>258</sup> This tool consists of 30 questions covering seven factors: subjective positive attitudes, subjective negative attitudes, health/illness, physician, control, prevention, and harm, but has been found to correctly classify adherence in only 68% of patients.<sup>259</sup> Criticized for limited construct validity, the DAI falls short in that it relies on clinicians' judgment for assessment, arbitrarily classifies compliance versus non-compliance, and relies on patient's attitudes towards the medication rather than inquiring directly about compliance.<sup>259</sup> The Medication Adherence Rating Scale (MARS) is a ten-item yes/no instrument developed from the DAI and the MMAS-4 specifically intended to better assess medication adherence for psychosis medication. The MARS has shown improved reliability and validity as compared to these previous measures but has not been widely tested for non-psychiatric conditions.<sup>259</sup>

An additional tool, the Brief Adherence Rating Scale (BARS), was designed to be administered by clinicians. The BARS consists of three questions about patients' knowledge of their medication regimen and missed medication in addition to an overall visual analog rating scale to assess the proportion of doses taken by the patient in the past month (0%–100%). The visual analog scale (VAS) rating determines the final adherence measure for this tool, which has shown good psychometric properties (73% sensitivity and 74% specificity in identifying nonadherent outpatients with schizophrenia).<sup>260</sup> The VAS alone, conducted by asking patients to estimate the percentage of medication doses that they took as prescribed over a determined period of time, has shown mixed results when applied to adherence to medication for HIV/AIDS. Some studies showed high correlation between the VAS and more objective, direct measures while others reported null associations between the VAS and objective adherence measures.<sup>261-264</sup>

Another promising measure of medication adherence is the Adherence to Refills and Medications scale (ARMS).<sup>265</sup> This scale contains the four items included in the abbreviated

MMAS-4, four additional items to evaluate how respondents take prescribed medication (including skipping and changing doses, among other common variants of non-adherence), and another four-item subscale assessing refill behaviors. Collectively, questions in the ARMS may also provide specific and actionable information on patient behaviors related to medication availability that are not included in many other adherence measures. A separate version of the ARMS, the ARMS-D, has been validated for use in diabetes research and is focused expressly on adherence to medication for diabetes, including questions about insulin therapy.<sup>266</sup>

#### The Role of Medication Adherence in Hypertension and Type 2 Diabetes

#### Hypertension

Poor or non-adherence to prescribed antihypertensive medication(s) is strongly associated with reduced blood pressure control.<sup>225,227,267,268</sup> While much evidence supports the relationship between lifestyle and nutrition in hypertension control independent from medication adherence, adherence to medication has long been posited as a principal factor on the causal pathway to improved disease control.<sup>269</sup> Early evidence of this relationship showed that it is largely driven by a higher level of interaction with health care providers and, in turn, improved detection and diagnosis of hypertension. Though researchers suggest that increased interaction with health providers also improves hypertension control by improving access to medications, this direct relationship was not tested in early studies. More recent studies, however, provide stronger support for the relationship between poor or non-adherence to prescribed medication and poor health outcomes in patients with chronic diseases.<sup>269-273</sup>

In addition to adverse health outcomes, inadequate adherence to prescribed medication has also been associated with increased health care costs in many studies in the United States and abroad.<sup>271,274-278</sup> Increased health costs attributed to patients who discontinue or switch therapies are clear, but the precise mechanism through which increased costs are incurred vary across studies. In addition to overall health costs, evidence supports the association between non-adherence and increased costs related to hospitalizations and emergency room visits, suggesting an increase in complications or worsening health outcomes given relatively low all-cause hospitalization rates observed for patients with the highest levels of measured medication adherence as compared to those with lower adherence for diabetes, hypertension, hypercholesterolemia, and congestive heart failure.<sup>271,279</sup>

#### Type 2 Diabetes

Better medication adherence has also been associated with improved glycemic control, specifically, reductions in HbA1C levels, in several empirical studies.<sup>280-285</sup> Existing literature also provides compelling evidence of an inverse relationship between medication adherence and hospitalizations or emergency department visits for patients prescribed medication for diabetes.<sup>271,286-292</sup>

Reduction in diabetes complications have been associated with increased adherence; however, there is a relative dearth of literature available estimating the effect of adherence on such outcomes compared to studies exploring other aspects of adherence.<sup>293,294</sup> Patients with worse intermediate health outcomes are more likely to increase adherence over time. Due to this and other factors contributing to the complex nature of the interaction between time-varying adherence and intermediate variables, conventional models are widely considered inappropriate and may explain the relative scarcity of evidence for these associations.<sup>294</sup> A retrospective longitudinal cohort study of type 2 diabetes patients in the California Medicaid claims database examined the effect of adherence on the risk of complications of diabetes using longitudinal marginal structural models that accounted for time-varying confounding, the results of which found that hypoglycemic adherence significantly reduced the risk of microvascular complications among diabetic patients (hazard ratio=0.73).<sup>294</sup> Adherent oral antidiabetic users have also shown a lower likelihood of developing ulcers, retinopathy, acute myocardial infarction, neuropathy, and amputations over shorter follow-up periods (18 months).<sup>293</sup> Startling evidence also shows the effect of Medication Possession Ratio (MPR) on mortality across races/ethnicities.<sup>295</sup>

As with hypertension, existing literature also establishes an association between medication adherence and overall medical costs for diabetes.<sup>225,280,292,296</sup> By comparing health care costs across adherence quintiles, an observational retrospective cohort study in the United States in 2005 estimated net savings per patient for a 20% increase in drug utilization of \$1,074, or an average return on investment of seven to one.<sup>271</sup> This evidence is tied to the "offset" effect often cited as a rationale for higher drug costs, which posits that higher prescription drug costs will be offset by other costs ultimately being lower (e.g., crisis-oriented care such as emergency room visits and inpatient hospitalizations).<sup>271</sup>

### Prevalence of Medication Adherence in Hypertension and Type 2 Diabetes

Current evidence suggests that as many as 50% of hypertension patients end treatment within the first year following diagnosis.<sup>297</sup> Moreover, of the remaining patients who continue treatment, only 50% to 80% take their prescribed medication.<sup>298</sup> General estimates of hypertension treatment adherence range similarly from 50% to 80%, depending upon the study design, sample population, and methods for measuring and determining adherence.<sup>299-304</sup> While adherence rates differ for newly diagnosed patients versus those with longer hypertension durations, it is estimated that between 16% to 50% of all hypertensive patients stop taking their medication within the first year of diagnosis and missed doses are commonly reported among those who continue medication beyond the first year.<sup>305,306</sup>

Type 2 diabetes medication adherence rates are similarly estimated and range from 70% to 80%.<sup>225</sup> A study of Medicaid-funded patients in the United States measured drug therapy adherence among patients with type 2 diabetes using pharmacy records and found that patients had an average of 130 days of continuous drug therapy per year. Additionally, after one year of study, only 15% of patients were persistent with filling prescribed single oral medication.<sup>307</sup>

The extent of medication non-adherence in low- and middle-income countries is expected to be higher than in developed countries due to factors such as greater barriers to health care access and lack of health resources, which have both been found to increase the impact of nonadherence and overall health outcomes.<sup>225</sup> While not extensively reported on, medication adherence among hypertensive Lebanese patients has previously been identified as a challenge to adequate disease control.<sup>308,309</sup> Medication adherence has not been widely studied among refugee populations, particularly adherence to chronic disease medications. While some studies have explored general medication adherence in refugee populations, the focus has largely been on antiretroviral therapy and tuberculosis medication in more traditional camp-based displacement settings.<sup>310-315</sup> A limited number of published studies assessed access to medications in conflictaffected, weak, and "disrupted" states; however, such studies examine only access and lack substantive evidence or discussion regarding the implications of access on medication adherence.<sup>316,317</sup> Furthermore, most of the settings in which research has been conducted are not necessarily comparable to the Lebanese context. Lebanon is still recovering from the end of its own civil war in 1990, but the health care system and infrastructure are quite good compared to other studied "disrupted" states.

Recent research on antihypertensive medication among Palestinian populations in the West Bank and Jordan may provide insight into utilization and adherence trends in populations facing circumstances similar to those of Syrian refugees in Lebanon. Hypertensive patients in the West Bank showed overall poor adherence to antihypertensive medication in a 2014 crosssectional survey in which only 16.9% of sampled patients had high adherence, while 28.9% had medium adherence and 54.2% had poor adherence (according to MMAS scores).<sup>318</sup> A study of antihypertensive medication utilization trends among Palestinians in Jordan from 2008 to 2012 showed that hypertensive patients persistently used at least two antihypertensive medications daily with significant differences in utilization by type of antihypertensive drug.<sup>319</sup> While not reported in the study, these differences may be reflective of variations in supply availability of certain drugs over others.

# **Determinants of Medication Adherence**

Medication adherence is complex, and the outcome is affected by the patient, condition, and cost of care. Though little empirical evidence is available from middle-income countries and even less from low-income countries, determinants of medication adherence (or non-adherence) among hypertensive and diabetic patients are well-researched in the developed world. While many determinants are similar between hypertensive and diabetic patients, the complexity of these conditions leads to various condition-specific determinants of adherence. Broadly, medication adherence determinants can be organized into patient characteristics, condition and regimen factors, patient/provider interaction, and health system-related factors.

#### Patient Characteristics

The most prominent patient characteristic determinants of medication adherence in hypertensive and diabetic patients examined in existing literature include age, sex, social support, and race/ethnicity, as well as patient behaviors, health beliefs, and health literacy. Evidence for the relationship between age and adherence among diabetic and hypertensive patients has been mixed, though declining memory, often a key component of treatment adherence among older populations, was found to be a key predictor of adherence in both diabetes and hypertension.<sup>289,293,309,320-326</sup> Evidence of the association between sex and medication adherence among diabetic and hypertensive patients are similarly diverse, though the inconsistency of these associations may be due to several factors from potential confounders or effect modifiers to differences in context.<sup>321-323,325,327,328</sup> Lower education levels were found to have a negative association with adherence to diabetes medications in numerous contexts.<sup>323,329</sup> Social support, including family structures and community networks, is positively associated with medication adherence among patients with type 2 diabetes, particularly with regard to support of family members.<sup>330,331</sup> While this relationship has not been assessed for the Lebanese or Syrian contexts, the strong, albeit complex, role of family in everyday life in these populations warrants exploration of the relationship.

Unlike the conflicting associations observed between age/sex and adherence, research has consistently shown a relationship between race and/or ethnicity and adherence to medication, particularly so among diabetic patients.<sup>332-335</sup> The effect of financial stress on adherence in previous studies reveals significant differences between racial and ethnic groups in patients taking less diabetes medication than prescribed because of cost.<sup>336</sup> Interestingly, study findings show that despite similarly low annual incomes among Vietnamese and Mexican American patients, Mexican Americans reported not only more cost-related medication non-adherence, but also more financial barriers to medical care and more perceived burden of their diabetes when compared to both Vietnamese and white patients, indicating that changes to medication cost or insurance coverage may not mitigate adherence barriers related to patients' perceptions and beliefs about financial burdens. Differences in associated adherence rates by ethnic minority groups, in addition to regional and urban/rural differences indicate a need to explore contextual factors

influencing adherence and to evaluate determinants of adherence specific to the context and population(s) in which intervention is intended.<sup>323,335,337-341</sup>

Patient behaviors related to known risk factors for hypertension have been strongly associated with adherence to antihypertensive medication regimens in several studies. Smoking has shown a negative association with adherence to antihypertensive medications and a recent study of medication adherence in Lebanese hypertensive patients found that not only is smoking related to medication nonadherence, but the number of cigarettes per day and the duration of cigarette smoking were also negatively associated with medication adherence.<sup>308,321</sup> The same study found a statistically significant association between adding salt to food and decreased adherence to antihypertensive medication and, as logically follows, a significant increase in adherence for patients following a recommended diet.<sup>308</sup>

In addition to patient health behaviors, health beliefs held by patients also influence medication adherence for both hypertension and type 2 diabetes in many ways. Low perceived need for medication is strongly associated with low medication adherence in many chronic health conditions including hypertension and type 2 diabetes.<sup>214,280,342-345</sup> In a cross-sectional study of patients with chronic diseases, beliefs about medications were found to be stronger predictors of adherence than sociodemographic characteristics and clinic factors.<sup>214</sup> The beliefs in the aforementioned study included: disease belief ("I have diabetes only when the glucose is high"), necessity related medication belief (not taking medicines when sugar is normal), concerns related medication belief (worrying about side-effects), regimen complexity beliefs (reporting medicines were hard to take), and, self-efficacy (confidence in controlling their diabetes or more generally, confidence in controlling future health).<sup>344</sup> Moreover, specific medication and condition-related beliefs were also predictive of poor adherence in the adjusted analysis of a cross-sectional study of patients with diabetes in the U.S.<sup>344</sup> Diabetes fatalism, defined as "a complex psychological

cycle characterized by perceptions of despair, hopelessness, and powerlessness," is also predictive of poor medication adherence.<sup>345-348</sup> Early studies found a significant association between diabetes fatalism and patient self-care, poor glycemic control, and decreased quality of life; a direct association between increased diabetes fatalism and decreased medication adherence (as measured using the MMAS), after adjusting for diet, exercise, blood sugar testing, foot care, and diabetes knowledge has also been reported.<sup>346,347</sup>

In the Lebanese context specifically, hypertensive patients' health literacy was shown to influence adherence to antihypertensive medications. Specifically, patient knowledge in terms of understanding not only how to take prescribed medication, but also of their disease (measured as knowing the normal blood pressure range) were both significantly associated with higher medication adherence in bivariate analysis. In logistic regression analysis of the same study, patients who knew the normal blood pressure range were nearly five times more adherent than those who did not know the normal range (odds ratio=4.9).<sup>308</sup>

### Condition and Regimen Factors

Beyond patient characteristics, factors related to the condition and medication regimens are also associated with medication adherence. Among diabetics, treatment intensification by adding another drug and/or with dose increases are predictive of decreased adherence.<sup>349</sup> Concurrent medication use has shown mixed results with both positive and negative association with medication adherence in a number of other studies of diabetic patients, though most often, the association has been negative.<sup>325,350-353</sup> Lebanese hypertensive patients taking any over-thecounter medication showed significantly lower adherence than those not taking over-the-counter medications, supporting some of the previously cited evidence on concurrent medication use.<sup>308</sup> In addition to use of multiple medications, the complexity of medication regimens negatively impacts adherence to chronic disease medication. Overall, patients adhere better to once-daily medications, reportedly because they find it more convenient and easier to manage with daily activities.<sup>280,354</sup> As such, simplified drug regimens in which unnecessary medication is omitted, whether by reducing the number of pills per day and/or dose frequency, has been found to improve adherence, often through use of fixed dose combinations.<sup>355-357</sup>

Specific drug classes are related to adherence as well, though the results of these studies are mixed. With regard to hypertensive patients, Lebanese patients taking beta blockers as an antihypertensive medication were found to have reduced adherence rates compared to those taking combination drugs and those taking calcium channel blockers (CCB) were approximately three times more adherent than those taking other types of medication.<sup>308</sup> The authors speculate that this association may be due to the fact that CCBs are generally prescribed for patients with higher blood pressure levels or those at higher risk of coronary disease, diabetes, indicating more advanced conditions or comorbidities that further the perceived importance of adhering to prescribed medication.

Given the dearth of evidence in low- and middle-income countries and even greater absence of evidence from conflict settings results from studies in the United States provide some insight into potential determinants of medication adherence. For example, while a 1999 study of U.S. Medicare beneficiaries showed that the *highest* annual fill rates (the annual number of fills per drug class per year) were for metformin and sulfonylureas (annual fill rate=8.3) compared with newer drug classes (thiazolidinediones, meglitinides, and  $\alpha$ -glucosidase inhibitors; annual fill rate=5.8), a 2008 study of Texas Medicaid recipients reported the *lowest* mean MPR (79.7%) to be for metformin when compared to other monotherapy drugs (84.4%).<sup>358,359</sup> Adverse effects also strongly influence medication adherence. Studies in various contexts have shown lower adherence among both diabetic and hypertensive patients when medications were not tolerated or side effects were experienced.<sup>280,309,360,361</sup> In addition to adverse events experienced for currently prescribed regimens, poor past medication experience can negatively influence adherence to currently prescribed regimens.<sup>362</sup>

Several factors associated with patients' conditions have been found to influence adherence. Shorter duration of diabetes and the presence of fewer diabetes complications are negatively associated with medication adherence; however, these associations may be more related to multicollinearity between higher numbers of complications, disease duration, and adherence than to the direct association between complications and medication adherence.<sup>324,363</sup> The association between comorbidities and adherence to hypertension or diabetes medications are widely studied, though results are inconsistent with regard to the nature of this association across comorbid conditions.<sup>280,325,351,364,365</sup>

### Patient/Provider Interaction

It is commonly believed that patients who have an ongoing relationship with a provider will be more likely to understand their condition, the necessity and effectiveness of prescribed therapy(ies), and the importance of adherence to prescribed therapy. Lower continuity of care has been associated with poor adherence to medication among people with type 2 diabetes.<sup>366-368</sup> Evidence of this association is somewhat limited for hypertensive patients; however, qualitative research in Greece found that "good communication and a rewarding behavior of the physician" facilitated adherence.<sup>369</sup> The association between patient-provider relationship and medication adherence has also been shown in a number of studies in a variety of countries and contexts including a 2015 cross-sectional study of hypertensive patients in Saudi Arabia that found more

than two times higher odds of antihypertensive medication adherence for patients reporting a good relationship with their provider after adjusting for demographic and disease characteristics such as gender, age, marital status, education and employment status, smoking, income, time since diagnosis, and comorbidities.<sup>370,371</sup>

The patient-provider relationship is also important in treatment adherence even in the absence of continuity of provider care. Evidence supports the importance of providers engaging patients in their treatment plan and involving patients in the decision-making process rather than just counseling about selected medication. A 2002 study of patients seen at four U.S. Veterans' Affairs outpatient clinics found that patients more actively involved in their treatment decisions reported significantly higher hypertension medication compliance.<sup>372</sup> Such engagement not only gives patients a sense of ownership of their treatment but also further educates them beyond standard counseling often provided by physicians when prescribing medication, relating to the association between patient beliefs and medication adherence previously discussed.<sup>309,373-378</sup>

# Health System-Related Factors

Economic factors have been strongly associated with adherence to prescribed medication among patients with diabetes in high-, middle-, and low-income countries alike. Many studies in the United States aiming to identify predictors of non-adherence report cost or other financial concerns as a factor, if not a central barrier, to non-adherence.<sup>293,324,379-381</sup> For example, a 2012 study of patients seen at community-based primary care practices in the U.S. showed a significant inverse relationship between antihypertensive medication adherence and cost-related adherence burden. In their 2004 study on cost-related medication underuse among chronically ill adults in the U.S., Piette et al. found that after adjusting for age, race, gender, education level, income, number of prescriptions, and prescription coverage, patients with monthly hypertension prescription costs between US\$51 and US\$99 had 2.0 times higher odds of cost-related underuse compared to those with monthly out-of-pocket prescription cost of US\$50 and under; monthly prescription costs of US\$100 or more were associated with 4.6 times higher adjusted odds of cost-related underuse compared to monthly out-of-pocket prescription costs of US\$50 and under.<sup>382</sup> The association between monthly prescription costs and cost-related medication underuse were not statistically significant among diabetic patients in the same study; however, when adjusted for all covariates in the primary model except monthly out-of-pocket prescription costs, diabetes patients with no prescription coverage had statistically significantly higher odds (odds ratio = 2.3) of cost-related underuse than diabetic patients with prescription coverage.<sup>382</sup>

Significant changes in adherence have previously been observed among type 2 diabetes patients with differing co-payment amounts.<sup>289,293,383-386</sup> Colombi et al.'s 2008 study on the effect of copayments on adherence to oral diabetes medication found a statistically significant decrease in adherence prevalence with increased copayment amounts.<sup>289</sup> Similar findings were supported by Gibson et al.'s 2010 study that found decreased adherence with increased levels of prescription drug cost sharing (measured using a cost-sharing index). Smaller, though still significant decreases in adherence were also associated with higher cost sharing for physician visits in this study.<sup>293</sup> Countless studies of type 2 diabetics in low- and middle-income countries cite cost as the main factor related to non-adherence of prescribed medication; however, this presumption did not stand upon analysis in a study of Lebanese patients with chronic health conditions in which neither drug cost per patient, nor the presence of medical insurance were predictive of adherence.<sup>322,387,388</sup> This null finding supports results from previous literature in which drug cost is less predictive of medication adherence than other criteria; however, conflicting results have been reported in previous studies of type 2 diabetes medication adherence

wherein increased medication costs were negatively associated with adherence, indicating a complex and likely context-specific relationship between costs and adherence.<sup>214,293,309,322,375,388,389</sup>

In addition to cost factors, numerous other health system factors have previously shown association with adherence. Though not specific to diabetes or hypertension treatments, low accessibility of health services, long provider wait times, and difficulty obtaining prescriptions have previously shown association with poor medication adherence.<sup>390-396</sup> Increased distance to the nearest pharmacy was inversely associated with compliance to therapy for type 2 diabetes and evidence in various settings indicates a similar relationship among patients with hypertension.<sup>362,371,397</sup> Low patient satisfaction with the care they received or with past clinic visit experience(s) has also been associated with poor medication adherence, though not specific to diabetes or hypertension treatments.<sup>394,398-400</sup> Individual clinic-level variation in adherence to oral hypoglycemic agents observed in a 2012 study of patients with diabetes treated in U.S. Department of Veterans Affairs primary health care clinics indicate the potential for an association between additional facility-level factors and adherence.<sup>401</sup>

# **Chapter 4. Methodology**

## 4.1. Conceptual Framework

This study and its analytic strategy are guided by a conceptual framework of the association between patient, environment, and provider characteristics; individual health behaviors; and condition-related outcomes (Figure 4-1). The framework derives from Andersen and colleague's behavioral model of health services utilization.<sup>402,403</sup> That model has been elaborated since its conception in the 1960s. This study uses the fourth formal version of the behavioral model (1995), which combines individual level characteristics with health care system factors, personal health behaviors, health status outcomes, and, uniquely, the "dynamic and recursive nature" of the use of health services through various feedback loops.<sup>402,403</sup> The behavioral model classifies individual and contextual determinants of health service utilization as predisposing, enabling, or need characteristics. *Predisposing* factors for care utilization include demographic/biological features, psychosocial elements, or health beliefs that incline an individual's use of health services. *Enabling* characteristics such as income/socioeconomic status, competing demands, and access to information either facilitate or hinder a person's ability to use services given their predisposition. Need-related characteristics indicate the level of either measured or perceived conditions requiring care. These factors are understood to influence individuals' health behaviors (e.g., health service utilization and treatment adherence), which ultimately affect health-related outcomes (e.g., condition control, satisfaction with services, etc.).

Upon the foundation of Andersen's behavioral model, this study's framework was adapted to reflect: (i) the Syrian refugee displacement context in Lebanon, (ii) the study's specific focus on hypertension and type 2 diabetes, and (iii) medication adherence as an additional outcome of interest. Adaptations included the addition of specific determinants of care utilization and medication adherence identified in Brown et al.'s 2004 framework on socioeconomic position and health among persons with diabetes mellitus, in addition to several other commonly cited models for health care utilization and literature referenced in the previous chapter.<sup>141,172,402-<sup>405</sup> These factors were then classified based upon Andersen's model as predisposing, enabling, and need-focused. Additional variables are also included to account for environmental (including health system) and provider-related determinants based upon evidence identified in the literature review.</sup>

The content of this research focuses on the relationship between selected predisposing and enabling factors in this framework (including structural, patient, and disease factors) and individual health behaviors, namely health care utilization and medication adherence.

#### 4.2. Overview

As outlined in Chapter 1, the aims of this dissertation are to assess healthcare utilization and medication adherence for hypertension and type 2 diabetes among Syrian refugees and host communities in Lebanon, and to identify factors associated with care-seeking and medication adherence for these conditions among refugees. Two primary data sources were used for this research:

1. A population level survey of health access and utilization conducted in Lebanon in 2015

Survey data were used in Paper 1 to assess care-seeking and medication adherence at the population level among a representative sample of Syrian refugees and affected host communities in accessible areas throughout Lebanon. 2. Baseline data from a longitudinal cohort study

Collected in 2015, these baseline data are used in Papers 2 and 3 to examine healthcare utilization and medication adherence in greater depth among careseekers at select primary level health facilities, excluding questions about initial contact with the health system.

When combined, these data provide multifaceted information about healthcare utilization and medication adherence. A visual overview of the organization of the three papers' data sources, sample populations, and outcomes of interest is provided in Figure 4-2.

# 4.3. Paper 1

Paper 1 characterizes care-seeking, health service utilization, and adherence to medication for hypertension and diabetes among Syrian refugees and host communities in Lebanon at the population level and explores household level determinants of care-seeking and medication adherence for these conditions among Syrian refugees.

# **Data Source**

Paper 1 utilized data from the *Household Survey of Syrian Refugee Health Status and Access to Care in Lebanon.* This survey was conducted in March and April 2015 to characterize overall health-seeking behaviors and health service access. A total of 1,376 refugee and 686 host community households were surveyed using a cluster design with probability proportional to size sampling. Data are representative of Syrian refugees and affected host communities in accessible areas throughout Lebanon. Sampling, design, and implementation methods for this survey are published elsewhere and provided in Appendix A for ease of reference.<sup>73,116,406,407</sup>

# **Analytical Methods**

Exploratory data analyses were conducted to investigate the extent of missingness and distribution of variables to be included in analyses, incorporating visual displays and diagnostic assessment to determine the appropriateness of analytical techniques. Care utilization, out-of-pocket spending, and medication prescription and use were assessed using descriptive statistics and standard methods for comparison of means and proportions. Differences in household characteristics by population group, care-seeking, and interrupted medication adherence classification were examined using Pearson's chi-square and t-test methods. *P*-values and 95% confidence intervals were obtained from the data, accounting for survey cluster effects. Finally, logistic regression was performed to estimate the crude and adjusted odds of care-seeking and interrupted medication adherence among Syrian refugees and the nature of their relationship with relevant measured characteristics.

# 4.4. Paper 2

Paper 2 focuses on care utilization for hypertension and type 2 diabetes among Syrian refugees and host community members receiving care at select primary health facilities in Lebanon and investigates both clinical and demographic factors associated with utilization of health services.

# **Data Source**

For this paper, baseline data from the *Treatment Guidelines for Hypertension and Type 2 Diabetes in Syrian Refugees and Host Communities in Lebanon* study were utilized. Parent study interventions, objectives, and longitudinal methods are published elsewhere and provided in Appendix B for ease of reference.<sup>408,409</sup>

### Participants and Sample Methods

Study participants consisted of Syrian refugee, Lebanese, and in smaller number, Iraqi and Armenian care-seekers at ten primary health facilities in Lebanon supported by the International Organization for Migration (IOM) and International Medical Corps (IMC) in the South, Bekaa, Beirut, and Mount Lebanon governorates (Figure 4-3). Individuals without a hypertension or type 2 diabetes diagnosis, those less than 40 years of age, and adults lacking the capacity to independently participate in interviews were excluded from the study.

The planned sample size for the parent study was based on the estimated existing caseload and projected newly diagnosed cases for each participating health facility. The total estimated caseload, anticipated proportions that could be reached by phone (estimated at 80%) and that would consent to participate (estimated at 80%), as well as the planned and maximum sample sizes to be enrolled from each health facility are presented in Table 4-1. The final enrolled sample size is presented by population group and diagnosed condition in Table 4-2.

Potential participants were recruited using lists of diabetes and hypertension patients who visited each health facility within six months prior to the start of study enrollment. Study facilities submitted updated patient lists to IOM for study recruitment weekly through the end of the enrollment period, concluding after the first longitudinal study intervention was implemented in that facility. Interviewers called patients identified on these lists using the primary contact number provided and began by reading a brief script introducing the reason for the call and providing information about the study and the patient's rights to decline participation. During this call, informed consent was obtained by interviewers trained in human subjects research and data collection practices, including the data collection tools to be used for the study. Of the 2,295 individuals contacted to participate in the study, 21.6% (n=498) provided an incorrect phone number, 25.7% (n=592) were unavailable or unable to be reached by phone, 3.9% (n=89) did not

meet study criteria, 4.5% (n=104) refused to participate, and 0.1% (n=2) were deceased since the recorded care visit. A total of 1,010 patients (43.8%) were enrolled in the study, including 637 Syrian refugees (63.1%), 330 Lebanese (32.6%), and 43 individuals of other nationalities (4.3%).

# Data Collection

This study was designed using a mixed method approach utilizing both qualitative and quantitative data collection methods.

# Quantitative Data Collection

<u>Health facility assessments</u> were performed at the start of the study to collect information about available equipment, drug supplies, and facility conditions. Facility assessments also included observation of the physical space, and documentation of the numbers of providers by type, facility operating hours, record-keeping practices, availability of equipment for diagnosis and management of hypertension and diabetes, as well as recent inventory and dispensing of medicines for these conditions.

<u>Enrollment interviews</u> were conducted with every patient. In addition to providing consent for study participation, key indicators collected through these structured phone interviews included patient demographic and migration information; medical history and recent care seeking behaviors; and knowledge, attitudes, and practices related to diabetes and/or hypertension.

<u>Medical record reviews</u> were conducted for each patient following enrollment. Key indicators included in record reviews related to provider compliance with guidelines and quality of care, frequency of patient visits, and both generic (death and loss to follow-up) and diseasespecific (complications and adverse events of hypertension and diabetes) patient outcomes. All patient interviews were conducted by phone to ensure confidentiality and reduce the gratuity bias of interviews performed at health facilities. All data were collected on tablets using the Magpi mobile data platform by DataDyne LLC (Washington, DC).

#### Qualitative Data Collection

In addition to quantitative data collected via phone interviews, a total of 19 focus group discussions (FGDs) were conducted with Syrian refugees and Lebanese host community patients enrolled in the study, as well as health care providers working at study health facilities. Interview content focused on care-seeking and medication adherence, providing a more nuanced understanding of barriers to care, as well as treatment and medication adherence from both patient and provider perspectives. Two key informant interviews (KIIs) were also conducted with staff from humanitarian organizations providing services or programming for NCDs among Syrian refugees in Lebanon.

Qualitative data collection was conducted by local IOM staff with one note-taker and one interviewer at each FGD. Oral informed consent was obtained from each participant before initiating the group discussion. FGDs were facilitated using semi-structured interview guides and lasted between 30 and 90 minutes, depending on time participants had available and interest in participation.

Separate focus group discussions were conducted for Syrian refugees and Lebanese host community members in each geographic region. Groups were then further separated based upon whether care was sought for hypertension and/or type 2 diabetes in the six months prior to data collection. Table 4-3 presents the number of FGD participants by location and participant group.

Focus groups were recorded to allow facilitators to more fully engage without compromising documentation. Following each discussion, the facilitator and note-taker discussed participants' contributions, interactions within the group, and how group composition or other factors may have influenced participants' responses. Detailed notes were typed using recordings to expand upon notes taken during focus groups, then reviewed by data collection team members. FGD facilitators also debriefed with the Johns Hopkins Bloomberg School of Public Health (JHSPH) field coordinator throughout data collection to discuss questions, concerns, challenges faced, strengths, and weaknesses of each discussion.

FGD summaries and field notes were analyzed using content analysis methods to identify key themes, consensus viewpoints, and viewpoints of a minority within groups, in addition to views that were unique to particular contexts or locations. FGD notes were analyzed separately for each participant group, after which findings were analyzed across groups to examine common themes further.

# Preliminary Data Cleaning

A sequenced process-based classification used patient records, clinical data, and prescriptions to assign a uniform diagnosis category to patients in cases where reporting was inconsistent across data sources. Eight patients remained with an unclassified diagnosis and were subsequently dropped from analyses to ensure reliable reporting by condition. A similar process was used to classify population group (i.e., Syrian refugee, Lebanese host community, or other) among participants with conflicting reports across data sources; all participants were successfully classified.

# **Limitations**

Restricting the study sample to individuals seeking care at study health facilities, while necessary for the main study objectives, is a limitation of this research in that it limits representativeness to a small subset of the population of Syrian refugees and host communities in Lebanon who sought care in these locations. The prevalence of hypertension and type 2 diabetes is likely to be much higher in the community than only those recruited for the study without additional screening of the general population, and persons getting care from private clinics, pharmacies, or Syrian doctors practicing within the refugee community may well have different findings. As such, results are not necessarily applicable to all individuals with hypertension and/or diabetes who are not receiving care or who receive care at different types of health facilities or in other geographic areas of Lebanon. This is limiting because outcomes among patients not receiving care could be presumed to be far worse than in those receiving some level of care; however, results from this research can neither confirm nor preclude those assumptions.

### **Analytical Methods**

For paper 2, data were first explored to characterize the degree and nature of missing observations, to examine frequencies and distributions, and to assess multicollinearity. Differences in health service utilization between Syrian refugees and Lebanese host community patients were examined using Pearson's chi-square and Wilcoxon-Mann-Whitney test methods. An alpha of 0.05 was used for all hypothesis testing. Equidispersion in utilization outcome variables was assessed using the Lagrange Multiplier test, which identified overdispersion both in the number of visits to a general practitioner (GP) and in visits to a relevant specialist (endocrinologist and/or cardiologist).<sup>410</sup> To address the presence of excess zeros in the data, zero-inflated and hurdle models were compared to determine the most appropriate regression model to employ in analyses. Akaike (AIC) and Bayesian Information Criterion (BIC) values indicated a preference for negative binomial hurdle models in all utilization outcome variables. The data is believed to contain only sampling excess zeros, further supporting the use of hurdle rather than zero-inflated models. Regression analyses included only Syrian refugees due to insufficient host community sample size.

### 4.5. Paper 3

Paper 3 focuses on prescription and adherence to medication for hypertension and type 2 diabetes among Syrian refugees and host community primary care patients and examines individual and household level determinants of interrupted medication use among Syrian refugees.

### **Data Source**

As with Paper 2, analyses for Paper 3 utilized baseline data from the *Treatment Guidelines for Hypertension and Type 2 Diabetes in Syrian Refugees and Host Communities in Lebanon* study described in detail in the previous section.

# **Analytical Methods**

Exploratory data analyses for paper 3 included visual displays of the distribution of variables of interest and diagnostic assessment of the suitability of planned analytical techniques. Differences in participant characteristics by population group and interrupted medication adherence classification were then examined using Pearson's chi-square tests. Finally, logistic regression was performed to determine the crude and adjusted odds of interrupted medication adherence among Syrian refugees and the association between interrupted adherence and measured demographic and clinical characteristics. Variables included in the base model were selected using evidence from the literature and the conceptual framework described previously. Given the relatively small host community sample size, insufficient number of host community participants reporting interrupted medication adherence, and the distribution of covariates of interest, regression analyses included only Syrian refugees.
# 4.6. Ethical Considerations

The Syrian Refugee and Affected Host Community Health Access and Utilization Survey in Lebanon was approved by the Institutional Review Board at the American University of Beirut. The Johns Hopkins Bloomberg School of Public Health (JHSPH) Institutional Review Board also reviewed the protocol and determined that members of the JHSPH team were not involved in human subjects research because they did not have direct contact with participants or access to personal identifiers.

All interviewers received training in basic principles of human subjects' protection, as well as the informed consent processes and data collection practices for this study. To protect the anonymity of respondents, no information was recorded that could be used to identify the household or individual (including names, phone numbers, address, or other uniquely identifying characteristics). Interviewers obtained verbal informed consent from all participants by reading a consent form in Arabic outlining the purpose of the assessment, intended use of results, confidentiality, and the voluntary nature of participation. Potential respondents were informed that no identifying information would be recorded on the survey instrument or reported and that they had the right to decline to participate, stop the interview at any time, or to decline to answer any question. Potential respondents were also informed that the decision to take part or to refuse to take part would not influence their access to humanitarian assistance or protection. Interviewers were provided with information for participants on available services within the area and UNHCR registration in case this was requested.

The Treatment Guidelines for Hypertension and Type 2 Diabetes in Syrian Refugees and Host Communities in Lebanon study was approved by the Ministry of Public Health in Lebanon and Institutional Review Board at The Johns Hopkins Bloomberg School of Public Health. During the study, all interviews with patients were conducted over the phone.

Eligible patients identified for enrollment were called by interviewers, who read a brief consent script providing information about the study, expectations for contact with enrolled participants, and the patient's rights to decline participation. During this call, informed consent was obtained by interviewers (study staff) trained in human subjects research, informed consent processes, and data collection practices, including the data collection tools to be used for the study. Participants were also asked to go to a location where they are comfortable to complete each interview; participants were given the option of a call back at a later time if they were unable to have the call in a location they deemed as sufficiently private and conducive to completing the interview.

Health Facility	Current Caseload	New Cases*	Estimated Total Cases	# estimated to be reachable <sup>†</sup>	Estimated Sample <sup>‡</sup>		
IOM Supported Facilities							
Tyre	123	74	197	158	142		
Msayleh	193	116	309	247	223		
Nabatiyeh	140	84	224	179	161		
Bar Elias	N/A	N/A	125	100	90		
Taalabaya	16	18	34	27	25		
IMC Supported Facilities							
Saadnayel	324		324	259	233		
Tayouneh	183	<b>N</b> T (	183	146	132		
Fanar	50	Not applicable	50	40	36		
Mrayje	72		72	58	52		
Karagheusian	715		715	572	515		
Maximum Planned Sar	mple				1,609		

Table 4-1. Treatment Guidelines Study Sample Size and Power Calculations

\*estimated by taking 10% of the current caseload as newly identified cases monthly and extrapolating this out for a 6-month period during Phase 1; and <sup>†</sup>80% of the estimated cases; and <sup>‡</sup>estimated at 90% of the reachable cases

	Hypertension Only	Type 2 Diabetes Only	Hypertension & Type 2 Diabetes	Total
Syrian Refugees	325	85	227	637
Lebanese	129	35	166	330
Other Nationality	16	6	21	43
Total	470	126	414	1,010

 Table 4-2. Final Treatment Guidelines Study Sample by Population Group and Diagnosed Condition(s)

Participant Type	Beirut/Mt. Lebanon	Bekaa	South	Total
Health Care Providers				
Physicians	2	3	6	11
Nurses	3	4	4	11
Pharmacists	0	0	2	2
Total Provider FGD Sample	5	7	12	24
Patients				
Syrian Refugees				
Recently sought care	11	9	3	23
Did not recently seek care	12	8	8	28
Lebanese Host Community				
Recently sought care	8	3	2	13
Did not recently seek care	4	3	4	11
Total Patient FGD Sample	35	23	17	75

Table 4-3. Focus Group Discussion Participants by Location and Participant Group

13, and fically Juwwines		(professional & ion, & testing equipment	<ul> <li>Health Outcomes</li> </ul>	Intermediate: • <i>Glycemic control</i> • <i>Blood pressure control</i> • <i>Perceived health</i> • <i>Satisfaction with care</i> <u>Long-Term:</u> • Comorbidities • Retinopathy • Nephropathy • Nephropathy • Neuropathy • Neuropathy • Neuropathy • Neuropathy • Prevatable hospitalization • Increased health costs	-	
NIIIG, 11 CAUIICIIL DUIIAVIO	Health Care System	ailability of health care providers aprofessional), services, medicat at of services	→ Health Behavior ←	Use of Health Services• Primary care visits• Specialist care visits• HospitalizationsTreatment Adherence• Medicationadherence• Self-monitoringLifestyle Behaviors• Diet• Physical activity• Alcohol consumption		
INII AIIN DIADUUS CAI C-DUC	Environment	anization & complexity • Available Avail	+	Need Perceived need Evaluated need • Disease severity • Symptom severity • Complications • Comorbidities		rs Type of provider / specialty
	_	<ul> <li>Health system org</li> <li>Facility hours &amp; a</li> <li>Wait time</li> </ul>	<b>Patient Characteristics</b>	Enabling Resources Resources Socioeconomic status Receipt of public benefits / assistance Insurance Insurance Competing demands (incl. housing stability (incl. housing stability (incl. housing stability (incl. housing stability information Social networks & support Relationship with provider(s)	↔	Provider-Related Factor
rigure 7-1. Conceptual FI	External Environment	<ul> <li>Distance to health facility</li> <li>Transportation access &amp; cos</li> </ul>		Predisposing CharacteristicsDemographic• Age• Age• Sex• Marital status• Education• Education• Ethnicity/nationalityCondition & regimen• Regimen complexityHealth beliefs• Disease duration• Pisease knowledgePsychosocial• Emotional distress & fea		• Sex • Adherence

Figure 4.1. Conceptual Framework for Hypertension and Diabetes Care-Seeking. Treatment Behaviors. and Health Outcomes

Adapted from Andersen and colleague's behavioral model of health services utilization (1995) and Brown et al. (2004). Variables included in dissertation analyses indicated in **bold**; variables measured but lacking sufficient quality/completeness for analysis indicated in *italics*.

# Figure 4-2. Organization of Dissertation Papers by Sample Population, Data Source, and Outcomes of Interest



Figure 4-3. Treatment Guidelines Study Facilities by Geographic Area



# Chapter 5. Care-Seeking, Health Service Utilization, and Adherence to Medication for Hypertension and Diabetes Among Syrian Refugees and Affected Host Communities in Lebanon (Paper 1)

# 5.1. Abstract

**Background.** The inflow of Syrian refugees into Lebanon since 2011 has generated an immense demand on Lebanon's health system. The burden of non-communicable diseases among both Syrian refugees and the Lebanese host community, the high cost of providing continuous care, and complex comingling of barriers to adequate monitoring and drug treatment adherence have implications for meeting both populations' health needs.

**Methods.** In consideration of these challenges, this study uses data from a survey of Syrian refugees and Lebanese host communities conducted in early 2015 to characterize careseeking, health service utilization and spending, and medication prescribing and adherence for hypertension and diabetes. A total of 1,376 refugee and 686 host community households were surveyed using cluster design with probability proportional to size sampling.

**Results.** Results identified significant gaps between refugees and host community members in care-seeking, health facility utilization, out-of-pocket payments for care, and medication interruption. While host community cases had better access to care and fewer reports of medication interruption compared to refugees, out-of-pocket spending for the most recent care visit was significantly higher among host community care-seekers. Refugee care-seekers most frequently received care at primary health facilities, choosing to do so mainly for reasons related to cost, whereas host community care-seekers predominantly utilized private clinics with more concern for quality of care.

**Conclusions.** Further efforts are needed to facilitate lower and more predictable health service costs for refugees and vulnerable host community members, as is continued

communication on how to access subsidized care. Expansion of new financing models, such as the flat fee model and incorporating facility-side support to meet demand may reduce the gaps between need and care-seeking practices in both refugees and host Lebanese and ensure sustainable, high-quality care for both populations.

# **5.2. Introduction**

More than one million Syrian refugees have entered Lebanon since the start of the Syrian crisis, making it host to the highest number of refugees per capita worldwide.<sup>2,94</sup> Contrary to the traditional model of providing refugee health care through a separate, parallel system, refugee care is instead integrated into the Lebanese health system through existing health facilities.<sup>88,97,411,412</sup> The impact of this approach has been a considerable strain on the country's health system, particularly given the high prevalence of chronic non-communicable diseases (NCDs) in both Lebanese and Syrian populations.<sup>93,413</sup>

Through the joint Non-Communicable Disease Program (NCDP) with the World Health Organization (WHO) and the associated National Program on Controlling Diabetes, the network of health facilities regulated and supported by the Lebanese Ministry of Public Health (MoPH) are mandated to offer a range of services for NCDs. These services include education, screening, regular monitoring, and provision of essential medicines. The NCDP further aims to establish links for financial coverage of episodic hospitalization among those with chronic health conditions, including for complications of hypertension and diabetes.<sup>81</sup> At the time in which this survey was conducted (2015), care was available for vulnerable Lebanese nationals for reduced costs at primary healthcare centers (PHCCs) in the MoPH National Network.<sup>88</sup> As of August 2015, Syrian refugees, including those registered with the United Nations High Commissioner for Refugees (UNHCR) and unregistered refugees, could utilize primary health services care at approximately 116 of the more than 1,200 existing PHCCs/dispensaries across the country for a subsidized fee of approximately US\$2 to US\$3 per visit.<sup>13,79,88,96-99</sup> Medication for chronic conditions is also provided to refugees at dispensaries throughout Lebanon for a handling fee of US\$0.67, and for free at more than 400 facilities through the Young Men's Christian Association (YMCA) chronic medications program, or, in some cases, through privately funded primary health care facilities.<sup>414,415</sup>

Refugees meeting eligibility criteria and having an appropriate referral from a primary health care facility, or presenting with a life-threatening condition, are also entitled to UNHCR coverage of treatment costs for secondary and tertiary care. Since July 2018, UNHCR has supported referral care in accordance with standardized fees based upon MoPH fixed rates: refugees pay the first US\$100, while UNHCR covers 75% of costs above US\$100. Beneficiary cost shares are capped at US\$800, with all excess costs covered by UNHCR. Prior to July 2018, in most eligible cases, UNHCR covered upwards of 75% of hospital costs dependent upon refugees' vulnerability classification, though refugee shares were not capped.<sup>37,416,417</sup> Hospital cases deemed ineligible for coverage are submitted to the Exceptional Care Committee for reconsideration based on financial need, necessity of care, and the cost of referred services. Even with this level of support, Lebanon's highly privatized health system often makes care for refugees comparably as expensive as it is for vulnerable Lebanese.<sup>80,93</sup> Alternative financing mechanisms such as a flat fee model, which would include bundled services for a nominal predetermined fee, are being explored, though they are in pilot or early phases of scale-up.<sup>418-420</sup>

For refugees and vulnerable host populations, even those receiving subsidized care, the burden of out-of-pocket payments can be sufficient to prevent them from receiving care. This barrier is substantial considering the increasing debt and strained financial situation of many refugee households.<sup>102</sup> Despite wide coverage of subsidized care, 39% of Syrian refugees in

Lebanon are reportedly not receiving needed medical care due to treatment and/or medication costs.<sup>103</sup> Furthermore, a recent (2014) survey of Syrian refugees in Lebanon reported that 56.1% of households had a member with an NCD who was unable to access medicine or other health services, increasing the patient's risk of complications in the long-term and the costs incurred for more specialized intervention.<sup>71</sup>

There is a paucity of research exploring care-seeking rates in the Lebanese population; rather, previous studies focus primarily on treatment rates, often defined according to use of antihypertensive or antidiabetic medication(s). A 2015 study of prevalence, awareness, treatment, and control of hypertension in Lebanon reported the overall treatment rate to be 48.9%; however, this does not necessarily translate to the proportion of individuals with hypertension receiving regular monitoring and care from a health professional. Comparable estimates are scarce for Lebanese with diabetes, though it is estimated that almost three-quarters of patients on medications for chronic conditions receive incomplete therapeutic and safety monitoring tests recommended by standard treatment guidelines. In this same study, less than half of participants reported visiting a physician at least every six months, and three percent reported having medication dispensed by a pharmacist without physician consultation.<sup>123</sup>

In addition to continuity of follow-up care, effective management of hypertension and type 2 diabetes most often require adherence to pharmacological intervention. Poor adherence to prescribed medication(s) is associated not only with poor health outcomes but also increased health costs long-term, predominantly for specialized care, hospitalization, and emergency room visits.<sup>225,227,267,268,280-285</sup> An occasional missed dose is not uncommon for chronic medical conditions; reduced adherence beyond that, however, risks avoidable morbidity, complications, disability, and ultimately premature death.<sup>225,271,274-278,280,286-292,296</sup>

In the absence of a gold standard adherence measure, the diversity of measures applied across studies hinder comparison of reported adherence rates.<sup>421</sup> Moreover, there is no established standard for ideal or acceptable population-level adherence prevalence that is empirically related to improved or worsened population health outcomes.<sup>421-424</sup> Non-adherence to medication prescribed for chronic conditions was most recently (2017) estimated at 62% in a review of studies in the Middle East; however, estimates upon which this figure is based vary from 1.4% to 83.3%, a range so wide that it demonstrates the limitation of cross-study applications of measurement methods and context-specific nuances.<sup>425</sup> Equivalent estimates among Lebanese with chronic health conditions, including hypertension and diabetes, are also varied, with 22% to 57% of participants reporting low/poor adherence.<sup>308,309</sup> The only identified published estimate for Syrian refugees' adherence to chronic disease medications reported that among beneficiaries in a 2018 evaluation of primary care NCD services offered by Médecins Sans Frontières (MSF) in Irbid, Jordan, 89% were classified as having high adherence (according to the Medication Adherence Report Scale).<sup>426</sup> Qualitative results in the MSF evaluation differ from this estimate as non-adherence was reported by many more beneficiaries in focus group discussions and was noted by project staff.

This paper describes and provides empiric evidence on care-seeking, health service utilization and spending, and medication prescribing and adherence for hypertension and diabetes by Syrian refugees and host communities in Lebanon.

### 5.3. Methods

# **Data Source**

A national survey of Syrian refugees and affected host communities in Lebanon was conducted in March and April 2015 to characterize health-seeking behaviors and health service access. Detailed survey methods are provided in Appendix A for ease of reference.

Sample size was determined for key objectives based on the most conservative prevalence estimate of 50%; calculations assumed 80% power and a design effect of 2.0. The planned sample was increased from the minimum identified size of 900 refugee households to 1,400 refugee households and 700 Lebanese host community households to improve precision.

Given the concentration of Syrian refugees and the low cost of visiting many locations due to the country's small size, a 100 cluster x 21 household (14 Syrian refugee households and seven host community households) design was used. Clusters were assigned to cadastrals (lowlevel administrative units) using probability proportional to size (PPS) sampling with UNHCR registration data, assuming that non-registered refugees had similar residence patterns. Permission to conduct the survey could not be obtained in 22 cadastrals, requiring reassignment of 28 clusters to accessible areas using PPS methods. The final sample distribution included 35 clusters (35%) in the North governorate, 34 clusters (34%) in Bekaa governorate, 25 clusters (25%) in Mount Lebanon governorate, four clusters (4%) in Beirut governorate, and 2 clusters (2%) in the South governorate (Figure 5-1). A representative sample from the South could not be obtained because only two cadastrals were accessible; due to violation of sampling assumptions, analyses exclude the South governorate. A total of 2,165 households were approached to participate. Of these, 1.9% were not home, 0.2% were previously interviewed, 0.05% was ineligible, and 2.7% refused to participate. The final sample included 2,062 households (1,376 Syrian refugee and 686 host Lebanese), equating to a response rate of 93.6%.

ARC GIS software was used to allocate cluster start points within cadastrals randomly; only coordinates in populated areas were used. The nearest intersection to each start point, usually within a half kilometer, served as the starting location to which teams navigated using mapping software such as Google Maps. At the start location, interviewer pairs were sent in different directions to locate households; they approached the nearest business likely to be used by refugees (or community residents if there were no shops) and asked to be referred to nearby Syrian households. Upon interview completion, respondents were asked for a referral to the nearest Syrian household; this referral process was used until 14 Syrian refugee interviews were completed. Following every two interviews with Syrian households, the nearest Lebanese household was identified and interviewed. To improve the representativeness and coverage of the sample, no more than three households within an apartment building were included.

When start points were in or near informal settlements, the settlement's size was estimated by walking transects and/or the perimeter; larger settlements were sub-divided and assigned to different interviewers. Interviewers located the middle of the settlement/area and walked in a randomly selected direction, counting the number of shelters before reaching the edge of the settlement/area. A randomly selected number between one and the total number of shelters passed was used to identify the starting household. Interval sampling was then used in place of referrals in informal settlements to reduce the potential for bias. Only Syrian households arriving in Lebanon in 2011 or later were eligible to participate, as the aim was to capture the experiences of those displaced by the conflict. Families with both Lebanese and Syrian members were considered refugees if they came from Syria in or after 2011. The questionnaire was initially developed for use in Jordan and subsequently adapted for the Lebanese context. The questionnaire focused on health service utilization, access and barriers to care, children's health, and chronic medical conditions. Interviewers received two days of classroom training that focused on the questionnaire, e-data collection, interview techniques, basic principles of human subjects' protections, and sampling followed by two additional days of field training. To protect the anonymity of respondents, no unique identifiers were recorded, and verbal consent was obtained. Interviews lasted between 30-60 minutes depending on the household size, number of children, and individuals with chronic medical conditions. Data was collected on tablets using the Magpi mobile data platform by DataDyne LLC (Washington, DC).

The study was approved by the Institutional Review Board at the American University of Beirut. The Johns Hopkins Bloomberg School of Public Health (JHSPH) Institutional Review Board also reviewed the protocol and determined that members of the JHSPH team were not involved in human subjects research because they did not have direct contact with participants or access to personal identifiers.

# Variables

The outcome variables of interested included care-seeking and medication adherence. Proper management of both hypertension and diabetes requires regular monitoring and health provider visits, which have been shown to have a positive association with health outcomes for both conditions (blood pressure and blood glucose), as well as secondary benefits including lower risk of hospitalization.<sup>110-115</sup> Care-seeking was assessed for household index cases of hypertension and diabetes based on a series of questions about their most recent care visit for the condition. Care-seeking was classified as a binary outcome, according to whether or not the most recent visit was within the six months preceding interview. Care-seeking was modeled in the preceding six months based upon the distribution of most recent care-seeking timing in the data and because it is the most conservative recommended follow-up interval for adults with elevated blood pressure according to the 2017 ACC/AHA guidelines for blood pressure management.<sup>105</sup> Adherence was assessed as a binary variable for index cases based on whether or not respondents reported having stopped medication for two weeks or more in the preceding year.

Explanatory variables included in analyses consisted primarily of household level characteristics and are detailed in Appendix C.

#### **Data Analysis**

Data were analyzed using Stata 13 (College Station, TX). Descriptive statistics and visual displays of explanatory and outcome variables were examined to identify the extent and patterns of missingness, distributions, and to determine the analytical strategy's appropriateness.

Differences in care utilization, out-of-pocket spending, and medication prescription and use by population group were examined using Pearson's chi-square and t-test methods. *P*-values and 95% confidence intervals were obtained from the data, accounting for cluster effects using the Rao and Scott second-order corrected Pearson statistic for dichotomous variables and adjusted F-statistics for continuous variables. This procedure results in standard errors of point estimates and model coefficients that are adjusted for survey design effects.<sup>427</sup> An alpha of 0.05 was used for all significance testing.

Given the fundamental differences between hypertension and diabetes clinically and in the patient's experience of the disease, as well as the effect that these differences may have on the outcomes of interest, care-seeking and adherence outcomes were modeled separately for each of the two conditions. Differences between refugee and host community populations are explored through descriptive statistics and compared using Pearson's chi-square and t-test methods as described previously. Due to insufficient reports of interrupted medication adherence among Lebanese host community cases (8.6% for hypertension and 8.5% for diabetes) to support modeling, regression analyses included only Syrian refugees. This focus also allowed for the inclusion of refugee-specific variables (e.g., receipt of cash assistance and time of arrival in Lebanon) that are likely to be useful for future program refinements.

The crude and adjusted odds of care-seeking and interrupted medication adherence were estimated using similar logistic regression methods. Interaction terms for key explanatory variables were tested *in toto*, as well as with sequential addition of interaction terms. The Akaike (AIC) and Bayesian Information Criterion (BIC), which compare the quality of individual models relative to one another by giving preference to lower AIC/BIC values, indicated preference for the null model excluding all interaction terms.<sup>428</sup> Wald and likelihood ratio tests, which assess variation in model fit when different variables are included, similarly indicated a preference for null models for all outcomes of interest, resulting in exclusion of interactions from final models.<sup>429</sup>

# 5.4. Results

# **Care-Seeking and Health Service Utilization**

#### Hypertension

Care-seeking for hypertension was high among both Syrian refugees and Lebanese host community members. Of the 282 Syrian refugee hypertension index cases, most saw a doctor for hypertension in Lebanon (80.9%, CI: 75.2-85.5%) since arriving as early as 2011; 64.5% (CI: 58.5-70.1%) reported seeking care in the preceding six months and 51.4% (CI: 45.2-57.6%)

within the past three months (Table 5-1). Lebanese host community members were significantly more likely to have sought care than refugees (P<0.001) with 98.3% (CI: 95.6-99.4%) of the 236 cases reporting they had seen a health provider for hypertension in Lebanon. Although the timing of care-seeking for hypertension significantly differed between Syrian refugees and Lebanese host community cases, this is primarily driven by the 18.4% of refugees who never sought care in Lebanon as compared to only 0.4% of Lebanese (P<0.001). Similar to refugees, many host community index cases sought care for hypertension in the past six months (72.9%, CI: 66.1-78.7%), and just over half reported receiving care within the past three months (55.1%, CI: 48.4-61.6%).

Significant differences between refugees and the host community were observed in the location in which care was sought (P<0.001). Of the 195 refugees receiving care for hypertension in the year preceding interview, most were treated in primary health facilities (54.9%, CI: 47.6-61.9%), followed by private clinics (21.5%, CI: 16.6-27.5%), pharmacies (9.6%, CI: 5.6-14.8%), hospitals (8.2%, CI: 5.1-12.9%), and other facility types including mobile medical units (MMUs) and home-based providers (6.2%, CI: 3.0-12.3%).

Of the 196 host community cases receiving care for hypertension in the prior year, over half were treated in private clinics (59.2%, CI: 51.0-69.9%), a significantly larger proportion as compared to Syrian refugees (P<0.001). Host community care-seekers were less likely to receive care at primary health facilities (19.4%, CI: 14.3-25.7%) and more likely to receive care at hospitals (15.8%, CI: 11.4-21.6%), though use of these locations was still less commonly reported. Other infrequently reported care-seeking locations among host community cases included pharmacies (2.6%, CI: 1.0-6.1%) and other facilities such as those mentioned above (3.1%, CI: 1.2-7.5%). No significant differences in care-seeker characteristics (household head education attainment, socioeconomic quartile, crowding, region of residence, and for refugees, year of arrival in Lebanon and UNHCR registration status) were observed by facility type or sector where care was sought, either for refugees or host community members.

The most frequently reported reasons for selecting the location where care was most recently sought for hypertension differed between refugee and host community care-seekers (Table 5-1 and Figure 5-2; P<0.001). Refugees most commonly selected facilities for cost-related reasons (65.6%, CI: 58.0-72.5%); smaller proportions were motivated by quality of care<sup>†</sup> (13.8%, CI: 9.4-19.9%), geographic location (12.8%, CI: 8.5-18.8%), or other reasons, including availability of needed services or medical emergency (7.7%, CI: 4.3-13.4%). Conversely, only 17.9% (CI: 12.7-24.5%) of host community care-seekers selected facilities for reasons associated with cost, as reflected by the high utilization of private clinics. Nearly half of host community care-seekers selected facilities based on perceived quality of care or continuity of care by their usual/family doctor (49%, CI: 40.8-57.2%), and less frequently by geographic location (15.3%, CI: 10.4-21.9%) or other reasons (17.9%, CI: 13.0-24.0%).

The primary reason for selecting the facility type visited also significantly differed between Syrian refugees and Lebanese host community cases when stratified by type of facility (P<0.001 for both primary health facilities and private clinics) (Figure 5-2). This suggests that differences in reasons for selecting care locations between refugees and host community cases are not entirely driven by underlying differences in the distribution of facility types utilized by each population. The majority of refugees seeking hypertension care at primary health facilities (92.5%, CI: 85.6-96.3%) did so for reasons related to cost, with other motivations reported by only nominal proportions of refugees. Cost was also the most commonly reported motivation for host community primary health facility care-seekers (60.5%, CI: 43.0-75.7%), though perceived

<sup>&</sup>lt;sup>†</sup> "Quality of care" also includes liking facility staff or family doctor practicing at the facility

quality of care/family doctor(s) practicing in the selected facility (15.8%, CI: 7.7-29.6%) and location (15.8%, CI: 6.7-32.8%) were reported more by host community cases than by refugees. Among those seeking hypertension care at private clinics, quality of care and continuity of care by their family doctor was the leading motivation both for refugee (47.6%, CI: 32.0-63.7%) and host community cases (69.0%, CI: 58.6-77.7%). Smaller proportions of refugees chose to visit private clinics because of location (26.2%, CI: 14.5-42.6%), and cost (19.1%, CI: 10.1-33.1%). Lebanese host community cases who sought care at private clinics also did so less frequently because of location (14.7%, CI: 9.3-22.4%), while only 1.7% (CI: 0.4-6.8%) cited cost as the reason for selecting to utilize a private clinic.

#### **Diabetes**

As with hypertension, care-seeking for diabetes was similarly high among both Syrian refugees and the Lebanese host community. Among the 136 diabetes index cases in refugee households, most received care for the condition in Lebanon (88.2%, CI: 81.8-92.6%). Many refugees sought care within the past six months (71.3%, CI: 63.6-78.0%) and more than half (61.8%, CI: 53.8-69.2%) sought care in the past three months. Care-seeking for diabetes was significantly higher among Lebanese host community members (97.2%, CI: 92.9-98.9%) compared to refugees (P=0.005). Most of the 144 host community diabetes index cases had received care in Lebanon (97.2%, CI: 92.9-98.9). The majority of host community cases sought care in the past six months (82.6%, CI: 75.9-87.8%), and more than half reported receiving care within the past three months (66.0%, CI: 58.3-72.9%). The timing of diabetes care-seeking for diabetes was not significantly different between Syrian refugees and Lebanese host community members (P=0.126) (Table 5-1).

Diabetes care-seeking location also significantly differed between refugees and the Lebanese host community (*P*<0.001). Of the 102 refugees receiving care for diabetes in the year preceding the interview, more than half received care in primary health facilities (60.8%, CI: 50.7-70.1%). Primary health facilities were utilized by only 17.5% (CI: 12.1-24.5%) of the 126 host community cases that sought care for diabetes in the preceding year. Among host community care-seekers, care was most commonly sought at private clinics (59.5%, CI: 51.2-67.3%), while a much smaller proportion of refugee care-seekers sought care at private clinics (20.6%, CI: 13.7-29.7%). The remaining refugee care-seekers sought care at pharmacies (9.8%, CI: 5.5-16.8%), hospitals (3.9%, CI: 1.5-9.9%), and other facility types (4.9%, CI: 2.1-11.1%). Diabetes care was also less commonly sought by host community care-seekers at these locations (15.9%, CI:10.7-22.8% at hospitals; 6.3%, CI:3.3-12.0% at pharmacies; and 0.8%, CI:0.1-5.6% at other types of facilities). As with hypertension care, no significant differences were observed in care-seeker characteristics by facility type or sector where care was sought for either population group.

Reasons for selecting facilities for diabetes care were distributed similarly to those for hypertension with significant differences between refugee and host community care-seekers (Table 5-1 and Figure 5-2; P<0.001). Refugees most frequently sought care for reasons related to cost (78.4%, CI: 69.1-85.5%); geographic location (9.8%, CI: 5.4-17.1%), quality of care/family doctor(s) practicing in the selected facility (7.8%, CI: 4.1-14.6%), and other reasons (3.9%, CI: 1.5-10.1%) were less commonly reported. Quality of care/preference for their family doctor was the leading reason for host community facility selection, reported by 50.8% (CI: 42.1-59.4%) of care-seekers. Host community members selected facilities for cost-related reasons far less frequently (20.6%, CI: 14.4-28.6%) than refugees, perhaps explaining higher utilization of private clinics among host community cases as compared to refugees. Host community care-seekers were

less frequently motivated by facility location (16.7%, CI: 10.8-24.8%) and other reasons (11.9%, CI: 6.8-20.0%).

When stratified by the type of facility, Syrian refugees and Lebanese host community cases differed in the motivations that led them to seek diabetes care (P<0.001 for primary health facilities; P=0.009 for private clinics) (Figure 5-2). Refugee care-seekers' motivation for visiting primary health facilities were focused primarily on cost (93.6%, CI: 83.7-97.6%) and varied less than the reasons reported by host community cases. Although 50.0% (CI: 29.9-70.1%) of host community cases utilized primary facilities mainly for cost-related reasons, perceived quality of care/preference for their family doctor (22.7%, CI: 9.6-44.8%) and location (27.3%, CI: 12.6-49.4%) were also frequently reported reasons. Refugees seeking diabetes care at private clinics did so largely because of cost (47.6%, CI: 26.7-69.4%), with smaller proportions reporting reasons related to quality of care/family doctor(s) (23.8%, CI: 10.3-46.0%), location (19.1%, CI: 7.9-39.3%), or other motivations (9.5%, CI: 2.3-32.2%). Lebanese host community cases who sought care at private clinics, however, did so largely because of perceived quality of care/family doctor(s) practicing in the selected facility (68.0%, CI: 55.1-78.6%), with smaller proportions motivated by cost, geographic location, or other reasons.

#### **Predictors of Care-Seeking**

Results of univariate and multivariate logistic regression analyses of predictors of careseeking for hypertension and diabetes in the six months before the interview among Syrian Refugees are presented in Table 5-2. There was no significant difference in the adjusted odds of care-seeking for hypertension or diabetes by household head sex, household head education level, monthly household expenditures, year of arrival in Lebanon, or receipt of cash and/or voucher assistance. Adjusted odds of care-seeking for hypertension in the prior six months were significantly associated only with region of residence in univariate and multivariate regression analyses. Adjusting for other variables of interest, refugees in the North governorate had 1.94 times higher odds of care-seeking (CI: 1.01-3.73) as compared to those in Beirut and Mount Lebanon governorates (P=0.046). The odds of care-seeking for diabetes in the six months prior to interview were significantly associated with region of residence in univariate analysis, though this relationship was only marginally statistically significant in the adjusted analysis. Refugees in Bekaa governorate had significantly lower odds of diabetes care-seeking (0.35, CI: 0.12-1.01) compared to refugees living in Beirut/Mount Lebanon governorates in multivariate regression analyses (P=0.053). While cases from households with above average monthly household expenditures had significantly higher odds of care-seeking as compared to those with below average monthly expenditures, this relationship was significant only in univariate analysis (P=0.040; adjusted P=0.119).

#### **Spending on Health Services**

For household index cases who reported seeking care for hypertension or diabetes in the year preceding the interview, self-reported cost of care-seeking for the most recent visit was collected. Care-seeking cost included out-of-pocket payment(s) made for the consultation, including any diagnostic and laboratory tests. Medication payments and payments made on the patient's behalf by the United Nations, insurance, or another organization were excluded. Data on out-of-pocket expenditures are summarized in Figure 5-3 and presented in more detail in Appendix D. Out-of-pocket costs reported by respondents reflect reported expenditures at primary health care centers in public networks (MoPH and Ministry of Social Affairs (MoSA) facilities) as well as those operated privately and by non-governmental organizations (NGOs); further differentiation of costs at between facilities within and outside the MoPH-PHCC network was not possible.

# Hypertension

Overall, 66.7% (CI: 59.2-73.4%) of refugee hypertension cases and 77.0% (CI: 70.7-82.3%) of host community hypertension cases reported an out-of-pocket consultation payment (Figure 5-3; P=0.017). The average out-of-pocket consultation payment was US\$14.4 (CI: 9.8-18.9; median US\$3) for refugees and US\$29.5 (CI: 24.8-34.2; median US\$33) for host community members (P<0.001). Among only those who paid for care, the average out-of-pocket payment was US\$21.7 (CI: 14.9-28.5; median US\$10) for refugees and US\$38.4 (CI: 33.3-43.5; median US\$33) among the host community (P<0.001).

Out-of-pocket expenditures for hypertension and diabetes care by facility type are presented in Figure 5-3. The highest proportion of Syrian refugee care-seekers incurring an out-of-pocket cost was at private clinics (85.7%, CI: 71.8-93.4%) and the lowest in primary health facilities (73.8%, CI: 63.7-82.0%) (P=0.136). Significant differences in the cost of hypertension care by facility type were observed for Syrian refugee care-seekers (P=0.001). Not surprisingly, the highest average out-of-pocket cost (among care-seekers incurring any cost) was at hospitals US\$81.4 (CI: 29.5-133.2; median=US\$27) and the lowest at primary health facilities (average cost=US\$10.0, CI: 4.6-15.4; median=US\$5).

Unlike among Syrian refugees, the highest proportion of host community care-seekers reporting out-of-pocket costs was among those who sought care at a primary health facility (86.6%, CI: 71.7-94.5%) and the lowest among those seeking care at hospitals (64.5%, CI: 45.6-79.8%) (P=0.092). Despite this, the amount of out-of-pocket costs incurred by host community care-seekers reporting any payment was highest at hospitals (mean=US\$69.8, CI: 47.1-92.4; median=US\$50) and lowest at primary facilities (mean=US\$21.7, CI: 12.1-31.2; median=US\$10) (P<0.001).

Differences in the proportion of patients with any out-of-pocket payments between Lebanese and Syrian refugee care-seekers were not statistically significant within each facility type (primary level facility P=0.115, private clinic P=0.657, and hospital P=0.897). However, average out-of-pocket payment amounts at primary facilities were significantly lower for Syrian refugees (US\$7.4, CI: 3.3-11.4; median=US\$3) as compared to the Lebanese host community (US\$18.8, CI: 10.1-27.5; median=US\$10) (P=0.012).

# **Diabetes**

Out-of-pocket consultation payments for diabetes were reported by 70.6% (CI: 62.3-77.7%) of refugees and 82.5% (CI: 74.5-88.4%) of host community cases (P=0.025). The average out-of-pocket consultation payment among refugees was US\$12.0 (CI: 8.2-15.7; median US\$5) and US\$31.6 (95% CI 26.7-36.5; median US\$33) for host community members (P<0.001). Among those reporting any out-of-pocket payment for care, the average amount was US\$17.1 (CI: 12.0-22.2; median US\$10) for refugees and US\$38.7 (CI: 33.3-44.0; median US \$33) among the host community (P<0.001).

As with hypertension care, the highest proportion of Syrian refugees receiving care for diabetes who reported any out-of-pocket cost was at private clinics (90.5%, CI: 69.5-97.5%). Unlike hypertension care, however, the lowest proportion of refugees incurring out-of-pocket costs was among hospital care-seekers (50.0%, CI: 12.0-88.0%) (*P*=0.167). Accordingly, of refugee care-seekers incurring any out-of-pocket payment, the cost of diabetes care was highest at private clinics (US\$26.9, CI: 19.7-34.1; median=US\$23), which was significantly greater than at primary level facilities (US\$13.5, CI: US\$6.8-20.1; median=US\$7) (*P*=0.010). Though the lowest cost among refugees with any payment was at hospitals, only two cases reported cost amounts for

hospital care (both of whom paid US\$6.6, presumably reflecting financial support from UNHCR or another organization); thus, reliable hypothesis testing was not possible.

The highest proportion of host community care-seekers reporting any out-of-pocket costs was at private clinics (94.7%, CI: 86.6-98.0%), but unlike refugees, the lowest proportion with payment was among primary level facility care-seekers (77.3%, CI: 55.2-90.4%) (P=0.029). Accordingly, the amount of out-of-pocket costs incurred by host community care-seekers reporting any payment was highest at private clinics (mean=US\$44.2, CI: 38.2-50.2; median=US\$10) (P=0.015). No significant differences in the proportion of patients with out-of-pocket payments were observed between Lebanese and Syrian refugee care-seekers within each facility type (primary level facility P=0.866, private clinic P=0.480, and hospital P=0.211). Statistically significant differences in out-of-pocket payments between Syrian refugees and host Lebanese were observed only at private clinics, where the average cost was US\$26.9 (CI: 19.7-34.1; median=US\$23) among refugees and US\$44.2 (CI: 38.2-50.2; median=US\$33) among host community care-seekers (P=0.001). The number of hospital care-seekers reporting exact cost amounts was not sufficient to test population group differences.

#### **Medication Prescription and Current Use**

Summaries of medication prescription, current use, and interrupted use among household index cases of hypertension and diabetes are presented in Table 5-3.

# Hypertension

Of the 282 Syrian refugee hypertension cases, medication for hypertension was prescribed for 97.2% (CI: 94.4-98.6); of these, 40.1% (CI: 33.0-47.7) were prescribed medication in Syria and 59.9% (CI: 52.3-67.0) in Lebanon. The country in which medication was prescribed

did not vary by length of time in Lebanon, however, and may be more a reflection of time since the initial diagnosis and/or prescription of the current medication. A high proportion of cases reported currently taking hypertension medication (79.4%, CI: 74.4-83.6); however, nearly onethird (30.5%, CI: 24.8-36.9) reported having stopped their medication for two weeks or longer in the preceding year, mostly against medical advice (27.8% of all cases, CI: 22.3-34.1). Of those who stopped medication, 11.1% (CI: 5.0-23.0) did so in Syria and 88.9% (CI: 77.0-95.0) in Lebanon. The most common reason for refugees to stop taking hypertension medication was their inability to afford the medicine (77.8%, CI: 68.2-85.1).

Of the 236 Lebanese host community hypertension cases, medication was prescribed for 99.2% (CI: 96.6-99.8) and most cases reported currently taking medication (95.8%, CI: 91.9-97.8). A small proportion (9.0%, CI: 6.0-13.3) of Lebanese hypertension cases reported having stopped their hypertension medication for two weeks or longer in the past year, and most stopped without instruction from a physician (8.6%, CI: 5.7-12.8). As with Syrian refugees, the most common reason members of the Lebanese host community reported for stopping hypertension medication was inability to afford the medicine (75.0%, CI: 51.3-89.5). Differences between Syrian refugees and Lebanese host community hypertension cases were significant concerning current medication use (P < 0.001) and stopping medication, either with or without instructions from a physician (P < 0.001) with Syrian refugees having lower adherence than the Lebanese host community.

#### **Diabetes**

Nearly all (98.5%, CI: 94.2-99.6) of the 136 Syrian refugee diabetes cases were prescribed medication either in Syria (33.6%, CI: 26.4-41.7) or Lebanon (66.4%, CI: 58.3-73.6) (Table 5-3). Many (89.7%, CI: 83.0-93.9) reported currently taking prescribed medication, including oral hypoglycemic drugs as well as insulin. Of all refugee diabetes cases, 26.3% (CI: 19.5-34.6) reported having stopped their medication for two weeks or longer in the prior year, mostly without a physician's instruction to cease medication (25.0% of all cases, CI: 18.4-33.0). Of those who reported stopping medication, 11.8% (CI: 4.6-27.0) did so in Syria and 88.2% (CI: 73.0-95.4) in Lebanon. Again, the most common primary reason for stopping diabetes medication was inability to afford the medicine (76.5%, CI: 57.8-88.5).

Almost all (97.2%, CI: 92.9-98.9) of the 144 Lebanese host community diabetes cases were prescribed medication for the condition (Table 5-3) and most (95.1%, CI: 90.4-97.6) were currently taking diabetes medication. Of all host community diabetes cases, 11.4% (CI: 7.2-17.7) reported stopping medication for longer than two weeks in the past year; 8.5% (CI: 4.9-14.3) of all cases did so without instruction by a physician. Again, the most common reason for stopping medication for diabetes, excluding those who stopped per instruction by a physician, was cost (91.7%, CI: 57.8-98.9). Unlike in cases of hypertension, however, one-quarter (25.0%, CI: 9.5-51.3) of diabetes cases that stopped taking medication did so per a doctor's recommendation. Significant differences between Syrian refugees and Lebanese host community members with diabetes were observed in stopping medication (P=0.002 for any stopping; P <0.001 for medication stopped against medical advice), with Syrian refugees having lower adherence than the Lebanese host community.

# **Predictors of Interrupted Medication Adherence**

#### **Hypertension**

Results of univariate and multivariate logistic regression analyses for predictors of interrupted medication adherence among Syrian refugees are presented in Table 5-4. Adjusted odds of interrupted adherence to hypertension medication were significantly associated only with

having seen a health provider for hypertension in the preceding three months, which was protective (0.58, CI: 0.34-0.99) as compared to those who did not have a care visit in that period (P=0.046). There was no significant difference, either in univariate or multivariate analyses, in the odds of interrupted medication adherence by region, household head sex or education, monthly household expenditures, receipt of cash/voucher assistance, or year of arrival in Lebanon.

# **Diabetes**

In multivariate regression analyses, odds of interrupted adherence to medication for diabetes were significantly associated only with monthly household expenditures. Being in a household with expenditures above the median was protective, showing reduced odds of medication interruption (OR= 0.35; CI: 0.14-0.91) as compared to index cases from households reporting below average monthly expenditures (*P*=0.031).

There was no statistically significant difference in adjusted odds of interrupted medication adherence for diabetes by care-seeking in the preceding three months, region, household head sex or education, receipt of cash/voucher assistance, or year of arrival in Lebanon.

# 5.5. Discussion

The influx of Syrian refugees into Lebanon since 2011 has strained health system capacity to provide care, including medical services and essential medicines, to refugee and host Lebanese populations alike. This paper presents evidence of important differences in careseeking, health service utilization, and medication adherence for hypertension and diabetes between Syrian refugees and host communities in Lebanon. These activities are interconnected and potentially influenced by care facility type and location, cost relative to a household's ability to pay, perceived quality of care, and medical need.

#### **Care-Seeking and Utilization**

Continuous, quality care from a qualified healthcare provider is the essential foundation to effectively managing diabetes and hypertension. As patients experience the two conditions differently, their motivations can be influenced by the silent nature of hypertension versus symptomatic diabetes. However, differential prioritization of cost and perceived quality of care/family doctor(s) practicing in the selected facility by refugees and host community members suggest the further impact of contextual factors on care-seeking behavior.

Care-seeking for hypertension and diabetes in Lebanon diverged between refugee and host community members. Host community cases were more likely to seek care than were refugees, and to have done so within the past six months. Although care-seeking is, on average, high in both populations, those who are not regularly seeking care for chronic conditions such as hypertension and diabetes can experience differences in adverse clinical events that more regular care might avoid.<sup>100</sup>

Refugee hypertension care-seekers differ from host community care-seekers by the weight they give to the relative importance of facility type, cost, and quality/continuity. As refugees most often sought care in primary level health facilities, it is not surprising that cost was a priority motivation for treatment decisions, and that refugees were more cost-sensitive than host community cases. Similarly, host community cases' predominant concern with quality of care is consistent with their greater use of private clinics. Unexpectedly, facility location was not a primary consideration either for refugees or host community individuals with hypertension. Prioritized reasons for seeking care for diabetes, such as cost or location, were similar to those for

hypertension overall; however, the reasons for selecting care locations for diabetes differed once responses were stratified by facility type. Host community members varied much more in their primary motivation for choosing a facility than refugees, the majority of whom were concerned with cost regardless of which facility type was used. Lebanese host community cases sought care at private clinics for their perceived quality, determined by prior care or family doctor(s) practicing in the selected facility. Refugees who sought care at private clinics, however, predominantly reported doing so for reasons related to [low] cost.

At the time in which this study was conducted, primary health care was, and continues to be, provided to Syrian refugees for a consultation fee between US\$2 to US\$3 per visit in more than 100 primary level facilities (PHCCs and dispensaries) across the country. These include facilities both in and outside of the MoPH-PHCC Network.<sup>13,79,88,96-99</sup> Care is likewise provided to vulnerable Lebanese at the same subsidized rates in these facilities, as is reduced cost care at all PHCCs in the MoPH network, where fees for Lebanese patients are capped at US\$12.<sup>430</sup> Refugees seeking care at private clinics for reasons related to cost may reflect their misunderstanding about relative costs of care at primary facilities versus private clinics, which has been previously documented among Syrian refugees in Lebanon. Alternatively, care-seekers may believe that the specific clinics utilized were among those providing reduced-cost care for refugees.<sup>100,431</sup>

During pilot testing and data collection, it was apparent that many refugees were unable to reliably classify the type of health facility they most recently visited. In particular, distinctions between PHCCs in the MoPH network and primary care facilities supported by UNHCR or NGOs were generally classified by refugees as one and the same, hence their inclusion as a single response option in the final questionnaire. This difficulty identifying facility types may also have extended to misclassification of private clinics, and in itself suggests telling evidence of many refugees' vague understanding of available support and where it can be accessed. This knowledge gap is consistent with refugee knowledge of available services reported in UNHCR's annual Health Access and Utilization Survey (HAUS). According to the 2014 HAUS, which provides the most comparable findings to the time period in which data were collected, only 54% of Syrian refugees knew they should pay between 3,000 and 5,000 LBP (approximately US\$2-US\$3) for consultation at PHCCs.<sup>71</sup> While there has been a slight improvement in knowledge of subsidized consultation fees, still only 60% of refugees reported knowledge of payment amounts in 2018, indication that the gap in awareness persists.<sup>432</sup>

Refugee knowledge that chronic medication is available for a maximum of 1,000 LBP (US\$0.66) was only reported in the 2013 and 2014 HAUS, and was much lower; only 1% of refugees reported knowing this in 2013 and 23.8% in 2014.<sup>71</sup> In addition to distributing regularly updated health brochures with detailed information on how to access health care in Lebanon, UNHCR has also increased communication to refugees through various media such as (i) direct SMS messaging; (ii) a "health chatbot" on Facebook called Ask Noor where refugees can ask questions about health services and receive an immediate response; and (iii) Refugees Lebanon, a website created solely to provide information on a wide range of assistance for Syrian refugees in Lebanon including audio and video content.<sup>412,433,434</sup> With continued communication efforts, UNHCR has reported marked improvement since 2013 in refugees' knowledge of available health services and their cost. Despite improvements, a sizable proportion of Syrian refugees remain unaware of either the services available to them or the associated costs.

The HAUS and numerous other studies of health care utilization by Syrian refugees in Lebanon have consistently shown cost to be the prime barrier to care-seeking generally and for chronic NCDs specifically.<sup>3,71,117,432,435-440</sup> Limited awareness, confusion, or incorrect understanding about the cost of health care and subsidized services may contribute to the influence that inability to afford care has on health behaviors, decreasing the likelihood of careseeking. This care-seeking decrement can apply both for refugees' initial health care visit after arriving in Lebanon and subsequent visits where out-of-pocket payment was not as expected.

Regression analyses were conducted only among Syrian refugees and among the variables in the conceptual model that guides analyses, the only statistically significant predictor in the adjusted analysis of the odds of care-seeking in the preceding six months was region of residence. Refugees living in the North governorate were significantly more likely than those living in Beirut/Mt. Lebanon to seek care for hypertension. This is aligned with regional trends in overall access to care in the most recent (2018) Vulnerability Assessment of Syrian Refugees in Lebanon, where access was reportedly lowest in Beirut and Mount Lebanon (70%) and highest in Akkar (98%; included in the North region in the present analyses;).<sup>3</sup> Regional variations in healthcare access may be due to differences in the accessibility, number, and distribution of facilities providing subsidized care, sociodemographic characteristics, and refugees' knowledge of available services. For diabetes, average household monthly expenditure was statistically significantly predictive of care-seeking in univariate analysis – the higher the household's expenditures, the more likely care was sought. Household expenditures in this context are used as a proxy for the household's overall socioeconomic status, and thus, their ability to pay for health care. As such, it is inferred that this "ability to pay", rather than only household spending, is associated with care-seeking. This is consistent with previous studies linking households with greater ability to pay and/or socioeconomic status with increased care-seeking generally, as well as for chronic and/or non-communicable conditions specifically.

# **Spending on Health Services**

Although the main aim of this work is to assess utilization, out-of-pocket consultation cost is also a central consideration for healthcare utilization, particularly as cost is a primary barrier to care-seeking for refugees. The proportion of refugees reporting out-of-pocket payments and refugee payment amounts were lower than those of host community members both for hypertension and for diabetes. This suggests that current humanitarian programming may be contributing to effectively maintaining refugee access to NCD care for those who are aware of where and how subsidized care is provided. The majority both of refugee and host community care-seekers reported some out-of-pocket payments, with an overall higher median cost for host community care-seekers (US\$33 for both hypertension and diabetes) compared to Syrian refugees (US\$3 for hypertension, US\$5 for diabetes). This difference is likely due to subsidized care provided for refugees at many primary level facilities, which are far more commonly utilized by refugees. Payments were reported by a larger proportion of host community cases both for hypertension and for diabetes, consistent both with higher overall costs for host community careseekers and differential use of primary care facilities by refugees and private clinics by the host community. Host community care-seekers in this sample reflect households from communities among the most vulnerable and affected by the influx of Syrian refugees rather than the broader Lebanese population. Such disproportionally higher costs observed among the host community thus raises concerns about their continued ability to afford needed care.

Among hypertension and diabetes refugee index case households, 74% and 72% respectively reported that all members were currently registered with UNHCR, and another 12% in both groups reported that some members were registered. Notwithstanding this, average reported consultation costs of US\$10 for hypertension and US\$14 for diabetes among refugees reporting any out-of-pocket payment at primary level health facilities exceed the standard

subsidized cost of US\$2 – US\$3 for such care. Median costs were lower (US\$5 for hypertension and US\$7 for diabetes), but only 47% of hypertension care-seekers and 42% of diabetes careseekers reported costs of US\$3 or less at primary level facilities. The large proportion of primary level care-seekers reporting costs above the standard subsidized rate likely indicates care being sought at facilities outside the MoPH-PHCC network or not supported by UNHCR or NGOs.

Another possible reason for costs reported above standard subsidized rates is that respondents included payment for medication and/or diagnostic testing when reporting consultation costs, resulting in a broader range of payment amounts. Although out-of-pocket costs for consultation and most medication for chronic conditions are offered for flat fees, cost-sharing for diagnostic testing is structured such that UNHCR covers 85% of tests, leaving the remaining 15% for refugees to pay. Diagnostic and laboratory testing costs are unpredictable for careseekers and, especially in Lebanon's highly privatized and specialist-centered health system, can reach unaffordable amounts. Moreover, subsidized diagnostic costs are provided only for specific "vulnerable" groups, such as children under five years, adults 60 years and older, those with disabilities, and pregnant or nursing women. Within the Lebanese health system's pluralistic and fragmented structure, base costs for testing vary dramatically across facilities. This variability could be driving, or at least contributing to, individuals not seeking needed care. Instances of delaying or avoiding care-seeking may be prevented through bundled services provided at set costs communicated in advance of care.

Two projects, the Emergency Primary Healthcare Restoration Project (EPHRP) and the Reducing Economic Barriers to Accessing Health Services (REBAHS) project, seek to address the inconsistency and unpredictability of overall healthcare spending as barriers to care among Syrian refugees and host communities in Lebanon. In an effort to meet the health needs of vulnerable Lebanese households, the World Bank, in partnership with the Lebanese MoPH, began implementation of the EPHRP in 2016 with the objective of "restor[ing] access to essential healthcare services for poor Lebanese affected by the influx of Syrian refugees".<sup>419</sup> Through the end of 2019, the EPHRP will pilot provision of an essential health care package in the MoPH network of PHCCs and hospitals for 150,000 Lebanese with limited income. Specifically, the EPHRP provides an NCD service package free of charge to enrolled beneficiaries for case management of diabetes (consisting of five mandatory doctor's visits per year, annual electrocardiogram (EKG), lab tests, foot exam, and medications) and hypertension (five mandatory doctor's visits per year, annual EKG, lab tests, counseling, medications), as well as similar services for coronary artery disease.<sup>420</sup> By December 2018, more than 120,000 individuals were enrolled in the project, with 101,454 users. Of these users, 14% received care through the diabetes package and 20% through the hypertension package.<sup>441</sup>

Implementation of the REBAHS project began in January 2018 led by a consortium of international NGOs (INGOs) including Première Urgence Internationale, International Medical Corps, and the Foundation for the Social Promotion of Culture. The REBAHS project has similar objectives to reduce the burden of healthcare costs on "crisis-affected populations" in Lebanon and serves mostly Syrian refugees along with some vulnerable Lebanese.<sup>418</sup> Much like the EPHRP, the REBAHS project provides support to select PHCCs through subsidized consultations and laboratory testing. Services are subsidized based on a flat fee model that requires a 3,000 LBP (US\$2) out-of-pocket payment for consultation, while the remaining visit costs, including those for laboratory and imaging tests, as well as medication, are covered by the supporting INGO. Both the EPHRP and REBAHS are still in the pilot phase, and evidence of their impact is not yet available. Early reports suggest that in this context, they are a promising model for reforming health financing to facilitate greater access for those most in need. The financial support provided through these projects enables regular, predictable costs to beneficiaries,

mitigating the fear of and potential for devastating expenditures on individuals requiring continuous care for conditions such as diabetes and hypertension. Both projects have already shown a substantial increase in demand at participating PHCCs. EPHRP monitoring indicated an increase in the utilization of PHCCs by Lebanese of 88% from 2015 to 2017, and a pilot project preceding REBAHS reported a 41% increase in the number of patients at participating PHCCs following implementation of a flat fee model.<sup>418,430,442</sup> Subsidies such as these should continue to be explored, and evidence of their impact documented alongside plans to scale up both projects.

Aside from subsidized costs, facility-level support interventions are an essential component for such projects' sustainability. In addition to financial coverage for patient care, these projects also reinforce the Lebanese health system and facilitate improved quality of care through capacity building for enhanced service delivery quality and supply chain management, community outreach, and in-kind buffer stocks of essential medicines to prevent shortages and stock-outs.<sup>79,418-420</sup> PHCCs' ability to meet increased demands while maintaining sufficient quality of care relies on such complementary support, together with further financial support for increased staffing, facility maintenance, and operating costs.

Improving refugee access to affordable health care cannot be considered without addressing existing barriers to care faced by many Lebanese. Doing so would risk furthering tensions between the two populations.<sup>443</sup> Continuation of projects such as EPHRP and REBAHS has the potential to address both the immediate patient needs and development-centered goals of strengthening the health system. This presents an opportunity for equitable access to health care previously not realized for all Lebanese, irrespective of the additional challenges brought on by the Syrian crisis.<sup>430</sup> The sustainability of the flat-fee model, similar subsidy approaches, and/or shifts towards universal health coverage depend upon continued external funding from the international community. Current funding shortfalls threaten the sustainability of assistance
approaches that are vital to improving the health of refugees and host Lebanese, and to sustaining improvements in the Lebanese health system.

#### **Medication Prescription and Adherence**

Nearly all hypertension and diabetes cases in this survey had been prescribed medication for their condition. Correspondingly large proportions of refugee and host community cases were currently taking prescribed medication for diabetes; however, a significantly smaller percentage of refugees reported currently taking prescribed medication for hypertension as compared to host community cases. Consequently, interrupted medication use (i.e., stopping for two weeks or longer) was significantly higher among refugees than among host community cases, though surprisingly similar between hypertension and diabetes. For both conditions, interrupted medication use was reported by more than one-quarter of refugees, which in both conditions is also more than three times as high as interruption reported by host community cases.

Cost was the primary reason for medication interruption among both population groups and both conditions. More than three-quarters of cases that interrupted use of medication for hypertension and over half of those with interrupted use of medication for diabetes did so because of inability to afford the medication, which confirms the role of financial burden in health decision-making. As with care-seeking, gaps in knowledge about options for free or low-cost medication for hypertension and diabetes may be leading individuals to divert from prescribed treatment regimens, dosage, or even to forego medication use altogether when they may otherwise adhere to prescribed treatment if they were aware of the subsidized options. In 2014, only 23.8% of refugees were aware that chronic medication prescriptions could be filled for a maximum of 1,000 LBP/US\$0.67; unfortunately, more recent data assessing refugee knowledge of medication assistance options are not available.<sup>71</sup> Reported stock-outs or inconsistent availability of medications can influence patients' ability to afford medication and may also result in the need to obtain medication at private pharmacies where free or reduced-cost medication is provided. This suggests an opportunity for training and intervention to enhance inventory management and drug availability.

Predictors of interrupted medication adherence were limited and differed between hypertension and diabetes. The relationship between care utilization and interrupted adherence was not significant for diabetes; however, receiving care for hypertension in the preceding three months was associated with lower odds of interrupted medication adherence. The discordance in this association for hypertension and diabetes could arise from the pathological differences of the two conditions. Diabetes most often presents symptoms that interfere with patients' day-to-day lives, serving as both a reminder and possibly a motivator for more consistent care-seeking and compliance with treatment regimens. Conversely, hypertension is mostly asymptomatic. In the absence of daily "reminders" in the form of noticeable symptoms, health provider visits may serve as more of a reminder or motivation for treatment compliance. Better management of both conditions may be achieved by promoting more regular clinic visits, even if visits are just for a medication check-up rather than for a complete specialist examination. Among diabetics, higher socioeconomic status, characterized as households reporting monthly expenditures above the median for Syrian refugees, was protective against medication interruption, which is also consistent with cost being cited as the primary reason for interrupted adherence.

#### Limitations

As with all studies, it is necessary to consider the limitations when interpreting results. Concerning sampling, reliance on UNHCR registration data for sample design and cluster allocation may have resulted in sampling bias if the geographic distribution of registered and unregistered refugees is different. Reallocation of clusters in areas controlled by military and political factions where permission to conduct the survey was not secured resulted in large areas of the country being excluded. The survey coverage area included only 53% of registered refugees and thus is not representative of the entire Syrian refugee population in Lebanon. Another sampling limitation was the 2:1 ratio of refugee to host community households. The primary aim of the assessment was to characterize health access for Syrian refugees; budget limitations precluded a larger sample size, and a decision was made to prioritize a larger refugee sample to enable regional comparisons. The smaller host community sample was a limitation in instances of rare occurrences (such as medication interruption or reasons for not seeking care). Larger sample size may have resulted in statistically significant differences for comparison across regions within Lebanon, as well as comparisons between refugees and the host community.

The within cluster referral process also presents a potential for bias, as respondents may not have always referred the interview team to the nearest household. Referral procedures ensured that households were referred by different respondents and small clusters may have helped to attenuate within-cluster similarities and the associated design effect. Replacement sampling, which was done for logistical purposes, also could contribute to bias if there were systematic differences between households in which no one was home compared with those in which someone was present. Finally, the Lebanese host community sample was selected using a neighborhood approach and thus is reflective of those communities hosting the largest number of refugees. Findings on the Lebanese host community population should not be generalized to the Lebanese population at large. Host community respondents are representative of only a subset of the Lebanese population, which is likely to be of lower economic status and a different geographic distribution than the Lebanese population as a whole. Interviews were conducted by Lebanese, which could have resulted in a higher refusal rate, hesitance or influence on Syrian refugees in responding to certain questions than if Syrians had conducted the interviews. As such, sensitive topics such as income or experiences in Syria may be susceptible to bias because of the interviewer nationalities.

Respondents' inadequate ability to accurately distinguish between different types of facilities that provide primary care in Lebanon is another limitation identified when pilot testing the survey questionnaire. The complex assortment of primary care facilities in Lebanon includes those in the MoPH network, a large number of centers operated by the MoSA and local organizations, public sector facilities supported by humanitarian NGOs, and a well-established number of private sector clinics. A single facility may fall into more than one of these categories, making classification for brief household surveys quite challenging. Despite extensive efforts by the study team to develop suitable response categories for the various types of primary care facilities, more specific classification of facilities lacked adequate reliability and validity and thus was excluded from the final version of the questionnaire. Regarding results disaggregated by types of health facilities, this survey is not able to differentiate between care-seeking and out-of-pocket costs at PHCCs in the MoPH network and other primary level facilities. As such, results presented for primary level health facilities are not intended to indicate whether these facilities are in the MoPH network or operated/supported by NGOs, MoSA, or private entities.

Additional limitations include the use of self-report for key outcome measures as overreporting care-seeking and medication adherence is likely increased due to social desirability and recall biases. Moreover, the single question medication adherence measure captures medication underuse; however, other manners of non-compliance are not explicitly measured (e.g., improper dosage, timing, and overuse). The cross-sectional study design prevents causal inference, limiting results to identifying associations instead of causality. Finally, the skewed distribution of key variables and notably high overall reporting of medication adherence hinders detection of weaker associations.

# 5.6. Conclusion

This study provides empiric information regarding refugee and host community health care behaviors for managing hypertension and diabetes. Findings demonstrate significant disparities between the two populations in care-seeking, health facility utilization, out-of-pocket payments for care, and medication interruption. Results show greater access to care, preference for private clinics over primary level health facilities, and fewer reports of medication interruption in host community cases. Out-of-pocket spending, however, was significantly higher in host community cases than among refugees, reflecting differential financial support available to the two groups and, potentially, means for affording care. Results also show differences in motivation for treatment location selection, with host community cases demonstrating more concern for quality of care and continuity of care from their usual/family doctor(s) and refugees being more cost-sensitive, even when choosing to seek care at private sector facilities.

The goal of sustainable, high-quality medical care is the same for refugees and the Lebanese host community. New models such as flat fee models being used in the EPHRP and REBAHS projects may be effective means for achieving this goal, and for closing gaps between need and care-seeking practices. Based on the present research, additional efforts are needed to facilitate minimal and predictable out-of-pocket payments for health services and to ensure that refugees and vulnerable Lebanese are aware that subsidized care is available to them and how it can be accessed.

	HYPERTENSION		DIABETES			
	Syrian	Host	Syrian	Host		
	<b>Refugees</b> % (95% CI)	<b>Community</b> % (95% CI)	<b>Refugees</b> % (95% CI)	<b>Community</b> % (95% CI)		
Last time care was	<i>n</i> =282	<i>n</i> =236	n=136	n=144		
sought <sup>*</sup>						
Less than one month	26.2 (21.3-31.9)	25.0 (20.1-30.6)	33.1 (25.2-42.1)	25.7 (19.0-33.7)		
ago						
1 - 2 months ago	25.2 (20.4-30.7)	30.1 (24.8-35.9)	28.7 (21.7-36.9)	40.3 (32.7-48.4)		
3 - 6 months ago	13.1 (9.4-18.0)	17.8 (13.5-23.1)	9.6 (5.8-15.3)	16.7 (11.2-24.0)		
7 months - 1 year ago	4.6 (2.6-8.0)	10.2 (6.9-14.7)	3.7 (1.5-8.5)	4.9 (2.4-9.6)		
> 1 year ago	11.7 (8.1-16.6)	15.3 (10.9-20.9)	13.2 (8.7-19.6)	9.7 (5.7-16.0)		
Never sought in	18.4 (13.8-24.2)	0.4 (0.1-3.0)	10.3 (6.2-16.6)	0.7 (0.1-4.9)		
Lebanon						
P-value <sup>†</sup>	< 0.	001	0.126			
Saw a doctor in	80.9 (75.2-85.5)	98.3 (95.6-99.4)	88.2 (81.8-92.6)	97.2 (92.9-98.9)		
Lebanon <sup>‡</sup>						
P-value <sup>†</sup>	< 0.	< 0.001 0.005		05		
Most recent care	n=195	n=196	n=102	n=126		
location <sup>‡</sup>						
Primary level facility	54.9 (47.6-61.9)	19.4 (14.3-25.7)	60.8 (50.7-70.1)	17.5 (12.1-24.5)		
Private clinic	21.5 (16.6-27.5)	59.2 (51.0-66.9)	20.6 (13.7-29.7)	59.5 (51.2-67.3)		
Hospital	8.2 (5.1-12.9)	15.8 (11.4-21.6)	3.9 (1.5-9.9)	15.9 (10.7-22.8)		
Pharmacy	9.2 (5.6-14.8)	2.6 (1.0-6.1)	9.8 (5.5-16.8)	6.3 (3.3-12.0)		
Other	6.2 (3.0-12.3)	3.1 (1.2-7.5)	4.9 (2.1-11.1)	0.8 (0.1-5.6)		
P-value <sup>†</sup>	< 0.001		< 0.001			
Reason for selecting	n=195	n=196	n=102	n=126		
location <sup>‡</sup>						
Low cost consultation	48.2 (40.5-56.0)	11.2 (7.6-16.3)	59.8 (50.0-68.9)	13.5 (8.1-21.5)		
Free consultation	17.4 (13.0-22.9)	6.6 (3.8-11.3)	18.6 (12.4-27.0)	7.1 (3.8-12.9)		
Like staff, quality,	13.8 (9.4-19.9)	49.0 (40.8-57.2)	7.8 (4.1-14.6)	50.8 (42.1-59.4)		
family doctor						
Closest to residence	12.8 (8.5-18.8)	15.3 (10.4-21.9)	9.8 (5.4-17.1)	16.7 (10.8-24.8)		
Availability of needed	2.1 (0.8-5.3)	11.2 (7.1-17.3)	2.0 (0.5-7.6)	7.9 (4.0-15.2)		
services	. /					
Medical emergency	2.6 (1.1-6.1)	4.6 (2.3-9.1)	1.0 (0.1-6.8)	2.4 (0.8-7.2)		
Other	3.1 (1.0-9.2)	2.0 (0.8-5.3)	1.0 (0.1-6.9)	1.6 (0.4-6.3)		
P-value <sup>†</sup>	< 0.001		< 0.001			

Table 5-1. Care-Seeking for Hypertension and Diabetes

\* As percent of household index cases reporting hypertension or diabetes diagnosis

<sup>†</sup> Group comparison using Pearson's chi-square for proportions. Statistical significance indicated in bold (*P*<0.05) and bold italics (*P*<0.001).

\* As percent of household index cases receiving care in Lebanon for the condition in the year prior to interview

	Crude O	Crude OR Adjusted O		R
	OR (95% CI)	P-value	OR (95% CI)	P-value
Н	YPERTENSION			
Region of residence (ref: Beirut/Mt. Lebanon)				
Bekaa	1.34 (0.71-2.54)	0.368	1.44 (0.74-2.80)	0.283
North	1.93 (1.01-3.68)	0.047	1.94 (1.01-3.73)	0.046
Female-headed HH	1.86 (0.91-3.79)	0.088	1.82 (0.88-3.79)	0.105
HH head completed $\geq$ primary education	0.81 (0.43-1.53)	0.512	1.03 (0.53-1.98)	0.935
Above median monthly HH expenditures*	1.34 (0.78-2.29)	0.280	1.32 (0.74-2.35)	0.337
Arrived in Lebanon 2013-2015 (ref: 2011-2012)	0.61 (0.37-1.02)	0.060	0.62 (0.37-1.04)	0.072
Receipt of cash and/or voucher assistance $^{\dagger}$	1.16 (0.62-2.16)	0.642	1.12 (0.59-2.11)	0.735
	DIABETES			
Region of residence (ref: Beirut/Mt. Lebanon)				
Bekaa	0.31 (0.11-0.85)	0.023	0.35 (0.12-1.01)	0.053
North	0.57 (0.20-1.58)	0.272	0.59 (0.20-1.74)	0.335
Female-headed HH	2.13 (0.62-7.30)	0.224	2.16 (0.62-7.57)	0.224
HH head completed $\geq$ primary education	0.86 (0.27-2.68)	0.786	0.90 (0.23-3.44)	0.873
Above median monthly HH expenditures*	2.05 (1.03-4.06)	0.040	1.79 (0.86-3.74)	0.119
Arrived in Lebanon 2013-2015 (ref: 2011-2012)	0.70 (0.34-1.42)	0.314	0.70 (0.34-1.46)	0.337
Receipt of cash and/or voucher assistance $^{\dagger}$	1.42 (0.66-3.05)	0.362	1.58 (0.72-3.48)	0.254

# Table 5-2. Estimated Odds of Hypertension and Diabetes Care-Seeking in the Preceding Six Months Among Syrian Refugees

OR = odds ratio; HH= household. Statistical significance indicated in bold (P < 0.05) and bold italics (P < 0.001).

\* Relative to median monthly HH expenditures reported by Syrian refugees

<sup>†</sup> Includes cash or voucher assistance received from a United Nations agency, NGO, or other religious or community group in the month preceding interview. Reference: no cash/voucher assistance received in previous month.

	HYPERTENSION		DIABETES		
	Syrian	Host	Syrian	Host	
	Refugee	Community	Refugee	Community	
	% (95% CI)	% (95% CI)	% (95% CI)	% (95% CI)	
<b>Medication Prescription</b>	(n=282)	(n=236)	(n=136)	(n=144)	
Ever prescribed medication for condition	97.2 (94.4-98.6)	99.2 (96.6-99.8)	98.5 (94.2-99.6)	97.2 (92.9-98.9)	
P-value*	e* 0.072 0.453		-53		
Country where prescribed <sup>†</sup>	(n=274)		(n=134)		
Syria	40.1 (33.0-47.7)		33.6 (26.4-41.7)		
Lebanon	59.9 (52.3-67.0)		66.4 (58.3-73.6)		
Currently taking medication <sup>†</sup>	79.4 (74.4-83.6)	95.8 (91.9-97.8)	89.7 (83.0-93.9)	95.1 (90.4-97.6)	
<i>P</i> -value	< 0.	.001	0.0	80	
Adherence	(n=259)	(n=233)	(n=133)	(n=140)	
Stopped medication for >2 weeks in past year	30.5 (24.8-36.9)	9.0 (6.0-13.3)	26.3 (19.5-34.6)	11.4 (7.2-17.7)	
P-value*	< 0.001		0.002		
Stopped medication for >2 weeks in past year against medical advice	27.8 (22.3-34.1)	8.6 (5.7-12.8)	25.0 (18.4-33.0)	8.5 (4.9-14.3)	
P-value*	< 0.	.001	< 0.	< 0.001	
Where medication was stopped <sup>‡</sup>	(n=72)		(n=34)		
Syria	11.1 (5.0-23.0)		11.8 (4.6-27.0)		
Lebanon	88.9 (77.0-95.0)		88.2 (73.0-95.4)		
Reason for stopping medication <sup>§</sup>	(n=72)	(n=20)	(n=34)	(n=12)	
Household could not afford the medication	77.8 (68.2-85.1)	75.0 (51.3-89.5)	76.5 (57.8-88.5)	91.7 (57.8-98.9)	
Symptoms improved/felt better	6.9 (3.1-15.0)	10.0 (2.4-33.1)	8.8 (3.1-22.7)	8.3 (1.1-42.2)	
Did not know where to get the medication	5.6 (2.1-13.9)	5.0 (0.7-29.1)	0.0	0.0	
Did not like available medications	1.4 (0.2-9.4)	10.0 (2.4-33.1)	0.0	0.0	
Not available at pharmacy/health facility	2.8 (0.7-9.9)	0.0	5.9 (1.4-21.4)	0.0	
Other	5.6 (2.1-13.9)	0.0	8.8 (2.9-24.2)	0.0	
P-value*	0.348		0.559		

Table 5-3. Medication Use for Hypertension and Diabetes

\* Group comparison using Pearson's chi-square for proportions. Statistical significance indicated in bold (P<0.05) and bold italics (P<0.001).

<sup>†</sup> As percent of household index cases diagnosed with hypertension/diabetes

<sup>‡</sup> As percent of refugee index cases who stopped taking medication for >2 weeks in past year against medical advice

<sup>§</sup> As percent of all household index cases who stopped taking medication for >2 weeks in past year

	Crude OR Adjusted O		OR	
	OR (95% CI)	P-value	OR (95% CI)	P-value
НҮРЕ	RTENSION			
Any hypertension care in past 3 months	0.59 (0.35-1.00)	0.052	0.58 (0.34-0.99)	0.046
Region of residence (ref: Beirut/Mt. Lebanon)				
Bekaa	1.04 (0.50-2.15)	0.911	1.00 (0.45-2.20)	0.999
North	1.03 (0.48-2.24)	0.931	1.06 (0.47-2.37)	0.888
Female-headed HH	1.39 (0.67-2.88)	0.367	1.30 (0.58-2.89)	0.523
HH head completed $\geq$ primary education	0.73 (0.38-1.40)	0.340	0.77 (0.38-1.56)	0.464
Above median monthly HH expenditures*	0.86 (0.49-1.52)	0.610	0.94 (0.53-1.66)	0.816
Arrived in Lebanon 2013-2015 (ref: 2011-2012)	1.11 (0.66-1.87)	0.682	1.09 (0.65-1.83)	0.738
Receipt of cash and/or voucher assistance $^{\dagger}$	1.26 (0.61-2.59)	0.524	1.28 (0.61-2.71)	0.514
DI	ABETES			
Any diabetes care in past 3 months	0.72 (0.30-1.74)	0.461	0.81 (0.32-2.07)	0.652
Region of residence (ref: Beirut/Mt. Lebanon)				
Bekaa	0.62 (0.22-1.79)	0.374	0.46 (0.14-1.55)	0.209
North	0.66 (0.27-1.59)	0.348	0.62 (0.25-1.56)	0.309
Female-headed HH	0.58 (0.18-1.88)	0.361	0.71 (0.22-2.33)	0.566
HH head completed $\geq$ primary education	2.52 (0.65-9.72)	0.177	2.29 (0.60-8.70)	0.219
Above median monthly HH expenditures*	0.43 (0.17-1.10)	0.076	0.35 (0.14-0.91)	0.031
Arrived in Lebanon 2013-2015 (ref: 2011-2012)	1.00 (0.41-2.44)	1.000	0.93 (0.36-2.35)	0.869
Receipt of cash and/or voucher assistance $^{\dagger}$	1.60 (0.60-4.26)	0.345	1.85 (0.59-5.82)	0.287

Table 5-4. Estimated Odds of Interrupted Medication Adherence Among Syrian Refugees

HH= household. Statistical significance indicated in bold (P < 0.05) and bold italics (P < 0.001).

Interrupted medication adherence is defined as having stopped medication for hypertension/diabetes for two weeks or longer in the preceding year without instructions from a doctor to do so

\* Relative to median monthly household expenditures reported by Syrian refugees

<sup>†</sup> Includes cash or voucher assistance received from a United Nations agency, NGO, or other religious or community group in the month preceding interview. Reference: no cash/voucher assistance received in previous month.



Figure 5-1. Health Access Survey Cluster Assignment by Governorate



Figure 5-2. Reason for Selecting Most Recent Hypertension and Diabetes Care Locations by Facility Type Utilized

\* Includes perceived quality of care, family doctor, or liking facility staff

<sup>†</sup> Includes availability of needed services, medical emergency, and "other"



Figure 5-3. Out-of-Pocket Payments for Hypertension and Diabetes Care in Lebanon by Facility Type Utilized

# Chapter 6. Care-Seeking and Health Service Utilization for Hypertension and Type 2 Diabetes Among Syrian Refugee and Host Community Care-Seekers at Select Primary-Level Health Facilities in Lebanon (Paper 2)

# 6.1. Abstract

**Background**. The ongoing Syrian refugee crisis in Lebanon poses challenges to managing chronic medical conditions. Policies and practices to facilitate care without crowding out Lebanese patients have had some impact; however, the sustained high level of medical need requires evidence to adapt intervention to ongoing demand for quality care.

**Methods**. This paper presents a baseline assessment of patients enrolled in 2015 in a longitudinal cohort study of care-seekers at ten primary health facilities in Lebanon. The primary objectives of this analysis are to assess the baseline frequency of general practitioner (GP) and specialist care visits among Syrian refugee and Lebanese patients, and identify factors associated with continued health care-seeking for hypertension and type 2 diabetes among Syrian refugees in Lebanon. Descriptive analyses were used to explore differences in care utilization between refugee and host community patients. Four negative binomial hurdle regression (NBH) models were used to evaluate the odds and frequency of care utilization for GP and specialist care utilization among Syrian refugees with separate models for hypertension and type 2 diabetes and for GP and specialist visits.

**Results**. Utilization was consistently high for both populations. Refugees were more likely than Lebanese patients to seek care from GPs and to report higher GP visit frequency. Although Lebanese patients tended to rely on specialists' care (cardiologist and/or endocrinologist), the difference from refugees was not significant. In multivariate NBH analyses for patients with hypertension, female sex, YMCA program enrollment and knowledge of stroke as a complication were associated with fewer GP visits and those with above median monthly expenditures had fewer specialist visits. Age between 51-60 years (versus 40-50 years) was also associated with increased frequency of GP care but decreased odds of specialist care. Higher educational attainment had increased odds of GP care, while longer hypertension duration had increased odds of specialist care. Odds and frequency of specialist care decreased for housing instability, but frequency of specialist care increased for comorbid diabetes.

For patients with diabetes, YMCA participants also had less frequent GP care, but increased odds of specialist care. Specialist odds also increased with above median household expenditures. Housing instability was associated with decreased odds and frequency of specialist care; however, the interaction between having above median household expenditures and housing instability had increased odds of GP care-seeking. Age was not significant for patients with diabetes, but the interaction of older age (over 60 years) and longer disease duration (longer than 10 years) had increased GP care odds.

Focus group discussions with patients and health providers identified factors motivating care utilization in both populations: cost, obtaining medication, and the tendency for Lebanese participants to delay care until an emergency required hospital care. They also revealed care system concerns including limited availability of specialists in study clinics and GP self-doubt about clinical knowledge to care for these conditions.

**Conclusions**. Findings illustrate the overall high, but differential care-seeking behaviors of refugee and Lebanese patients and a complex interplay of factors influencing care utilization distinctly for GP and specialist care among refugees. Expanded training to increase GPs' proficiency in managing hypertension and diabetes and improve all providers' adherence to standard treatment guidelines, in addition to improving and scaling coverage of the YMCA program could further support ongoing efforts to improve the quality of non-communicable disease management and health outcomes.

# **6.2. Introduction**

As of June 2019, the Government of Lebanon estimates the country is hosting 1.5 million individuals fleeing the conflict in Syria.<sup>444</sup> Lebanon's health system is strained beyond capacity by the health needs of Syrian refugees and continued host community needs. This burden is exacerbated by the high prevalence of chronic non-communicable diseases (NCDs) in both Lebanese and Syrian populations, notably, type 2 diabetes (estimated prevalence of 8.8% in Syria and 14.9% in Lebanon) and hypertension (estimated prevalence of 24.9% in Syria and 28.8% in Lebanon).<sup>40,49-56,64-66</sup> These conditions require lifelong management, including regular monitoring and follow-up by a health professional to reduce the risk of severe complications.<sup>268,445,446</sup> The emergency response in Lebanon integrates humanitarian and stabilization efforts, seeking to meet refugees' immediate needs while also supporting Lebanon's national capacity, local institutions, and host communities.<sup>447</sup> Healthcare for refugees is embedded in Lebanon's existing health system. Primary healthcare for Syrian refugees is available at subsidized rates (US\$2 to US\$3 per consultation) through more than 100 existing primary health facilities across the country, including the Ministry of Public Health's (MoPH) National Network of Primary Healthcare Centers (PHCCs).<sup>13,79,88,96-99</sup> Lebanon's health system is pluralistic, marked by high out-of-pocket expenditures, disjointed oversight, a dominant private sector, and a surplus of specialists, which account for 81% of providers in the MoPH-PHCC network.<sup>79,80,430</sup> Medication for chronic health conditions are available for the cost of US\$0.67 at more than 400 PHCCs and dispensaries through the Young Men's Christian Association (YMCA) chronic medications program, and the United Nations High Commissioner for Refugees (UNHCR) covers 85% of diagnostic costs in

supported facilities.<sup>414,415</sup> Hospital care for refugees meeting eligibility criteria (i.e., referred from a PHCC or presenting with a life-threatening condition) is subsidized, with UNHCR paying 75% of associated costs above US\$100 and any remaining costs if beneficiary shares exceed US\$800.<sup>37,416,417</sup>

Despite the importance of consistent monitoring and professional care, little is known about NCD patients' care-seeking behaviors in the Lebanese population, and even less so among Syrian refugees. According to a 2014 study of chronic pharmacologic treatment in Lebanon, only 43% of Lebanese patients on antihypertension medication and 35% of those taking oral antidiabetic drugs had all recommended monitoring performed, while 15% of those on antihypertensives and 3% of those on oral antidiabetics did not complete any recommended monitoring tests.<sup>123</sup> In the same study, half of all chronic health condition patients reported visiting a physician annually or less and three percent had medication dispensed by pharmacists with no physician consultation. Though care utilization was not analyzed separately by diagnosed condition(s), 63% of those with partial or no monitoring tests completed for diabetes treatment reported visiting a physician once per year or less (comparable data for patients on antihypertensives were not reported). A 2017 study of Lebanese hypertensive patients had similar results – 56% of hypertensive patients reported not regularly seeing a health provider.<sup>448</sup> Other studies measure treatment rates overall or for select treatment components (e.g., medication prescription, adherence, or behavioral risk factors) rather than care utilization. No estimate of the frequency or regularity of care utilization among Syrian patients was identified either before the crisis or since; however, according to UNHCR's 2018 Health Access and Utilization Survey, 66% of Syrian refugee household members with a chronic condition reported accessing medical care and/or medicines for the condition in the preceding three months.<sup>432</sup>

Since the country's civil war ended in 1990, the MoPH of Lebanon has enacted multiple health system reforms that have substantially improved service delivery, governance, and health outcomes for the Lebanese population. However, disparities in health outcomes and healthcare availability persist by geographic region, sex, and socioeconomic status.<sup>79,449</sup> According to the MoPH, the number of Syrian refugees treated at PHCCs increased by 7.1% from 2013 to 2014 while in the same period, the number of Lebanese patients decreased by 16.6%.<sup>79</sup> Since the added needs of Syrian refugees are on a system not designed or adequately resourced to meet these additional demands, the system's capacity and infrastructure leave both refugee and host communities with unmet health needs.<sup>450</sup> The largest effect has been in the historically underserved and impoverished Lebanese communities, which also have the highest refugee concentrations.

Health service utilization has been extensively researched, though the evidence of factors associated with chronic disease care-seeking primarily comes from stable and/or high-income settings. Common predictors of regular care utilization for chronic conditions across frameworks and models for understanding care-seeking behaviors are extensive and include patient-related factors, provider characteristics, and environmental (including health system) features.<sup>149-157</sup> Prevailing patient-related factors include: (i) demographic and socioeconomic characteristics (e.g., age, sex, education, income, competing resource demands); (ii) condition characteristics such as disease duration, comorbidities, and illness complexity; (iii) attitudes and beliefs including self-efficacy, perceived risks and benefits of care, perceived severity of the illness or need for care; and (iv) psychosocial characteristics such as support and social networks and personal stress.<sup>139-146,151,152,155,156,176,177,181,185,191,451,452</sup> Some provider-related factors that influence care-seeking include the patient-provider interaction/relationship, adherence to clinical guidelines, and provider type (i.e. generalist versus specialist physician, nurse, pharmacist,

etc.).<sup>144,146,147,149,151,156,185,191</sup> Environmental factors include distance to the health facility, health policies, and acceptability, availability, accessibility, and affordability of services.<sup>144-</sup>

Despite a substantial body of research on care-seeking by different populations in varying contexts and, in particular, on care-seeking for hypertension and/or diabetes in stable, highincome settings, there is a paucity of evidence identifying determinants of care utilization for chronic NCDs in contexts of protracted urban displacement such as Lebanon.<sup>139-147</sup> According to the United Nations Interagency Task Force on NCDs, the risk of NCD-related complications is increased in emergency contexts, presumably from disrupted access to medication and/or health services and prolonged interruptions in treatment.<sup>453</sup> Little is empirically known about care-seeking behaviors in these contexts, and importantly about the factors associated with the nature and volume of chronic NCD care-seeking in populations affected by protracted displacement. To improve the humanitarian health response, better evidence is needed about what motivates and what inhibits care-seeking, and how refugees and host communities understand the healthcare and cost options available to them.

The objectives of this analysis are to assess the baseline frequency of general practitioner (GP) and specialist care visits among Syrian refugee and Lebanese patients, and to build upon previous health service utilization models by characterizing factors associated with continued health care-seeking for hypertension and type 2 diabetes among Syrian refugees in Lebanon.

# 6.3. Methods

#### **Data Source**

This paper presents a baseline assessment of health care utilization among Syrian refugee and Lebanese patients enrolled in the *Treatment Guidelines for Hypertension and Type 2*  *Diabetes in Syrian Refugees and Host Communities in Lebanon* study in early 2015. Detailed methods of the parent study are published elsewhere and provided in Chapter 4 and Appendix B for ease of reference.<sup>408,409</sup>

Sample size calculations were based on the parent study's objective of improved quality of care (adherence to guidelines) and reported clinic caseload. A total of 1,010 care-seekers at 10 primary health facilities in the South (n=3), Bekaa (n=3), and Beirut/Mount Lebanon (n=4) governorates were enrolled in the parent study (Figure 6-1). Individuals of all nationalities were eligible to participate; however, those without a diagnosis of hypertension or type 2 diabetes, less than 40 years of age, and adults lacking the capacity to independently participate in interviews were excluded. This analysis presents results from 967 enrolled Syrian and Lebanese patients; other nationalities were excluded due to small sample size and the desired focus on refugees and host community patients.

This study was designed using a mixed methods approach using both qualitative and quantitative data. Patients were recruited from study health facilities. If they indicated an interest in participation, a follow up phone call was made during which verbal consent was obtained and a baseline interview was conducted to collect information on demographic characteristics; medical history and recent care seeking behaviors; and knowledge, attitudes, and practices related to type 2 diabetes and/or hypertension.

In addition to quantitative data collected via phone interviews, 19 focus group discussions (FGDs) were conducted with enrolled Syrian refugee and Lebanese host community patients (75 patient FGD participants), as well as health care providers working at study health facilities (24 provider FGD participants). FGD content concentrated on understanding barriers to care-seeking, treatment, and medication adherence from both patient and provider perspectives. The MoPH in Lebanon and the Institutional Review Board at the Johns Hopkins Bloomberg School of Public Health (JHSPH) approved this study.

#### **Data Analysis**

The care utilization variables analyzed as the outcome of interest were the number of visits to a GP and relevant specialist (endocrinologist, and/or cardiologist). These data were collected in a series of questions during the enrollment interview where each patient was asked how many times they had visited a GP, an endocrinologist, and a cardiologist in the last six months. Given the general and context-specific implications, both positive and negative, of seeking care from a GP versus a specialist, separate analyses were performed to explore utilization in terms of visits to a GP and a specialist. Two-stage models used these care-seeking dependent variables in separate sequential models: first, binarily classified as having had any visit to a GP/specialist, and second, continuously analyzed as the number of visits to a GP/specialist if at least one visit was reported in the first stage model. Explanatory analysis variables included individual and household characteristics and are detailed in Appendix C.

Data were analyzed using Stata 13 (College Station, TX). Initial analyses were conducted to examine the extent of missingness and distribution of variables. Differences between refugee and host community patients were explored through basic descriptive statistics and visual displays of patient characteristics and health service utilization. The type of provider (GP, endocrinologist, cardiologist, etc.) visited was first examined for all patients combined, then separately for Syrian refugees and Lebanese host community patients using Pearson's chi-square and Wilcoxon-Mann-Whitney test methods to compare population groups.<sup>454</sup> An alpha of 0.05 was used for all hypothesis testing.

Syrian refugees and host communities differ substantially. Additionally, financial support for health services can also vary materially between populations, potentially influencing careseeking and the frequency of health care. These differences argue against a single model for both populations, while the small sample of Lebanese patients led to conducting multivariate regression analyses only among Syrian refugees. Care utilization for hypertension and diabetes were analyzed using separate models since each condition has unique characteristics and distinct associations with barriers to and facilitators of care utilization.

Utilization was modeled using negative binomial hurdle (NBH) models, which assume separate decision-making processes for choosing to seek care and for the frequency with which care is sought. In count data such as these, the assumption of equidispersion (i.e., the variance is greater than the mean) necessary for general Poisson models is often violated.<sup>455</sup> Lagrange Multiplier tests identified overdispersion both in the number of visits to a GP and in visits to a relevant specialist for both hypertension and type 2 diabetes patients.<sup>410</sup> As such, six models including Poisson, negative binomial, zero-inflated, and hurdle models were tested for each of the utilization outcome variables included in this analysis. Methods for model testing and selection, as well as goodness-of-fit statistics are provided in detail in Appendix E. Based on quantitative model comparison and consideration of the analysis objectives, final analyses employed four distinct NBH models: (i) GP care utilization among patients with hypertension, (iii) GP care utilization among patients with type 2 diabetes, and (iv) specialist care utilization among patients with type 2 diabetes.

Variable selection for empirical analyses aimed to build uniform models for each outcome variable (i.e., visits to a GP and to a specialist for hypertension and for diabetes) while balancing sufficient parsimony to accommodate statistical modeling assumptions with preservation of the integrity of results. Regression models for both clinical conditions and both GP and specialist care visits without interaction terms were compared to more complex models that incorporated the following interaction terms: (i) time since diagnosis and age, (ii) time since diagnosis and hypertension/diabetes comorbidity, (iii) time since diagnosis and knowledge of condition complication(s), (iv) time since diagnosis and sex, (v) comorbidity and age, and (vi) time in current residence and household expenditure level. To determine whether to include the identified interactions in each of the final models, Akaike (AIC) and Bayesian information criterion (BIC) values were compared following sequential and joint addition of interaction terms to the base model. Interaction terms producing models with a difference of AIC greater than four from the base model were retained.<sup>456</sup> Because hypertension and diabetes manifest differently and in ways that can influence care-seeking behavior, and since utilization of generalist and specialists care vary, this group of interaction terms did not uniformly meet criteria for inclusion in all final models. In the logit model for care received from a GP by patients with diabetes, interaction terms between time since diagnosis and patient age, and between time in current residence and household expenditure level met this criterion and thus were included in the final model. These interactions failed to materially improve the other three outcome models, as did all other interaction terms tested, so were excluded from final models. All models were adjusted with robust estimators of the standard errors to account for heterogeneity between participants recruited from the ten different health facilities.

# 6.4. Results

#### Health Service Utilization: Descriptive Overview

Summaries of patient-reported care utilization in the preceding six months are presented for hypertension (Table 6-1) and type 2 diabetes (Table 6-2). Results are also presented in Figure 6-2 with further disaggregation by condition diagnosis, including comorbid hypertension and diabetes, within each population group.

#### Hypertension

Enrollment interview results indicated that nearly all study participants diagnosed with hypertension (97.7%, CI: 96.4-98.6%) had one or more visits with a health provider in the sixmonths prior to interview, both among Syrian refugees and host Lebanese. Care utilization was highest for visits with GPs, who were seen by 66.1% (CI: 62.8-69.3%) of patients with hypertension. A significantly higher proportion of refugees (69.0%, CI: 65.0-72.9%) saw a GP than did host community patients (60.7%, CI: 54.8-66.3%; P=0.015). Among those reporting any visit to a GP, refugees also reported a significantly higher mean number of visits (2.9, CI: 2.6-3.2) as compared to host community patients (2.0, CI: 1.8- 2.2) (P<0.001).

Cardiologists were the second most commonly utilized provider type among hypertension patients overall (62.8%, CI: 59.5-66.1%) and the most common provider utilized by host community patients (69.2%, CI: 63.5-74.4%). Lebanese cardiologist care-seeking was significantly higher than refugees (59.4%, CI: 55.2-63.5%; P=0.005); however, among patients reporting any care received from a cardiologist, both refugee and host community patients reported a mean of 2.2 visits in the preceding six months (P=0.751).

Fewer than half of patients with hypertension (44.0%, CI: 40.7-47.5%) reported seeing an endocrinologist and an average of 2.3 (CI: 2.1-2.5) endocrinologist visits was reported by all patients with at least one visit. A much smaller proportion of refugee patients (39.1%, CI: 35.0-43.3%) received care from an endocrinologist as compared to host community patients (53.2%, CI: 47.3-59.0%) (P<0.001), though the number of visits was similar in both populations (P=0.513). The high proportion of hypertension patients receiving care from an endocrinologist is

partially due to the relatively high number of hypertension patients with comorbid diabetes (Figure 6-2), indicating more rational utilization than presumed when viewed solely by the presence of hypertension diagnosis. Of all refugee hypertension patients, 18.9% saw only a GP, 25.7% saw only an endocrinologist and/or cardiologist, and 55.4% reported visits to GPs and specialists. Lebanese utilization was similar with 6.1% having seen only a GP, 33.6% only a specialist, and 60.3% both GPs and specialists.

Other providers were utilized less commonly by patients with hypertension than were GPs, cardiologists, and endocrinologists. Ophthalmologist visits were reported by 19.7% (CI: 17.1-22.6%) of patients overall, and were less common among refugees (15.8%, CI: 12.8-19.1%) than Lebanese patients (27.1%, CI: 22.1-32.6%) (P<0.001). Ophthalmologist care was received a similar number of times by refugee and host community patients with an average of 1.4 (CI: 1.3-1.6) visits among all patients visiting at least once (P=0.067).

Visits to a nutritionist were reported by only 2.2% (CI: 1.4-3.5%) of patients, among whom there was an average of 2.2 visits (CI: 1.0-3.3). Relatively few patients (16.3%, CI: 13.9-19.0%) reported seeing other specialists in the preceding six-month period, with an average of 1.7 visits (CI: 1.5-1.9).

Hospitalizations in the same six-month period were reported by 11.8% (CI: 9.5-14.4%) of patients with hypertension. Patients who reported at least one hospitalization had an average of 2.1 (CI: 1.8-2.4) hospitalizations. Refugee and host community patients were similar both in the proportion with any hospitalization and in the average number of hospitalizations (P=0.881 and 0.078, respectively).

# Type 2 Diabetes

As with hypertension, care utilization was high among patients diagnosed with type 2 diabetes, of whom 97.6% (CI: 95.8-98.7%) reported at least one health provider visit within the preceding six months (Table 6-2). Unlike among patients with hypertension, endocrinologists were the most commonly utilized provider type among patients with type 2 diabetes (74.9%, CI: 70.9-78.6%). On average, patients reported 2.6 (CI: 2.3-2.8) endocrinologist visits in this period. GPs were the second most frequently utilized provider by diabetes patients, of whom 62.6% (CI: 58.2-66.8%) reported at least one visit, with an average of 2.5 (CI: 2.2-2.7) visits by GP care-seekers. Similar to hypertension, refugee patients with type 2 diabetes reported a significantly higher number of GP visits (2.8, CI: 2.54-3.2) as compared to Lebanese patients (1.9, CI: 1.7-2.1) (P=0.001). Cardiologists were seen by nearly half (48.9%, CI: 44.5-53.3%) of all patients with type 2 diabetes, with an average of 2.2 visits (CI: 1.9-2.4). Of all refugee diabetes patients, 12.8% saw only a GP, 30.5% saw only an endocrinologist and/or cardiologist, and 56.7% reported visits to GPs and specialists; 4.5% of Lebanese diabetes patients saw only a GP, 35.3% only a specialist, and 60.2% had GP and specialist visits.

Ophthalmologists were utilized by a smaller proportion of patients overall (21.2%, CI: 17.8-25.0%), though more commonly by Lebanese patients (28.9%, CI: 22.7-35.6%) as compared to refugees (16.3%, CI: 12.4-20.9%) (P=0.001). Similar numbers of visits were reported by refugee and Lebanese patients, averaging 1.5 (CI: 1.3-1.7) overall (P=0.135). Similar to hypertension patients, few patients with diabetes (3.1%, CI: 1.8-5.0%) saw a nutritionist in the preceding six months, with an average of 2.1 visits (CI: 1.1-3.2) or other specialist (17.0%, CI: 13.8-20.5%) with an average of 1.6 visits (CI: 1.4-1.8).

Compared to patients with hypertension, hospitalization was less common among those with type 2 diabetes, of whom 6.2% (CI: 4.2-8.8%) reported an average of 1.9 (CI:1.3-2.5)

hospitalizations in the preceding six months. Hospitalizations were similar between refugees and Lebanese, both in the proportion of patients reporting a hospitalization and in the number of hospitalizations (P=0.597 and 0.962, respectively).

#### Predictors of Refugee GP and Specialist Care Utilization

Results from the NBH models for GP and/or specialist care-seeking and utilization for hypertension and type 2 diabetes are presented in Table 6-3.

# Hypertension

#### Probability of care utilization (first stage)

Among patients with hypertension, the odds of having seen a GP were significantly associated only with patient education levels wherein care-seeking odds were 1.47 (CI: 1.01-2.13) times greater for patients who completed primary level education or higher compared to those that did not complete at least primary schooling (P=0.044).

Relative to patients 40 to 50 years old, the odds of specialist care for hypertension were reduced in patients between 51 and 60 years old (OR=0.72, CI: 0.56-0.93) (P=0.011); specialist care-seeking odds were similarly reduced for patients over 60 years in terms of magnitude, but this difference was not statistically significant (P=0.435). Patients who reported having lived in their current residence for one year or less also had significantly lower odds (OR=0.63, CI: 0.47-0.85) of specialist care for hypertension as compared to those who have been in their current residence more than one year (P=0.003). In terms of clinical characteristics, patients initially diagnosed with hypertension more than 10 years prior had odds of specialist care 1.38 (CI: 1.10-1.73) times higher than patients diagnosed within the past 10 years (P=0.005).

Neither GP nor specialist care-seeking by patients with hypertension was significantly associated with patient sex, household expenditures, diabetes diagnosis, enrollment in the YMCA chronic medications program, or knowledge of stroke as a complication of hypertension.

#### Frequency of care utilization (second stage)

Conditioned on reporting at least one visit to a GP within the preceding six months, hypertension patients between 51 and 60 years old had 28% (IRR=1.28, CI: 1.04-1.56) more GP visits than patients between 40 and 50 years old (P=0.018). As with the odds of GP care, the association between age and GP care utilization was not significant for patients over 60 years (P=0.699). Conversely, female patients had 20% (IRR=0.80, CI: 0.67 -0.94) fewer GP visits than men (P=0.008). The number of GP visits was also significantly lower in patients enrolled in the YMCA chronic medications program (IRR=0.43, CI: 0.33-0.56; P<0.001) and marginally lower in patients who were able to identify stroke as a complication of hypertension (IRR=0.77, CI: 0.60-0.99; P=0.042).

Conditioned on having at least one visit to a specialist in the preceding six months, patients with household expenditures above the median amount reported by all Syrian refugee patients had 17% (IRR=0.83, CI: 0.77-0.90) fewer specialist visits for hypertension as compared to those with below median (P<0.001). Housing instability was also associated with fewer specialist visits; patients living in their current residence for one year or less had 25% fewer visits than those in their current residence more than one year (IRR=0.75, CI: 0.57-0.99; P=0.042). In contrast, patients diagnosed with both hypertension and diabetes had 59% more specialist visits compared to patients without diabetes comorbidity (IRR=1.59, CI: 1.32-1.91; P<0.001). The number of GP and specialist hypertension care visits were not significantly associated with education attainment and time since initial hypertension diagnosis.

#### Type 2 Diabetes

#### *Probability of care utilization (first stage)*

For patients with diabetes, housing instability (i.e., having lived in their current residence for one year or less) alone was associated with significantly reduced odds of seeking care from a GP (OR=0.48, CI: 0.23-1.00; P=0.049). Although having above median monthly expenditures is not significant on its own, the interaction between the length of time in current residence and monthly expenditures reveals the effect of shorter time in current residence on reduced GP careseeking odds is overcome in patients reporting above median household expenditures. The main effects of age and time since diagnosis on the odds of GP diabetes care visits were not statistically significant; however, the presence of a significant interaction between these two variables indicates that patients between 51 and 60 years old who were diagnosed more than ten years previously were more likely to have received GP care than would be expected by reporting the main effects of age or time since diagnosis alone, even after adjusting for potential confounders.

As with GP care-seeking, the odds of specialist care-seeking for diabetes were significantly lower (OR=0.56, CI: 0.38-0.82) among those who lived in their current residence for one year or less (P=0.003). Patients reporting monthly household expenditures above the median amount for all refugees had 1.46 (CI: 1.10-1.93) times higher odds of seeking specialist care compared to those with below median household expenditures (P=0.008). Likewise, patients in the YMCA chronic medications program had more than four times higher odds of seeing a specialist (OR=4.23, CI: 1.49-11.95) than patients not enrolled in the program (P=0.007).

Neither GP nor specialist care-seeking for diabetes was significantly associated with sex, education attainment, hypertension comorbidity, knowledge of at least one complication of diabetes, patient age alone [i.e. main effect], and time since diagnosis alone [i.e. main effect].

#### Frequency of care utilization (second stage)

Among patients with diabetes who saw a GP in the preceding six months, those in the YMCA chronic medications program had fewer than half as many GP visits as patients not enrolled in the program (IRR=0.47, CI: 0.31-0.73; P=0.001). Patients living in their current residence for one year or less had 34% fewer visits relative to those with residence durations longer than one year (IRR=0.66, CI: 0.46-0.95; *P*=0.025).

Neither the frequency of visits to a GP nor to a specialist were significantly associated with patient age, sex, or education attainment, household expenditures, hypertension comorbidity, time since initial diabetes diagnosis, or knowledge of at least one complication of diabetes.

#### **Qualitative Findings**

FGDs conducted with patients and health care providers supply additional insights into factors motivating care utilization for hypertension and diabetes in the Lebanese context. When prompted to discuss reasons why patients may not regularly visit health providers for hypertension/diabetes care in Lebanon, nearly all patient FGD participants cited financial reasons first despite existing policies that attempt to reduce financial barriers. At all study facilities, consultations were provided to patients for a nominal fee (approximately US\$2-3 for refugees and comparable, though variable amounts for Lebanese). Although many participants recognized that this subsidized fee schedule is potentially helpful in making care more accessible, they emphasized that even relatively small fees are still not affordable for many people. This affordability barrier was reported both in FGDs with Syrian refugees and in those with Lebanese. As one Lebanese participant summarized, "*All is due to poverty. When you don't have money, you can't seek care.*" Furthermore, when asked how often they visit a health worker for their condition in Lebanon as compared to in Syria prior to displacement, most refugee participants reported seeking care for these conditions at least twice as often before coming to Lebanon. Although not all participants elaborated on why there is reduced care-seeking in Lebanon, all who did so attributed it to the high costs associated with care in Lebanon relative to Syria where they normally received free care. Cost concerns mainly focused on fees for consultation, diagnostic testing, and medications, but several refugee FGD participants in the Bekaa governorate identified transportation constraints, explaining that when they did go to the doctor, they only visit the clinic closest to their home because they cannot afford transportation elsewhere.

In all FGDs with patients and providers, there was a consensus that many, if not most, patients make health facility follow-up visits only to obtain prescribed medication refills. Many study facilities are partnered with the YMCA chronic medications program offering chronic disease medication for approximately US\$0.67; those not included in the YMCA program provide other, comparable assistance either through the supporting international nongovernmental organizations or subsidizing costs directly. Patients almost universally cited health facility provision of free or extremely low-cost medication as their primary incentive for regularly seeking care. Nurses and physicians also agreed that free or reduced-cost medication was the leading reason for patient follow-up visits. Nurses in one Beirut FGD offered a similar scenario based on the requirement for patients enrolled in the YMCA program to regularly see a physician to receive their medication: "Since it is chronic disease, they say we need to keep taking the same medication for the rest of our lives, so they don't come back for check-up. But they are stuck when they come to take their meds from the pharmacy, and they present a prescription which is one year old. At the pharmacy, they are informed that they need to be examined by the doctor. So, they do that not because they are convinced but because they know this is the only way for them to keep getting their meds." – Nurse, Beirut governorate

Similarly, medication stock-outs and unavailability were raised by Syrian and Lebanese patients in Beirut as their reason for not regularly visiting health providers. Participants did not see the value in visiting a doctor if their prescribed medication is not available at the health facility. Lebanese patients raised further concerns that led them to avoid seeking care including the disparity in subsidized costs for refugees relative to Lebanese, and the impact that the large number of Syrian patients has had on health facility conditions. According to many Lebanese patients and nurses in the Bekaa, there are long wait times, loud and uncomfortable waiting areas, and insufficient seating in waiting areas due to over-crowding from additional Syrian refugee patients. Collectively, these are reported to have driven many Lebanese patients to avoid follow-up visits entirely.

FGDs revealed a tendency for Lebanese patients to avoid care visits entirely unless it is for an emergency or they are symptomatic/acutely ill. Physicians and nurses all described instances of patients not receiving routine care until complications were present or comparable crises occurred. In all FGDs with Lebanese patients, at least one patient, and in some groups more than one patient, disclosed personally having not gone to the doctor for extended periods, only to experience an emergency related to their hypertension/diabetes that required them to go directly to the hospital for care. This was far less common with refugees, wherein only one participant claimed not to seek care unless "*the case was severe*."

Though FGD participants did not generally discuss utilization of GP versus specialist care, several described challenges with the overall availability of specialists in the facilities in

which they received care. In many facilities, specialists are only present on select days and during a set time, which limits their capacity to treat all patients seeking specialist care. GPs see patients in these facilities many more hours per week but are not necessarily more accessible for consult as they too have high patient loads. Though it did not emerge as a theme across FGDs with all providers, several GPs, notably those in the South governorate, recognized the limits of their capacities to treat patients with hypertension and/or diabetes and the needs for referral to a relevant specialist. One GP specifically did not prescribe medication for these conditions, explaining: "*I can't go into treatment 100%… Personally, I don't know which meds are available for chronic [conditions], I refer to [a] cardiologist.*"

Most of the study health facilities attempt to implement standards of referral for new hypertension and/or diabetes patients, giving preference to specialist care for patients with confirmed hypertension/diabetes diagnoses. This referral practice has care quality and cost implications depending on facility staffing patterns. For new cases, patients are first seen by a GP for diagnosis and then referred to a cardiologist (for hypertension care) and/or an endocrinologist (for diabetes care). This is minimally problematic in health facilities that have specialists on staff available to see these patients for the same consultation fee as a GP; however, not all facilities have the appropriate specialists working within their clinic, and even those that have specialists only have them on site for limited periods on certain days. When the initial care facility does not have a specialist, patients must pay for two separate visits, in addition to any testing ordered during each of the visits. Moreover, costs for specialist care at another facility may not be subsidized to the same extent as at the initial point of care, potentially involving catastrophically high out-of-pocket fees. Costs at health centers outside the MoPH-PHCC network and/or not supported by outside organizations can vary dramatically, particularly for specialist care, in many cases far exceeding patients' ability to pay. This is notably the case in private clinics, which are

frequently utilized by Lebanese patients, operating with limited, if any, oversight of fee schedules and provision of care.

# 6.5. Discussion

This study provides evidence on care-seeking and health service utilization at primary level health facilities in Lebanon by Syrian refugee and host community patients diagnosed with hypertension and type 2 diabetes. These conditions pose the risk of severe, life-threatening consequences if not properly managed. Both are ambulatory care sensitive conditions, meaning that appropriate intervention at the primary care level can reduce the risk of complications and their accompanying long-term requirements for secondary and tertiary care.<sup>457</sup> Managing these conditions is complex, and requires initiating and maintaining diet and lifestyle changes and, most often, daily pharmacotherapy. Regular monitoring and quality follow-up care by appropriately trained health providers are essential.

Except for hospitalization, which was uncommon for either condition, care utilization was consistently high. However, Syrian refugees and host Lebanese patients showed differing care-seeking behaviors. For each condition, refugees were more likely to seek care from GPs, and to report more frequent GP visits. Lebanese patients, by contrast, tended to rely more on specialists' care (cardiologist for both hypertension and diabetes, and endocrinologist for diabetes), though the difference was not statistically significant. Comorbid hypertension and type 2 diabetes was more common among Lebanese host community patients (50%) than in Syrian refugees (36%). Overall, this suggests that although comorbidity was high in both groups, Lebanese patients were comparatively more clinically complex, possibly contributing to their higher use of specialists. Coupled with Lebanese FGD participants' reported tendency to avoid care-seeking unless conditions require emergency care, and to use private clinics rather than primary level facilities, the long-term cost and clinical consequences of unmanaged comorbidity are potentially quite substantial.

For patients with hypertension, education attainment was the only characteristic associated with odds of seeking GP care - those with more formal education had increased odds of having received GP care in the preceding six months. Previous studies, mainly in higher income countries and not focused on displaced populations, have reported mixed results on the relationship between educational attainment and health utilization.<sup>458-461</sup> While knowledge of their disease (specifically, of stroke as a complication of hypertension) was associated with reduced GP use, the relationship was marginally significant and may be a data artifact. Alternatively, condition knowledge alone is insufficient to lead to the initiation and daily maintenance of the changes required to actively manage a chronic disease. The Transtheoretical or Stages of Change Model, which identifies five stages in the process of moving from initial diagnosis to action and maintenance, posits that each stage requires resources and information tailored to meet a patient's needs at that particular stage. <sup>462,463</sup> Knowledge of stroke as a potential outcome of unmanaged hypertension may not have aligned with the stages that many individual patients in our sample occupied, leading it alone to be insufficient motivation to drive behavior for regular careseeking.<sup>464</sup> In the process of change, in addition to "having the right tools at the right time", principally in terms of disease knowledge, other components of the Transtheoretical Model, such as patient self-efficacy to maintain care and treatment adherence, are critical to designing effective interventions.465,466

Overall high care-seeking rates in this context are likely due in part to subsidized services at study health facilities for both refugees and vulnerable Lebanese patients, and refugee patterns of care-seeking are influenced by numerous governmental, United Nations, and nongovernmental organizations' policies and programs. For example, enrollment in the YMCA chronic medications program was associated with reduced frequency of GP visits for both conditions, yet higher odds of specialist care-seeking for type 2 diabetes. Enrolling in the YMCA program requires extensive documentation, a recorded formal diagnosis with accompanying prescription, and a participating health facility through which patients are required to receive routine follow-up care. Once these have been accomplished, patients can receive medication from the health facility through which they were enrolled, provided that they also receive regular physician consultations, most often with a specialist. The inverse relationship between frequency of GP care with YMCA program enrollment and increased odds of specialist care for diabetes presumably reflect a medical history in Lebanon long enough to have identified and successfully enrolled in the YMCA program and thus established a care history sufficient to directly receive specialist care at the facility through which they are enrolled without triage by a GP. Expanding and improving the YMCA program, specifically in terms of ease of enrollment and implementation of follow-up care requirements, could reinforce access to specialist care in this context.

Beyond programs and policies, medical complexity can modify care-seeking. For example, specialist care for hypertension was understandably higher for those with comorbid diabetes, both in the odds of any care-seeking and in the frequency of visits, suggesting rational use of specialist care by patients with more complex conditions. In addition, the odds of specialist care-seeking for hypertension increased in patients who were diagnosed more than 10 years previously. Although the duration of diabetes alone was not related to odds of GP care-seeking, among patients over 60 years old, a longer duration of diagnosed diabetes was associated with significantly increased odds of GP care-seeking. This is an important interaction given continued efforts by humanitarian organizations and the MoPH to improve care for NCDs and differential targeting of assistance and vulnerability classifications tied to beneficiary age, specifically those 65 years and older. For example, the ongoing World Bank/MoPH Emergency Primary Healthcare Restoration Project (EPHRP) and similar projects include, or are planning to include, an essential care package for individuals 65 and older.<sup>418,419</sup>

For those diagnosed with diabetes more than ten years ago, recent care utilization suggests that a longstanding diagnosis may also be a proxy for established habits of care-seeking that preceded displacement. The elevated odds of GP care-seeking associated with being in the oldest patient age group (over 60 years) and having a diabetes diagnosis for at least 10 years needs to be distinguished from age alone and diabetes duration alone. Neither factor in itself was associated with care-seeking; however, together they identify a group that may be more adaptive or resilient to displacement changes based on experience or long-established routines for managing their condition(s).

Housing instability alone had reduced odds of GP care-seeking. For some, the time in their current residence may reflect an intentional move that would not otherwise indicate vulnerability or instability; however, compared to the 70% of refugees in this study who had been in their current residence for longer than one year, those who had lived in their current residence for less than one year also reported a significantly higher number of total relocations since arriving in Lebanon. This suggests that for many, residence duration may be a valid proxy for household stability, which in turn can influence health service utilization through various mediating factors. Though recent relocation may not innately signify household instability, it warrants further research, including exploration of other types of household instabilities and competing demands on financial resources.

Although the 2018 Vulnerability Assessment of Syrian Refugees in Lebanon (VASyR) found that most refugees had been living in the same accommodation for more than one year,
security of tenure and both individual and collective evictions pose continued concerns.<sup>3</sup> According to the 2018 VASyR, 10% of Syrian refugee households in Lebanon changed accommodation in the prior six months, of whom 36% moved due to eviction and 25% because they were unable to afford rent. More than 6% of households had been evicted at least once since arriving in Lebanon. Housing instability in this context is primarily linked to economic vulnerabilities such as adoption of emergency coping mechanisms, increasing rent costs, and accumulating debt.<sup>3,447</sup> Refugees are not a homogeneous group in terms of socioeconomic standing; consequently, instability in housing may be offset somewhat by higher socioeconomic status and resources. The interaction of having housing instability with above median monthly household expenditures in this study was associated with increased odds of GP care, suggesting that the ability to make greater expenditures may overcome the depression of care-seeking associated with housing instability alone. Alternatively, this and similar counter-intuitive results may reflect unobserved heterogeneity in the sample.

Patient relocation implies abandoning previously utilized facilities near their former residence and finding new providers/facilities in proximity to their new residence.<sup>432</sup> This would be especially difficult for patients enrolled in the YMCA program through a specific health facility/dispensary from which they receive care and medication(s).<sup>467</sup> If a refugee's relocation is not in proximity to their prior residence, identifying a new health facility participating in the YMCA program and reestablishing YMCA enrollment may deter some from continued routine care visits. FGDs in this study and reports from other surveys among Syrian refugees in Lebanon identified transportation costs, in addition to provider or facility costs, as a barrier to care-seeking, suggesting that patients may be unlikely to travel longer distances to see the same provider or obtain YMCA medication from a facility after relocating. The relationship between residence duration and odds of care-seeking, whether for GP or for specialist care, may also be

related to knowledge of subsidized services available in close proximity to their new residence. Despite improvements in recent years, Syrian refugees' knowledge of subsidized health care and services available to them, and where these services can be accessed continues to be cited as a fundamental impediment to care-seeking.<sup>71,432</sup>

Specialist care-seeking, unlike GP care, had no significant interactions. Several individual characteristics did, however, operate in contrasting directions for GP and specialist care-seeking: housing instability was associated with reduced odds of use, while being enrolled in the YMCA program and having above median monthly household expenditures were each associated with elevated odds of seeking specialist care.

Health service utilization is nuanced, and patient decisions reflect considerations based on the context in which care is sought. Syrian refugees in Lebanon are navigating a fragmented health system with a large private sector presence and an excess of specialists, which account for over 80% of physicians in the MoPH-PHCC network.<sup>80,430</sup> Generalist care is often a component of managing NCD patients, though previous evidence indicates benefits from disease control in patients who regularly receive specialist care. Some generalists (in FGDs for this research and in previous studies) report diabetes as being particularly complex to manage, and as having less clear guidance compared to other medical conditions on the steps to achieving treatment targets.<sup>191</sup> In Lebanon, GPs have graduated from medical school but do not complete a residency program, thus, the self-doubt in treating diabetes communicated by GPs during FGDs may not be unfounded.<sup>468</sup>

Though the number of individual specialists working in primary level health facilities often exceeds the number of GPs, specialists' working hours limit the functional supply. Specialists are often inadequately available in primary health facilities to meet the level of patient demand for their services, posing an additional hurdle for refugees seeking subsidized specialist care at supported health facilities. Despite receiving advanced training following medical school, there is little evidence establishing specialists' adherence to treatment guidelines in this context. Findings from the MoPH's initiative for cardiovascular services in the national PHCC network corroborate shortcomings in the quality of care provided for chronic conditions throughout Lebanon's primary healthcare network, noting physicians' overall "deliberate negligence in abiding by guidelines" and generalist physicians' continued tendency to refer patients with chronic NCDs for specialist treatment.<sup>137</sup>

An alternative means for bettering NCD care quality is to improve the care provided by GPs to treat common chronic conditions. Training and capacity building for GPs to treat diabetes and hypertension with a higher degree of both clinical knowledge and self-efficacy could more effectively utilize the existing workforce patterns and physician mix in Lebanon while supporting provision of quality care to all patients in accordance with international treatment guidelines and standards. Building upon the experience of the MoPH's cardiovascular service initiative and expanding health worker training on guidelines and standards of care incorporated into more recent projects such as the EPHRP, Reducing Economic Barriers to Accessing Health Services in Lebanon (REBAHS), and numerous small-scale projects have the potential to improve patient care quality and, in turn, health outcomes for Lebanese and refugee patients alike.<sup>79,137,418,469</sup>

Although past care-seeking behaviors, including preference for specialist/secondary/tertiary care among both Lebanese and Syrian populations do not appear to be prominent in this study, patient preferences, prior beliefs, and expectations of care providers may constrain increased reliance on GPs. Targeted research is needed to assess both Syrian and Lebanese patients' perceptions and beliefs regarding generalist versus specialist care for these conditions and, in turn, whether GP capacity building could be a viable near-term improvement. Previous research, including a 2005 study of collaborative practice in treating chronic illness in a primary health care center in Lebanon, provides evidence of the benefits of GP and specialist interactions and cooperation within health facilities on care quality, cost, and health outcomes.<sup>470,471</sup> Collaborative care models vary, but efficient coordination broadly relies on GPs to provide continuity of care, with limited specialist consultation for complex cases. While collaborative care models show promise, their implementation process, organization, and effectiveness can be condition- and setting-specific.<sup>472</sup> The feasibility of collaborative models requires further exploration at scale in the current Lebanese context.

Syrian refugees bring with them learned behaviors and expectations based on their previous health experiences. In Syria, prior to the current crisis, specialist care could be sought directly, without requiring a GP referral.<sup>473</sup> While this is generally the case in Lebanon, FGDs with health care providers distinguished that in practice many facilities still triage patients through a GP, requiring another visit to see the appropriate specialist, adding cost and likely delaying care. Lebanon does not have a formal referral system, but the ongoing National Accreditation Programme for PHCCs requires referral between primary and secondary care for all accredited facilities. In conjunction with ongoing accreditation efforts, the MoPH is currently piloting a referral system to link facilities in the MoPH-PHCC network with public hospitals in a limited number of municipalities; however, even when implemented at scale, the referral system would not likely include many private sector facilities.<sup>430</sup> Consequently, the public-private, specialist-generalist divide and reliance on insufficiently trained GPs in primary level facilities may persist. Inconsistent oversight within the plurality of Lebanon's health system hinders patient information sharing and inter-facility referrals, threatening the continuity of care essential to effective long-term management of chronic conditions. The scarcity of fully trained primary

care/family physicians and the high cost of specialist care concentrated in privately funded facilities jeopardize the quality, affordability, and long-term accessibility of NCD care.

# Limitations

As with all studies, interpretation of these findings should consider the limitations of the parent study (Appendix B) and present analysis. Use of cross-sectional enrollment data in this analysis prevents causal inference; findings indicate associations, but not necessarily directional causality. Furthermore, the use of self-report to measure multiple variables is a potential limitation of this analysis. Self-reported utilization may provide information not available in medical records; however, utilization is often underreported, especially among patients with higher frequency care-seeking. Additionally, patient knowledge of their exact age and recall of the duration since initial hypertension or diabetes diagnosis may also be inaccurate. Other variables previously demonstrated to be associated with care-seeking and care utilization, such as specific additional comorbidities, disease severity, perceptions and beliefs relating to the conditions studied, and other psychosocial factors were not included in data collection instruments and as such, are not available for this analysis.

### 6.6. Conclusion

These results present both success and areas of focus for improved refugee and Lebanese host community health service utilization for hypertension and type 2 diabetes. Overall GP and specialist care are more accessible than in most humanitarian settings. Findings show greater use of GPs by refugee patients while Lebanese patients rely more on specialist care. Distinct patterns in care-seeking and the factors associated with the odds and frequency of GP and specialist careseeking for both conditions make evident the complex interplay of care utilization determinants among refugees. The nature of Lebanon's health system adds further complexity to patient decisions regarding GP versus specialist care-seeking. Findings from the present study also demonstrate the widespread impact of enduring housing insecurity among Syrian refugees, underscoring the importance of continued advocacy, integrated response, and programs centered on rent support, income-generation, and poverty alleviation for outcomes across sectors.

Limited availability of specialists in primary health facilities despite their overrepresentation across the health system, inadequate GP capacity to treat complex conditions such as hypertension and diabetes, questions about all physicians' adherence to treatment guidelines, and inconsistent referral mechanisms all hinder consistent access to quality care. Expanded training to increase GPs' hypertension and diabetes management expertise and improve all providers' adherence to standard treatment guidelines can further support ongoing efforts to improve NCD management and health outcomes, while improving and scaling coverage of the YMCA program could reinforce access to specialist care.

	<b>Overall</b> (N=847) Point (95% CI)	Syrian Refugees (N=552) Point (95% CI)	Host Community (N=295) Point (95% CI)	P-value
% with ≥1 visit to any health provider	97.7%(96.4-98.6%)	98.0%(96.4-99.0%)	97.2% (94.6-98.8%)	0.506
Number of Health Provid	ler Visits			
General Practitioner				
% with $\geq 1$ visit	66.1%(62.8-69.3%)	69.0%(65.0-72.9%)	60.7%(54.8-66.3%)	0.015
Median <sup>*</sup>	2	2	2	< 0.001
Mean*	2.6(2.4-2.8)	2.9(2.6-3.2)	2.0(1.8-2.2)	• 0.001
Endocrinologist				
% with $\geq 1$ visit	44.0%(40.7-47.5%)	39.1%(35.0-43.3%)	53.2% (47.3-59.0%)	< 0.001
Median Mean*	$\frac{2}{23(21,25)}$	$\frac{2}{23(20,25)}$	$\frac{2}{24(21.26)}$	0.513
Candialagiat	2.3(2.1-2.3)	2.3 (2.0- 2.3)	2.4(2.1-2.0)	
% with >1 visit	62 8% (59 5-66 1%)	59 4% (55 2-63 5%)	69 2% (63 5-74 4%)	0.005
Median*	2	2	2	0.005
Mean*	2.2(2.0-2.3)	2.2 (2.0-2.4)	2.2 (2.0- 2.5)	0.751
Ophthalmologist		, , , , , , , , , , , , , , , , , , , ,		
% with ≥1 visit	19.7%(17.1-22.6%)	15.8%(12.8-19.1%)	27.1%(22.1-32.6%)	< 0.001
Median*	1	1	1	0.067
Mean*	1.4(1.3-1.6)	1.6(1.3-1.8)	1.3 (1.1-1.5)	0.007
Nutritionist				
% with $\geq 1$ visit	2.2%(1.4-3.5%)	1.6%(0.7-3.1%)	3.4% (1.6-6.1%)	0.099
Median			1	0.502
Mean	2.2(1.0-3.3)	2.6(0.6-4.6)	1.8(0.2-3.4)	
Other Specialist(s) $0$ ( with >1 wight	16 20/ (12 0 10 00/)	16 20/ (12 2 10 70/)	1(20/(1222100/))	0.000
$\%$ with $\ge 1$ visit Median*	10.3%(13.9-19.0%)	10.3% (13.3-19.7%)	10.5%(12.2-21.0%)	0.990
Mean*	1.7(1.5-1.9)	1.8(1.4-2.1)	1.5(1.3-1.7)	0.217
Hospitalizations	n=710	n=463	n=247	
% w/ any hospitalization	11.8%(9.5-14.4%)	11.9%(9.1-15.2%)	11.5%(7.8-16.2%)	0.881
Median <sup>†</sup>	2	2	2	0.001
Mean <sup>†</sup>	2.1 (1.8-2.4)	2.1 (1.8-2.5)	2.0(1.5-2.5)	0.708

Table 6-1. Hypertension Care Utilization in the Preceding Six Months

P-value for group comparisons using Pearson's chi-square for proportions and Wilcoxon-Mann-Whitney test methods for continuous variables. Statistical significance indicated in bold (P<0.05) and bold italics (P<0.001).

\* Median and mean number of visits for all hypertension patients with at least one visit to respective provider type

<sup>†</sup> Median and mean number of hospitalizations for those with at least one

	<b>Overall</b> (N=513) Point (95% CI)	Syrian Refugees (N=312) Point (95% CI)	Host Community (N=201) Point (95% CI)	P-value
% with ≥1 visit to any health provider	97.6% (95.8-98.7%)	98.0% (95.7-99.3%)	96.9% (93.4-98.9%)	0.436
Number of Health Provid	ler Visits			
General Practitioner				
% with $\geq 1$ visit	62.6% (58.2-66.8%)	64.7% (59.2-70.0%)	59.2% (52.1-66.1%)	0.206
Median <sup>*</sup>	$\frac{2}{25(22,27)}$	$\frac{2}{28(24,32)}$	2	0.001
Fndoorinologist	2.3 (2.2-2.7)	2.8 (2.4- 3.2)	1.9 (1.7-2.1)	
% with >1 visit	74.9% (70.9-78.6%)	71.8% (66.5-76.7%)	79.6% (73.4-84.9%)	0.047
Median*	2	2	2	0.972
Mean*	2.6 (2.3-2.8)	2.6 (2.3-2.9)	2.6 (2.3-2.9)	0.872
Cardiologist				
% with $\geq 1$ visit	48.9% (44.5-53.3%)	44.2% (38.6-49.9%)	56.2% (49.1-63.2%)	0.008
Median	$\frac{2}{2}$	$\frac{2}{2}$	$\frac{2}{2}$	0.288
Mean .	2.2 (1.9- 2.4)	2.1 (1.8-2.3)	2.3 (1.9-2.7)	
% with >1 visit	21 2% (17 8-25 0%)	16.3% (12.4-20.9%)	28 0% (22 7-35 6%)	0 001
70 with ≥1 visit Median <sup>*</sup>	1	10.370 (12.4-20.970)	1	0.001
Mean*	1.5 (1.3-1.7)	1.7 (1.4-2.1)	1.4 (1.2-1.6)	0.135
Nutritionist			~ /	
% with $\geq 1$ visit	3.1% (1.8-5.0%)	2.9% (1.3-5.4%)	3.5% (1.4-7.0%)	0.704
Median <sup>*</sup>	2	2	1	0 143
Mean*	2.1 (1.1-3.2)	2.8 (0.9-4.7)	1.3 (0.8-1.7)	0.115
Other Specialist(s)				
% with $\geq 1$ visit	17.0% (13.8-20.5%)	17.9% (13.9-22.7%)	15.4% (10.7-21.2%)	0.457
Median Mean <sup>*</sup>	$\frac{1}{16(14.18)}$	$\frac{1}{16(13-20)}$	$\frac{1}{15(13-18)}$	0.690
Hospitalizations	n=465	n-280	$\frac{1.5(1.5-1.6)}{n-1.85}$	
No spitalizations	n = 403	n-200 5 70/ (2 2 0 10/)	n = 10J	0.507
70 w/ any nospitanzation Median <sup>†</sup>	0.270 (4.2-0.070) 1	3./% (3.3-9.1%) 1	0.9% (3.7-11.3%) 1	0.39/
Mean <sup>†</sup>	1.9 (1.3-2.5)	1.9 (1.1-2.7)	1.9 (0.8-2.9)	0.962

Table 6-2. Type 2 Diabetes Care Utilization in the Preceding Six Mo	nths
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P-value for group comparisons using Pearson's chi-square for proportions and Wilcoxon-Mann-Whitney test methods for continuous variables. Statistical significance indicated in bold (P<0.05) and bold italics (P<0.001).

\* Median and mean number of visits for all type 2 diabetes patients with at least one visit to respective provider type

 $^{\dagger}$  Median and mean number of hospitalizations for those with at least one

	General Practitioner		Specialist			
	Logit	ZTNB	Logit	ZTNB		
	OR (95 % CI)	IRR (95 % CI)	OR (95 % CI)	IRR (95 % CI)		
HYPERTENSION						
Patient Characteristics						
Age (ref: 40 – 50 years)						
51 - 60 years	1.19 (0.61-2.34)	1.28 (1.04-1.56)	0.72 (0.56-0.93)	1.16 (0.96-1.40)		
> 60 years	2.01 (0.91-4.43)	1.04 (0.85-1.28)	0.71 (0.30-1.68)	1.32 (0.85-2.06)		
Female	1.34 (0.93-1.94)	0.80 (0.67-0.94)	0.72 (0.41-1.27)	0.96 (0.74-1.25)		
Completed ≥ primary education	1.47 (1.01-2.13)	0.81 (0.48-1.37)	0.69 (0.43-1.13)	1.08 (0.91-1.29)		
Above median monthly HH expenditures <sup>*</sup>	1.19 (0.99-1.43)	1.01 (0.68-1.49)	1.07 (0.50-2.28)	0.83 (0.77-0.90)		
In current residence $\leq 1$ year	1.36 (0.78-2.37)	1.02 (0.75-1.40)	0.63 (0.47-0.85)	0.75 (0.57-0.99)		
<b>Clinical Characteristics</b>	, , , , , ,	, , , , , , , , , , , , , , , , , , ,	, , ,	, , , , ,		
Diabetes Comorbidity	0.86 (0.63-1.16)	0.99 (0.82-1.20)	2.31 (0.99-5.40)	1.59 (1.32-1.91)		
>10 years since diagnosis	0.89 (0.65-1.22)	1.06 (0.75-1.50)	1.38 (1.10-1.73)	0.88 (0.73-1.07)		
Enrolled in YMCA Program	0.74 (0.55-1.00)	0.43 (0.33-0.56)	1.12 (0.44-2.89)	0.81 (0.60-1.10)		
Knowledge of stroke as a complication of HT	1.16 (0.83-1.61)	0.77 (0.60-0.99)	0.87 (0.61-1.24)	1.04 (0.75-1.45)		
	TYPE 2	DIABETES				
Patient Characteristics						
Age (ref: $40 - 50$ years)						
51 - 60 years	1.11 (0.61-2.04)	1.36 (0.85-2.18)	0.84 (0.53-1.33)	1.15 (0.85-1.57)		
> 60 years	1.12 (0.74-1.69)	1.33 (0.77-2.31)	1.09 (0.57-2.08)	1.01 (0.82-1.25)		
Female	0.96 (0.75-1.24)	1.01 (0.77-1.31)	0.85 (0.42-1.70)	1.00 (0.82-1.20)		
Completed ≥ primary education	1.07 (0.64-1.78)	0.68 (0.39-1.20)	0.68 (0.35-1.31)	1.17 (0.73-1.89)		
Above median monthly HH expenditures <sup>*</sup>	0.49 (0.23-1.02)	0.94 (0.60-1.46)	1.46 (1.10-1.93)	0.84 (0.61-1.16)		
In current residence $\leq 1$ year	0.48 (0.23-1.00)	0.95 (0.78-1.17)	0.56 (0.38-0.82)	0.66 (0.46-0.95)		
<b>Clinical Characteristics</b>	, , ,	, , , , , , , , , , , , , , , , , , ,	, , ,	, , , , ,		
HT Comorbidity	1.14 (0.59-2.17)	1.01 (0.74-1.37)	0.87 (0.56-1.36)	1.11 (0.66-1.85)		
>10 years since diagnosis	0.30 (0.08-1.06)	0.89 (0.55-1.45)	1.18 (0.66-2.10)	0.86 (0.63-1.17)		
Enrolled in YMCA Program	0.65 (0.34-1.24)	0.47 (0.31-0.73)	4.23 (1.49-11.95)	0.78 (0.55-1.12)		
Knowledge of ≥1 complication of diabetes <sup>†</sup>	1.20 (0.86-1.66)	1.18 (0.88-1.57)	0.93 (0.42-2.08)	1.02 (0.81-1.27)		
Interactions						
>10 years since diagnosis * age 51 – 60 years	4.31 (0.89-20.77)					
>10 years since diagnosis * age > 60 years	6.83 (1.32-35.46)					
Current residence ≤ 1 year * > median expenditures*	5.26 (1.43-19.31)					

Table 6-3. Odds and Frequency of Care Visits to General Practitioners and Specialists f	or
Hypertension and Type 2 Diabetes in the Preceding Six Months Among Syrian Refugees	5

ZTNB = zero-truncated negative binomial regression; OR = odds ratio; IRR = incidence rate ratio; HH = household; HT = hypertension. Statistical significance indicated in bold (P<0.05) and bold italics (P<0.001). \* Relative to median monthly household expenditures reported by Syrian refugees

<sup>†</sup> Defined as identifying at least one complication of diabetes, including eye problems, kidney problems, foot ulcers, and heart problems. Reference: not able to identify any complication of diabetes



Figure 6-1. Enrolled Sample by Population Group and Diagnosed Condition(s)





HT = hypertension; DM = diabetes mellitus (type 2)

# Chapter 7. Prescription and Adherence to Medication for Hypertension and Type 2 Diabetes Among Syrian Refugee and Host Community Care-Seekers at Select Primary Level Health Facilities in Lebanon (Paper 3)

# 7.1. Abstract

**Background**. Since 2011, the conflict in Syria has displaced more than one million refugees into Lebanon. The high prevalence of non-communicable diseases (NCDs) among both Syrian refugees and the host communities within which they are settled places an immense burden on Lebanon's health system for medicines and medical services. Adherence to prescribed medication is strongly tied to health outcomes for many chronic NCDs, particularly for hypertension and diabetes.

**Methods**. This paper presents a baseline assessment of patients from ten primary level health facilities in Lebanon enrolled in a longitudinal cohort study in 2015. This analysis sought to characterize medication prescription and adherence among Syrian refugee and host community patients, and to identify factors associated with interrupted adherence among Syrian refugees. Differences in household characteristics by population group and interrupted adherence to medication for hypertension and diabetes were examined using Pearson's chi-square and t-test methods. Logistic regression was performed to assess determinants of interrupted medication adherence only among Syrian refugees given insufficient sample size and reports of medication interruption by host community patients.

**Results**. Interrupted medication adherence was low among Syrian refugee and host community patients for both hypertension (12.8% and 1.6%, respectively) and type 2 diabetes (10.0% and 1.6%, respectively). Conversely, qualitative findings from focus group discussions indicate that non-adherence was most often reported for individual doses or a few days at a time, far shorter durations than two weeks or longer specified in the question used to measure

adherence quantitatively. This highlights a crucial shortcoming of quantitative analysis based on measurement of adherence interruption for longer periods of time in this context. For both hypertension and type 2 diabetes, older age and housing stability were protective against interrupted adherence to prescribed medication. Patient enrollment in the joint Ministry of Public Health/Young Men's Christian Association chronic medications program was also protective against interrupted adherence for hypertension, but not for diabetes. Longer time since initial diagnosis was associated with increased odds of medication interruption for diabetes, though not for hypertension. Findings also indicate a potential association between knowledge of the pathological condition, particularly knowledge of possible complications and medication adherence.

**Conclusions**. Continued efforts to scale-up employment of community health workers and/or refugee outreach volunteers to provide health education, monitoring, care, and referral services to vulnerable populations in Lebanon; consideration of diabetes distress in ongoing programming; enhanced pharmaceutical inventory management; and physician training and support for prescribing practices that consider drug availability and cost may support improved medication adherence in this population. This study further suggests that many methods for capturing adherence/non-adherence may lack sufficient reliability in this context given the range of influencing factors and types of non-adherence. As such, caution should be taken in interpreting adherence reports in previous studies, and further efforts made to utilize measures with increased sensitivity to the relevant type(s) of non-adherence in this context moving forward.

# 7.2. Introduction

Since the start of conflict in March 2011, an estimated 7.2 million Syrians have fled to neighboring countries across the region, approximately 1.5 million of whom are currently settled

in Lebanon.<sup>2</sup> The impact of this influx of refugees on the Lebanon's economy, demographics, and stability is pervasive as, with one in six people in the country considered a refugee under the United Nations High Commissioner for Refugees' (UNHCR) responsibility, Lebanon continues to host the world's highest number of refugees relative to its host population.<sup>94</sup> Unlike other countries hosting large numbers of Syrian refugees, Lebanon has not established formal camps for Syrian refugees and there are no health facilities dedicated to providing services only to Syrian refugees (as of the time of writing). UNHCR established an inter-agency mechanism with the Lebanese Government to coordinate the humanitarian response to the Syrian crisis across all sectors. Health assistance for Syrian refugees are subsidized in existing primary health facilities throughout the country and referrals for secondary and tertiary services managed by a private sector third-party administrator.<sup>88,97,98,411</sup>

Like many countries in the region, Lebanese and Syrian populations are in the late stages of the epidemiologic transition from communicable, maternal, neonatal, and nutritional conditions to non-communicable diseases (NCDs).<sup>44-48</sup> Diabetes prevalence has been estimated at 7.4% in Syria and 14.4% in Lebanon.<sup>40,49-54</sup> Though evidence of the burden of hypertension in Syria and Lebanon is not as widely available as diabetes estimates, previous literature has estimated regional prevalence of hypertension at 29.5%, with prevalence in Syria at 24.9%, and 28.8% in Lebanon.<sup>64-67</sup> While estimates of chronic disease prevalence specific to Syrian refugees in the region are limited, the most recently published rates among adult Syrian refugees in Lebanon (2016) estimated 7.4% prevalence for hypertension and 3.3% for diabetes.<sup>67,73</sup>

Effective treatment of hypertension and type 2 diabetes require continued follow-up and monitoring with recommended treatments involving both pharmacological and lifestyle interventions. Failure to intervene pharmacologically when systolic blood pressure is consistently above 130 mmHg or diastolic blood pressure is consistently above 80 mmHg is often associated with worse clinical outcomes including heart disease, stroke, loss of ophthalmic acuity, and kidney failure, resulting in premature disability and mortality.<sup>41,104-106</sup> Much like hypertension, type 2 diabetes management requires a combination of pharmacological, dietary, and lifestyle interventions to sustain "controlled" blood glucose levels (defined as HbA1C<sup>\*</sup> level of 7% or lower) and prevent potentially severe cardiovascular, ocular, renal, and neurological complications.<sup>108,109</sup>

Low or non-adherence to prescribed antihypertensive and antidiabetic medication(s) is strongly associated with poor blood pressure and glycemic control.<sup>225,227,267,268,280-285</sup> Existing evidence has also established an association between medication adherence and quality of life, as well as subsequent medical costs for patients with hypertension and diabetes. Though the specific mechanism through which increased costs are incurred varies, it is primarily related to increased costs related to hospitalizations, emergency room visits, and pathological sequalae associated with inadequate adherence.<sup>225,271,274-278,280,286-292,296</sup>

Comparison of medication adherence rates across studies is limited by the lack of uniform adherence definitions and measurements.<sup>421</sup> Furthermore, though prevailing patient adherence thresholds to meet therapeutic goals have been investigated based upon clinical implications, explicit standards against which to assess population level adherence rates have yet to be established.<sup>421-424</sup> Worldwide, as many as 50% of hypertension patients are estimated to end treatment within the first year following diagnosis; of those who continue treatment, between 50% and 80% consistently take medication(s) as prescribed.<sup>225,297,298</sup> Adherence rates for patients with type 2 diabetes trend similarly, with the bulk of evidence coming from developed countries

<sup>\*</sup> Glycated hemoglobin (HbA1C) is a standard test used to determine average blood sugar levels over extended periods of time (weeks or months)

reporting adherence prevalence ranging from 70% to 80%.<sup>225</sup> Though measurement methods and definitions of adherence vary across studies, a 2011 systematic review of medication adherence among patients with chronic conditions in the Middle East region reported estimated rates of non-adherence ranging from 1.4% to 88% for all chronic conditions; rates for patients with hypertension ranged from 23% to 49.5% and from 1.4% to 27.1% among patients with diabetes.<sup>474</sup> A more recent review of medication adherence in the region reported an overall average non-adherence prevalence of 61.7%, although individual study estimates ranged from 1.4% to 83.3%, further demonstrating the variability resulting from different contexts and measures.<sup>425</sup>

Though not extensively studied or reported, medication adherence among Lebanese with hypertension has previously been recognized as a challenge to disease management.<sup>308,309</sup> "High" medication adherence, as measured and classified by the Morisky Medication Adherence Scale (MMAS), was reported for half (50.5%) of respondents in a 2016 evaluation of medication adherence among Lebanese patients with hypertension, while 27.1% were classified with "medium" adherence, and the remaining 22.4% with "poor" adherence.<sup>308</sup> Another cross-sectional study of Lebanese patients in 2015 revealed far worse adherence for chronic diseases generally: 57.4% of patients were classified with low adherence, 25.7% with medium adherence, and only 16.9% highly adherent, also according to MMAS classifications.<sup>309</sup> Similarly poor adherence has been reported elsewhere in the region, most notably among Palestinian patients with hypertension in the West Bank, among whom the prevalence of "high" adherence was only 16.9%.<sup>318</sup> Comparable adherence estimates for hypertension, diabetes, or chronic conditions broadly among the Syrian population are sparse, both prior to and since the start of the current conflict.

Study of medication adherence among refugee populations is limited, particularly adherence to chronic disease medications. The only such adherence estimate published for Syrian refugees is a 2018 evaluation of primary care NCD services offered by Médecins Sans Frontières (MSF) in Irbid, Jordan. MSF reported that in a convenience sample of 300 Syrian refugee beneficiaries, 89% were classified as having high adherence according to the Medication Adherence Report Scale (MARS-5)<sup>426</sup>. In addition to limitations due to small sample size and selection bias in convenience sampling, this estimate was noted to have been contradicted by non-adherence reported in focus group discussions (FGDs) with sampled beneficiaries and staff accounts, implying potential social desirability bias in adherence reporting. Qualitative findings and ongoing program monitoring from MSF's evaluation found that many more patients reported skipping or reducing doses, temporarily stopping prescribed medication, and sharing medications with others in their families and communities. Comparable adherence estimates are not available for Syrian refugees in Lebanon; however, medication shortages, limited availability, and increasingly prohibitive costs have been reported since the start of the crisis with broad presumption that these and other challenges translate to reduced medication adherence among Syrian refugee populations throughout the country and the region.<sup>93,475,476</sup>

Subsidized consultations and provider services are afforded to Syrian refugees and many host Lebanese at a number of primary health facilities throughout the country. Chronic disease medications are also available at a nominal fee to those enrolled in the joint program between the Ministry of Public Health (MoPH) of Lebanon and the Young Men's Christian Association (YMCA). These medications can be obtained in select dispensaries across Lebanon; however, the process for receiving medicines through the program is extensive and sparsely documented. For refugees and vulnerable host populations, even those receiving subsidized care, the burden of even a small out-of-pocket payment can prevent receiving needed care given the increasing debt and strained financial situation of many households.<sup>102</sup> Despite wide coverage of subsidized care and medications, 39% of Syrian refugees in Lebanon are reportedly not receiving needed medical care due to treatment and/or medication costs. The long-term consequences of this are increased morbidity, mortality, and costs incurred for specialized care for later complications.<sup>103</sup>

The primary objective of this paper is to explore the relationship between predisposing factors and adherence to medication prescribed for hypertension and type 2 diabetes among Syrian refugees in Lebanon. Examining factors associated with reduced or non-adherence to medications for these conditions can inform programming and focus interventions to improve adherence and ultimately, clinical outcomes. Secondarily, this paper also characterizes differences in medication prescription and use between Syrian refugees and host communities to understand whether and to what extent disparities are present.

# 7.3. Methods

## **Data Source**

The present analysis utilizes baseline data from a larger study, *Treatment Guidelines for Hypertension and Type 2 Diabetes in Syrian Refugees and Host Communities in Lebanon*, implemented in ten primary health facilities in Lebanon from 2014 through 2016. Detailed methods of the parent study are provided in Chapter 4 and Appendix B.<sup>408,409</sup>

Participants consisted of patients at 10 study health facilities supported by the International Organization for Migration (IOM) or International Medical Corps (IMC). in Lebanon's South (n=3), Bekaa (n=3), and Beirut/Mount Lebanon (n=4) governorates. Individuals of all nationalities, including both Syrian and Iraqi refugees, in addition to Lebanese and Armenian patients, were enrolled; however, those without a diagnosis of hypertension or type 2 diabetes, less than 40 years of age, and adults lacking capacity to independently participate in interviews were deemed ineligible for participation. Sample size for the parent study was informed by clinic caseloads, and the proportions of patients expected to be reachable by phone (80%) and willing to participate (80%). Calculations assumed the most conservative baseline rate of 50% for provider adherence to guidelines,  $\alpha = 0.05$ ,  $\beta = 0.20$  (power = 0.80), and were one-sided based on the assumption that provider compliance would not decrease. A maximum sample size of 1,609 participants was projected; however, fewer participants were successfully enrolled due to over-estimation of clinic caseloads. The final study sample included 1,010 patients and is presented by population group and diagnosed condition in Table 7-1.

Patients at study health facilities with hypertension and/or type 2 diabetes diagnoses were identified by facility staff and asked if they were willing to participate in the parent study, A follow up phone call to patients interested in participation was made by study staff during which verbal informed consent was obtained and documented in survey forms. Verbal informed consent was obtained with approval of the Institutional Review Board at the Johns Hopkins Bloomberg School of Public Health (JHSPH) because interviews were conducted over the phone, and thus, did not involve in-person contact between the study team and patients. After consent, a baseline interview was conducted to collect patient demographic characteristics; medical history and recent care seeking behaviors; and knowledge, attitudes, and practices related to type 2 diabetes and/or hypertension. Medical record reviews were also conducted following enrollment, collecting data related to each patient's clinical history and provider compliance with guidelines.

In addition to quantitative data, 19 focus group discussions were conducted with enrolled Syrian refugee and Lebanese host community patients, in addition to health care providers working at study health facilities. FGD content centered on more detailed information about barriers to care-seeking, treatment, and medication adherence from both patient and provider perspectives. Detailed methods for qualitative data collection and analysis are provided with parent study methods in Chapter 4 and Appendix B.

This study was approved by the MoPH in Lebanon and the Institutional Review Board at the Johns Hopkins Bloomberg School of Public Health.

### Variables

A wide body of evidence supports the role of medication adherence as a principal factor on the causal pathway to improved disease control in patients with hypertension and type 2 diabetes.<sup>269</sup> Interrupted medication adherence was assessed as a binary variable based on whether or not patients reported having stopped medication for two weeks or more in the six months prior to study enrollment. Adherence was measured separately for medications to treat hypertension and those for diabetes. An analysis of the validation of this question for capturing adherence compared to the four-item Morisky Medication Adherence Scale (MMAS-4) is provided in Appendix F.

Explanatory variables included in analyses consisted of patient demographic and clinical characteristics and are provided in detail in Appendix C.

## **Data Analysis**

Results from the *Treatment Guidelines for Hypertension and Type 2 Diabetes in Syrian Refugees and Host Communities in Lebanon* study previously published elsewhere suggest a relatively minimal difference in key outcomes across study periods following longitudinal study intervention.<sup>408,477</sup> Additionally, considering the relatively rare reporting of interrupted medication adherence in patients with hypertension (8.9%) and type 2 diabetes (6.7%) alike, baseline data provides the largest available sample without the influence of loss to follow-up or parent study interventions. As such, this paper presents a baseline assessment of study participants, providing evidence of patients' behaviors and characteristics without additional intervention to most effectively inform recommendations for the Syrian refugee response in Lebanon.

Data were analyzed using Stata 13 (College Station, TX). Exploratory data analyses were conducted to investigate the extent of missingness and distribution of variables to be included in analyses. Basic descriptive statistics and visual displays of household characteristics and medication use were examined for the salient comparison groups: population group (Syrian refugee versus Lebanese host community), and interrupted medication adherence (stopped for two weeks or longer vs did not stop). Differences in participant characteristics by population group and interrupted medication adherence classification were examined using Pearson's chi-square and t-test methods. An alpha of 0.05 was used for all hypothesis testing.

Given the relatively small host community sample size, insufficient number of Lebanese host community participants reporting interrupted medication adherence, and the distribution of covariates of interest, multivariate logistic regression analysis was conducted only among Syrian refugees. Assessment of medication prescription and use in the host community was a secondary objective, thus, differences between refugee and host community populations are explored through descriptive statistics and compared using Pearson's chi-square and t-test methods but excluded from regression analyses.

Diagnostic assessments were performed to determine the appropriateness of analytical techniques. Taking into consideration the constraints of sample size that could be realized in this setting, variable selection for adjusted analyses sought parsimonious final models accommodating sufficient variance to meet model assumptions. Because the conditions themselves are in many

ways so different and the nature of illness can influence conditional or non-adherence, data for hypertension and diabetes were analyzed using separate models.

Logistic regression was performed to determine the crude and adjusted odds of interrupted medication adherence among Syrian refugees. Interaction terms for patient characteristics (e.g. age, sex, education, household expenditure level, time since diagnosis etc.) with key explanatory variables were tested using both joint and sequential additions to the base model. None of the tested interactions significantly improved the model fit for either hypertension or diabetes adherence models when assessed using the Akaike (AIC) and Bayesian information criterion (BIC) values as well as both Wald and likelihood ratio tests; thus, interaction terms are omitted from the final models.

### 7.4. Results

#### **Medication Prescription and Current Use**

A summary of prescription and adherence to medication for hypertension and type 2 diabetes as reported by enrolled patients is presented in Table 7-2. An overview of specific medication prescribed to patients based on facility health records is presented in Appendix G.

### Hypertension

Medication prescription for hypertension was consistently high in the study sample, with all patients self-reporting ever having been prescribed medication for hypertension and nearly all (98.1%, CI: 96.3-99.1%) reporting current medication use for hypertension (Table 7-2). Prescriptions were reported less frequently in the health records available for these patients wherein 69.9% (CI: 66.4-73.3%) of all patients with hypertension had documentation of prescribed medication. Sparse record keeping, coupled with varied incentives across the ten study facilities and overall absence of consequences for not recording dispensing in many cases may mean that there were an unknown number of medicines prescribed or dispensed but not recorded. Prescription reporting in health records was statistically significantly lower among Syrian refugee patients with hypertension (66.5%, CI: 62.1-70.6%) as compared to Lebanese host community patients (77.3%, CI: 71.3-82.6%) (P=0.003). Among all patients with hypertension, an average of 1.79 (CI: 1.71-1.86) medications for the condition were reported in health facility records at enrollment; this figure was similar for Syrian refugees and host community patients. Of the 502 patients with medication for hypertension reported in health facility records at enrollment, 30.3% (CI: 26.3-34.5%) had at least one medication newly prescribed at the most recent visit. Newly prescribed medication was significantly more common among Syrian refugee patients, of whom 38.8% (CI: 33.4-44.3%) reported at least one newly prescribed medication as compared to only 14.7% (CI: 9.8-20.8%) of Lebanese host community patients (P<0.001).

### Type 2 Diabetes

As with hypertension, all patients with type 2 diabetes self-reported medication prescription for the condition during study enrollment (Table 7-2). Prescriptions recorded in patient health records for those with type 2 diabetes were also similar to those with hypertension; 72.4% (67.1-77.2%) of all patients with type 2 diabetes had documentation of medication prescribed for the condition. As with prescriptions for hypertension however, limited record keeping in study health facilities may have resulted in additional medication prescribed or dispensed to participants but not documented in patient records.

Among patients with type 2 diabetes, an average of 1.43 (CI: 1.37-1.49) medications for the condition were reported in facility records at baseline; this was similar for Syrian refugees and Lebanese host community patients (P=0.659). At least one medication was newly prescribed at the most recent visit for 26.4% (CI: 21.5-31.7%) of the 307 patients with type 2 diabetes medication prescription(s) reported in facility records at enrollment. As with prescribing for patients with hypertension, the proportion of patients with diabetes with at least one newly prescribed medication was significantly higher among Syrian refugees (32.5%, CI: 26.0-39.5%) as compared to the Lebanese host community (15.5%, CI: 9.3-23.6%) (P=0.001).

#### **Interrupted Medication Adherence: Descriptive Overview**

Patients who reported having stopped medication prescribed for hypertension or type 2 diabetes against medical advice for two weeks or longer in the six months preceding interview were classified as having "interrupted medication adherence". Self-reported medication adherence was high among patients with hypertension and type 2 diabetes throughout follow-up (Table 7-2). At enrollment, 9.3% (CI: 7.3-11.7%) of all patients with hypertension reported having stopped prescribed medication for the period of time in question, while 8.9% (CI: 6.9-11.2%) of patients were classified as having interrupted medication adherence (i.e., having stopped without instruction from a health provider to do so). Among patients with type 2 diabetes, 7.1% (CI: 4.9-9.8%) reported having stopped prescribed medication and 6.7% (CI: 4.6-9.3%) were classified as having interrupted adherence. Observed differences in interruption of medication adherence for hypertension and diabetes without instruction from a physician were statistically significant between Syrian refugee and Lebanese host community patients. Among Syrian refugee patients with hypertension, 12.8% (CI: 9.9-16.2%) had interrupted medication adherence at enrollment compared to only 1.6% (CI: 0.4-4.1%) of host community patients (P<0.001). Interrupted adherence to medication for type 2 diabetes was observed in 10.0% (CI: 6.7-14.1%) of Syrian refugee patients as compared to only 1.6% (CI: 0.3-4.6%) of host community patients (P<0.001).

Reasons for medication interruption were similar by condition and primarily concentrated on cost, as was reported by 71% of patients with interrupted adherence to medication for hypertension and 77% of patients with type 2 diabetes. The other most frequently cited reasons for interruption were not knowing where to obtain the medication, inability to locate a pharmacy with the medication in stock, and patients' perceptions that their condition had improved. Interruption motivated by patients' perceived condition improvement is particularly challenging as, given that hypertension in particular is largely asymptomatic, patients may ascribe symptoms to their disease that may not be related.

# **Predictors of Interrupted Medication Adherence**

Results of univariate and multivariate logistic regression analyses for predictors of interrupted medication adherence for hypertension and type 2 diabetes among Syrian refugee patients are presented in Table 7-3.

### Hypertension

Odds of interrupted adherence to medication for hypertension were significantly associated with the number of years since diagnosis (-) and knowledge of stroke as a complication of hypertension (-) in univariate analysis but not in adjusted analysis. The crude odds of interrupted medication adherence were 0.48 (CI: 0.27-0.84) times lower for patients able to identify stroke as a possible complication of hypertension as compared to those unable to identify this complication (P = 0.010). The number of years since initial hypertension diagnosis was also protective, showing reduced odds of interrupted adherence in those diagnosed 10 or more years ago as compared to those diagnosed fewer than five years ago (OR=0.26, CI: 0.11-0.9765 P=0.004).

After adjusting for other covariates of interest, the odds of interrupted medication adherence were significantly associated with enrollment in the YMCA chronic medications program (-), patient age (-), education level completed (primary or higher) (+), and having lived in current residence location for one year or less (+). Patient enrollment in the YMCA chronic medications program was associated with decreased odds of interrupted medication adherence for hypertension (OR= 0.35, CI: 0.14-0.86, P = 0.023), as was older age (OR=0.96, CI: 0.93-0.99; P=0.025). Conversely, completion of primary education or higher was associated with significantly higher odds of medication interruption (OR= 2.48; CI: 1.26-4.88) compared to those who completed no formal or less than primary education, after adjusting for other variables of interest (P=0.008). Housing insecurity, measured as having lived in the current residence for one year or less, was also associated with significantly higher odds of medication interruption (OR= 2.70, CI: 1.46-4.99) as compared to patients who have lived in their current residence for longer than one year (P = 0.001).

There was no statistically significant relationship between the adjusted odds of interrupted medication adherence for hypertension and diabetes comorbidity, time since diagnosis, knowledge of stroke as a complication of hypertension, patient sex, or monthly household expenditures.

#### Type 2 Diabetes

The adjusted odds of interrupted adherence to medication for type 2 diabetes were significantly associated with time since diagnosis (+), patient age (-), and having lived in current residence for one year or less (+). Longer duration of time since diagnosis was associated with increased odds of interrupted adherence. Compared to patients initially diagnosed with diabetes less than five years ago, those diagnosed between five and nine years ago were 3.03 (CI: 1.03-

8.87) times more likely to report interrupted medication use (P=0.043). Patients diagnosed ten or more years ago had 3.59 (CI: 1.14-11.35) times higher odds of interruption compared to those diagnosed less than five years prior to the interview (P=0.030). Conversely, older age was associated with lower odds of interrupted adherence (OR: 0.92, CI: 0.87-0.98; P=0.011). Housing insecurity, defined as having lived in the current residence for one year or less, was also associated with higher odds of medication interruption (OR= 3.46, CI: 1.44-8.34, P=0.006).

There was no statistically significant difference in adjusted odds of interrupted adherence to medication for type 2 diabetes by hypertension comorbidity, patient enrollment in the YMCA chronic medications program, knowledge of at least one complication of diabetes, sex, education level completed, or monthly household expenditures.

### **Additional Contextual Factors and Considerations**

Quantitative results from this study indicate high levels of adherence in both Syrian refugee and Lebanese host populations, aligned with estimates from a 2018 evaluation of MSF's NCD care program for Syrian refugees in Jordan.<sup>426</sup> Qualitative evidence from the aforementioned evaluation however, in addition to program staff reports and documentation of medication shortages, availability concerns, and prohibitively high costs suggest that medication adherence is a particular challenge for Syrian refugee populations throughout the region with chronic health conditions managed with pharmacotherapy.<sup>93,475,476</sup>

Through FGDs conducted with individuals and health care providers participating in the *Treatment Guidelines* study and anecdotal feedback, insights were obtained that in some areas reconcile prior reports of medication accessibility, availability, and affordability challenges in this context with the current study's quantitative study findings. Many FGD participants, both Syrian and Lebanese, reported less than perfect adherence to medication prescribed for hypertension and

type 2 diabetes; however, the key insight from the qualitative data was that most often nonadherence was reported for durations of less than two weeks at a time. A few participants discussed stopping medication for one week at a time and a small number acknowledged simply forgetting to take the medication from time-to-time. Most patients, however, described intentionally skipping or reducing individual doses to make filled prescriptions last longer, albeit potentially at sub-therapeutic levels, rather than stopping medication for more extended periods of time. This would not be detected in the single-question measure of adherence used in quantitative tools for this study, which classified adherence based on stopping medication for a period of two weeks or longer. These observations suggest specific refinements to enhance the utility of quantitative adherence measures for future research.

Both Syrian refugees and Lebanese host community participants explained that they try to extend the time before refills in an effort to save on the cost of medication and also out of fear they would not be able to locate a pharmacy or health facility with medication in stock. When asked about the availability of medications prescribed for their conditions, participants' responses varied by the specific medication they sought. For example, one Lebanese participant in the Bekaa reported that Insulin had not been available for the preceding four months, and that other medications had been unavailable for varying periods ranging from one month to one year. Across geographic locations and participant nationalities, even if some medication is available at times, the sporadic and unpredictable nature of availability was a prominent concern and a clear driver of taking medication less frequently than instructed. As one Lebanese participant in the Bekaa claimed, "90% of people would take meds if they were provided."

The trend of patients' self-initiating modification of medication dosing was also raised by health care providers during FGDs, particularly in the South governorate. Physicians seemed aware of many patients skipping doses or otherwise not following instructions on how and when to take prescribed medications, and of the challenge of inconsistent availability of multiple classes of drugs. Many, though not all, providers described efforts to prescribe medication, or a medication class, that would be available at the health center.

In-house dispensaries at the ten health facilities included in this study varied in their size, capacity, staffing, sourcing, and reporting systems. Nonetheless, dispensing and stock-out reports from facility assessments conducted at the start of the study in late 2014 corroborate many of the medication availability challenges raised in FGDs with patients and providers. While some facilities maintain stock of all, or most, of the medications for hypertension and type 2 diabetes listed on Lebanon's 2014 Essential Medicines List, many include only some of these medications on their formularies. For example, one of the smaller study facilities located in the Greater Beirut/Mount Lebanon region reported only carrying Metformin (Glucophage) and Amlodipine (Amlor). Other essential medications for these and co-occurring conditions include Gliclazide (Diamicron), Acenocoumarol (Sintrom), Amiodarone (Cordarone), Digoxin (Lanoxin), Hydrochlorothiazide (Esidrex), Molsidomine (Corvasal), and Valsartan (Diovan). These medicines either have never been procured or were not procured in the year preceding facility assessment at all three facilities in the South governorate. This may support the reported limited medication availability raised in FGDs, particularly in the South governorate. For example, patient health records indicated that 52.6% of enrolled patients with type 2 diabetes were prescribed Gliclazide (Diamicron) during the study period, despite the facility assessments' indication this medication had never been purchased. At two larger health facilities in the Bekaa, Metformin (Glucophage) was prescribed for more than 65% of study patients with type 2 diabetes; however, that medicine was reportedly out of stock for 15 and 35 days, respectively, in the three months prior to baseline facility assessments. In one of these facilities, Amlodipine

(Amlor), prescribed for nearly 30% of patients with hypertension was also reportedly out of stock for 15 days in the same three-month period.

In FGDs, some physicians attributed skipped doses or interrupted medication adherence not only to financial reasons or medication availability, but also, or instead, to patients feeling well or "*think[ing] they aren't really sick*." In contrast to patient FGDs, much of the discussions with health providers focused on patients' ability to understand instructions on how and when to take prescribed medication and patient knowledge of complications that may present if they do not correctly take medication. Patient illiteracy was reported by many physicians as a barrier to medication adherence. While some described approaches for mitigating the issue, including giving oral instructions and drawing symbols on medication packaging to demonstrate when it should be taken, accommodations were not discussed by all participating health providers.

Providers also differed in their confidence in patients' understanding of complications of their condition(s) and the consequences of not taking medication as prescribed. Many physicians and nurses did not think patients adequately understood the severity and range of consequences they may face as a result of not adequately caring for themselves or adhering to prescribed medications. Others felt that, as a physician in the South governorate explained, "*some know the consequences, but neglect them.*" Participants in FGDs with both Lebanese and Syrian refugee patients not only reported knowing the consequences of non-adherence, but in many cases named specific complications and described experience with these complications, either directly or as experienced by family members and neighbors.

The divergence in emergent themes from FGDs with patients and those with providers may reflect providers' focus on the elements perceived to be more within their ability to affect, while overlooking the potential role of factors further from their ability to control directly in the patients' brief visits, such as psychosocial factors. The range of influences to which healthcare providers attributed poor medication adherence among patients reflects the breadth of factors that have previously been shown to influence self-management behaviors, including medication adherence. Substantial evidence has demonstrated that there is generally no single factor driving a patients' medication use, but rather a complex interplay among numerous domains including, but not limited to, medication affordability and availability; health literacy (including patients' understanding of diagnosed conditions, the importance of adherence to prescribed medication(s), the consequences of non-adherence, and potential complications); patient-provider relationships; patients' health beliefs; and psychosocial factors such as social support, psychological distress (particularly in the case of diabetes), and self-efficacy.<sup>225,276,324,331,338,342-345,379,381,382,384,478</sup>

Patient knowledge measured by their ability to identify complications of hypertension and diabetes during phone interviews was comparatively low relative to the large proportion of FGD participants who demonstrated an understanding of the complications of non-adherence to prescribed medication (Table 7-4). During enrollment interviews, only 42.2% (CI: 29.9-55.2%) of patients who reported having stopped anti-hypertension medication use for two weeks or longer correctly identified stroke as a complication of hypertension, as compared to 64.5% (CI: 60.8-68.2%) of patients who did not stop medication use in this period (P<0.001). Patients who did not stop diabetes medication also correctly identified a larger number of diabetes complications, on average, than patients reporting interrupted medication use (1.29 and 0.76, respectively; P=0.016). The proportion of patients with type 2 diabetes who were unable to identify any correct diabetes complications was larger among those who reported medication interruption (54.5%, CI: 36.4-71.9%) than among those without interruption (36.9%, CI: 32.5-41.5%) (P=0.043), indicating a potential area for intervention in future attempts at improving adherence in these populations.

# 7.5. Discussion

While multiple factors influence medication adherence among Syrian refugees in Lebanon, this study suggests that methods for capturing adherence/non-adherence have unstable reliability in this context. Nonetheless, these results indicate areas in which targeted interventions may reduce gaps in medication use for hypertension, type 2 diabetes, and potentially other chronic medical conditions requiring pharmacotherapy. Moreover, study results highlight specific methodological concerns that must be considered and addressed in future research and suggest substantive areas worthy of further study to strengthen evidence regarding factors influencing medication use and adherence in both Syrian refugee and host community populations in Lebanon.

#### **Implications and Recommendations for Intervention**

Among care-seekers at primary health facilities in this study, predictors of interrupted medication adherence were somewhat consistent between persons having hypertension and those with diabetes. For both hypertension and type 2 diabetes, older age and housing stability, defined as having lived in the current residence for longer than one year, were protective against interrupted adherence to prescribed medication. Previous studies have determined a clear link between housing stability and medication adherence for a number of chronic conditions.<sup>479-484</sup> It is not apparent from the data what additional factors may be influencing this relationship, though conceptually this may be tied to socioeconomic factors or increased awareness of how and where to access subsidized care and medications when living in a single location for longer periods. To our knowledge, this is the first demonstration of the association between stable housing and adherence in a humanitarian setting, providing support for multi-sectoral intervention efforts moving forward.

Education attainment in this study was also associated with interruption of medication for hypertension but not for diabetes and not in the expected direction: higher education attainment (i.e. having completed primary education or higher as compared to some primary or no education completed) was associated with significantly higher odds of medication interruption. Evidence from the literature regarding the association between education attainment and adherence is mixed. Most previous studies were unable to confirm a significant relationship, while others demonstrated improvement in medication adherence with increased general education.<sup>318,329,485-488</sup> It may be that the analysis categories, which are logically based on the distribution in this population, are too broad to detect this difference and that the protective effect of education is only present at higher levels of education (e.g. secondary schooling and beyond). Further research is warranted to confirm and better understand the mechanism(s) for this association.

Longer time since initial diagnosis was also associated with increased odds of interrupted medication adherence for diabetes, though not for hypertension. This association held despite tests of adjustment for the interaction between time since diagnosis and age, suggesting that the relationship is not simply an artifact of the association between age and medication adherence, which has been shown with mixed results in previous studies.<sup>289,293,320-322,324,325</sup>

While further exploration is needed, gaps in medication adherence with longer duration of disease may be a consequence of the burden of managing glycemic control and the emotional toll of long-term threat of complications, indicating that diabetes distress could expresses itself as a cumulative function over time. This possibility, coupled with emergent themes during FGDs with patients and health providers suggest that ongoing efforts by local and international organizations to mitigate the challenges Syrian refugees with diabetes face in meeting health needs (e.g. provider training, patient education, and support) may benefit from taking diabetes distress into account. Diabetes distress is a condition involving the specific emotional response to

diabetes diagnosis and the associated burden and worries. Distinct from clinical depression, distress specifically related to diabetes influences not only behavioral indicators (e.g. diabetes self-efficacy, self-management behaviors, and overall quality of life), but also biological indicators (e.g. glycemic control).<sup>489</sup> Diabetes distress is defined across four main domains: "(i) emotional burden (e.g., "feeling overwhelmed by the demands of living with diabetes"), (ii) physician-related distress (e.g., "feeling that my doctor doesn't take my concerns seriously enough"), (iii) regimen-related distress (e.g., "feeling that I am not sticking closely enough to a good meal plan"), and diabetes-related interpersonal distress (e.g., "feeling that my friends/family don't appreciate how difficult living with diabetes can be")".<sup>490,491</sup> While diabetes distress and the aforementioned psychosocial factors were not measured in our studies, it is possible that comments by providers during FGDs about the tendency for some patients to ignore treatment instructions despite understanding the consequences of non-adherence may be driven by these factors or a combination thereof. The higher prevalence of interrupted medication adherence among Syrian refugees than among Lebanese, though certainly reflecting population differences in numerous variables, may also be mediated by increased psychological distress brought about since the start of the crisis in Syria and continuing as they navigate the challenges of finding their way in a new life in Lebanon.

Diabetes distress can be integrated into existing programs in many ways, ranging from "acknowledgement, education and support that considers distress an expected part of diabetes" to formal problem solving training related to anticipating and addressing diabetes-related stressors.<sup>492</sup> Adaptations of existing programs to accomplish this aim require minimal effort and funding, and in other settings, have shown to improve patient outcomes in various domains including self-efficacy, self-management behaviors, and ultimately blood pressure, HbA1C, and related clinical outcomes.<sup>490,493</sup> Somewhat surprisingly, the odds for interrupted antihypertensive and antidiabetic medication use were not associated with hypertension/diabetes comorbidity, knowledge of stroke as a complication of hypertension/knowledge of at least one prominent complication of diabetes, patient sex, or monthly household expenditures. In addition to the findings discussed above that offer insight into potentially beneficial interventions, these and similar null findings, individually and collectively, can also guide the nature and focus of interventions to reduce interrupted medication adherence in this and similar contexts.

FGDs conducted with individuals and health care providers participating in the *Treatment Guidelines* study revealed information that reconcile previous suppositions about medication nonadherence and quantitative study findings. The central insight from FGDs is that non-adherence was most often reported for durations of less than two weeks at a time, highlighting the crucial shortcoming of quantitative measurement of adherence interruption for longer durations. While not counterintuitive, additional themes emerged in FGDs that support specific actionable programming interventions to reduce discontinuities in medication use for chronic medical conditions in which continuous high adherence to medication is essential to avoid serious secondary and tertiary consequences of the underlying disease. For example, limited patient understanding of the potential complications if these conditions are not properly managed and inconsistent availability of medication in accessible dispensaries.

Though a causal relationship cannot be demonstrated, both quantitative and qualitative findings indicate a possible association between a patient's knowledge of their pathological condition, particularly knowledge of possible complications or consequences of damage to the microvasculature, and medication adherence. General education is insufficient to influence adherence, condition-specific education is required. Potential strategies to employ could include contemporaneous patient health education and targeted health provider training. In particular,

increasing employment of community health workers (CHWs) and/or refugee outreach volunteers (ROVs) may provide an affordable approach for delivering not only health education, but also more continuous monitoring, care, and referral services, for Syrian refugees with chronic health conditions. Programs that make use of CHWs and ROVs for community-based implementation have shown promising results for improving chronic disease care among Syrian refugees and in numerous other contexts.<sup>494-502</sup> ROVs are an extension of the CHW concept, where refugee volunteers are trained in a variety of areas to provide information and services to other refugees in their communities. Expansion of the ROV workforce in Lebanon to provide health education sessions and to assist other refugees in accessing essential services for chronic health conditions have the potential to provide an affordable solution to the challenges highlighted in this study. Given the expectation that the Syrian refugee population will remain in Lebanon for quite some time, such community-driven, cost conscious, and sustainable interventions are essential to improve health behaviors and access to health care. As an added benefit, ROV programs have proven to be beneficial both to refugees with chronic conditions and to UNHCR and implementing partners. ROVs provide them with a link to refugee communities, a better understanding of the communities they serve, and a sustainable presence to improve organizations' reputation and legitimacy in refugee communities. Moreover, the sustainability of such programs is enhanced because they offer opportunities for refugees to "preserve and promote their dignity, self-esteem, and productive and creative potential."503

The discordance in patients' understanding of complications and consequences related to their condition between discussions with patients themselves versus physicians and nurses also raises questions about what measures are in place to support and encourage health providers to properly education patients. Health providers' reports of limited understanding among patients while patients directly reported not only knowledge of, but direct experience with consequences
of their condition(s) should be emphasized as it has meaningful operational implications. Activities to encourage physician compliance with guidelines, including sufficient patient education should be supported.

While more research is needed to explore the context of medication availability, existing electronic record systems in many primary health facilities throughout Lebanon and/or the mHealth application tested in the parent study can be expanded to include medication stock on-hand at facilities that include a dispensary. Linking patient health records, which should include data on prescribed medication(s), with dispensary stock has the potential to facilitate improvements in prescribing practices, communication to patients about stockouts at care facilities, and more strategic, informed procurement practices in cases where facilities have greater control over procurement. Inventory management systems separate from electronic patient records that have proven effective in other settings may also aide in improving stock communication and medication procurement in this context. This is particularly the case for facilities included in the YMCA program that generally have less control over procurement of medicines supplied through the program.<sup>504-509</sup>

The factors shown in this study and previously noted to influence medication use among Syrian refugees and host Lebanese, such as cost concern, condition understanding, medication availability, and side effects, among others, are not unique to this context. Although they may be intensified as a result of strain on the Lebanese health system with increased demand from refugee patients, or exacerbated by household resource limitations following displacement, the reasons for poor adherence in this context follow similar patterns across economic systems. Extensive evidence supports the role these factors have in patients' medication decision-making not just in Lebanon or the United States, but globally spanning varied health systems and social, cultural, and economic contexts.<sup>225,276,278,280,324,425,510</sup>

### **Suggested Further Research**

Results indicate a need for further investigation of medication availability and cost on the supply side at facilities, as well as on the demand side with patients. Out-of-pocket medication costs relative to patients' self-declared sufficiency of resources would also be informative in guiding intervention refinements such as improving targeting criteria and identifying rates for subsidized medications reflective of beneficiaries' means.

The intermittent and variable nature of medication availability reported in FGDs elevates the need for supply-side research. Supply chain management is critical in all health systems, but particularly so in systems facing sudden increases in demand by a displaced population of this size. Results from FGDs indicate that availability of prescribed medications may be a substantial barrier to continued medication adherence; however, additional data is needed to support and better understand the factors that determine medication availability and the associated influence of availability on patient adherence to prescribed medication(s). A comprehensive assessment of pharmaceutical procurement, distribution, and use in health facilities serving large populations of Syrian refugees and vulnerable Lebanese is needed to most effectively improve and target current interventions. In the interim, training programs based on a systems model of medicine selection, procurement, distribution, and use can improve stock availability. Gap analyses can identify specific management skill needs and guide targeted educational interventions.<sup>511</sup>

### **Methodological Implications**

The discordance between adherence reported during individual phone interviews with study participants and adherence described during FGDs is consistent with the limitation of using a single question measure of adherence. Single-item measures often capture only one type or stage of adherence, lack the ability to distinguish intentional from unintentional non-adherence, and seldom provide information on reasons for non-adherence such as those raised by focus group discussion participants (fear of medication availability for future refills, undesirable side effects, and misunderstanding how and precisely why to take prescribed medication, etc.). Caution should be taken when interpreting adherence reports from previous studies in which such measures are used. Moving forward, efforts should be made to consider the nature of adherence captured by available instruments and to utilize measures with increased sensitivity to the relevant type(s) of non-adherence (i.e. sporadic versus long-term, intentional versus unintentional, etc.) in this and similar contexts.

Future research in unstable or limited resource settings where the only feasible means of assessing medication adherence is through self-report should include more sensitive assessment characterized by the ability to capture and distinguish between the varied types of (e.g. more recent or shorter periods of non-adherence versus episodic non-adherence and missed or altered doses) and reasons for non-adherence. As demonstrated by this study and others with Syrian refugee populations in neighboring countries, mixed data collection methods including qualitative components can provide more nuanced results. These capture aspects and incidents of non-adherence possibly missed be by quantitative instruments for individual self-report.<sup>426</sup>

Established survey tools include many, but generally not all, of the factors identified in this study that influence medication adherence. While creation of a new, highly sensitive tool with the aforementioned characteristics would be ideal, taking into account the constraints of data collection in humanitarian settings, adapting an existing tool for greater context-specific sensitivity may sufficiently improve the quality of adherence measurement. When selecting survey instruments to capture medication adherence for future studies, researchers must consider the setting in which it will be implemented, the time available for administration, and the aim in measuring adherence. Adherence measures may focus on medication-taking behavior, barriers to adherence, or a combination thereof. Some tools are better suited for clinical settings and research intended to improve adherence in individual patients than for quantifying population or group level adherence measures such as prevalence or informing higher level intervention. The time needed for respondents to complete a questionnaire confronts a trade-off with practical time limits in field settings. Respondent burden is critical as excessively detailed instruments may be a barrier to obtaining sufficient completed questionnaires. The length of and administration time for other instruments likely diminishes their practical utility if they are included in much larger interview questionnaires.

Of the validated instruments available, the Adherence to Refills and Medications scale (ARMS) is among the best suited to capture the nature of non-adherence among Syrian refugees in Lebanon.<sup>265</sup> The ARMS incorporates the four items included in the abbreviated MMAS, plus four additional items that evaluate how respondents take prescribed medication, including skipping and changing doses, which were among the most commonly reported types of non-adherence raised during FGDs. Another four-item subscale of the ARMS assesses refill behaviors, providing granular and actionable information on patient behaviors that directly relate to concerns about medication availability that are not included in many other adherence scales.

Questions in the ARMS are rated using Likert scale responses ranging from "none of the time" to "all of the time", capturing less frequent behaviors that be missed with binary "yes/no" response options. Moreover, the scale includes explicit instruction and text to be read prior to administering the ARMS. This text is intended to calibrate the respondent and normalize adherence, thereby reducing bias in the individual responses. A separate version of the ARMS, revised to focus on adherence specific to medication for diabetes includes questions specific to insulin therapy and has been validated for use in diabetes-specific research.<sup>266</sup> The ARMS is well-suited for use with vulnerable and displaced populations in Lebanon, ideally with the addition of

a question to evaluate reasons for skipped doses and possible further adaptations based on pilot test in the field. The validity of the Hill-Bone Compliance to High Blood Pressure Therapy Scale (HB-HBP) or the Hill-Bone Medication Adherence Scale (HB-MAS) should also be explored in this context for possible use when a wider range of information about overall treatment adherence is needed.<sup>252-256</sup>

#### Limitations

As with all studies, the limitations of the parent studies (Chapter 4 and Appendix B) and present analysis must be considered when interpreting results. Differences in recall period will almost certainly influence the accuracy of adherence reporting. First, while the longer reference time period for having stopped medication use (i.e. six months preceding interview) may offer a general view of adherence, it also increases the potential for recall bias compared to shorter recall periods. While a shorter recall period may produce more reliable reporting, a longer period extends the time in which gaps in adherence could occur without being captured.<sup>512-517</sup> Additionally, the single question adherence measure focuses on capturing medication underuse; however, it did not capture other manners of non-compliance (e.g. improper dosage, timing, and overuse) nor mitigate occurrences of undetected non-adherence.

Use of self-report to assess medication adherence is another potential limitation of this study. Over-reporting medication adherence via self-report is likely increased due to social desirability and recall biases. Use of refill counts or pharmacy fills were not feasible in the study context however, limiting the potential for a more accurate and/or comprehensive understanding of adherence.

Other variables previously reported to be associated with adherence, such as specific comorbidities, severity of disease, generic versus brand-name medication use, perceptions and

beliefs related to diagnosed hypertension/diabetes, and other psychosocial factors, were not captured in data collection tools in the interest of maintaining a practical interview length. Thus, these variables were not available for the present analysis. Additionally, the parent study design precludes causal inference; results identify associations rather than directional causality. Finally, the relatively modest sample size, coupled with high overall reporting of adherence, limits the ability to detect weaker associations in both datasets.

### 7.6. Conclusion

In conclusion, this study demonstrates the shortcomings of single-measure methods of evaluating medication adherence among Syrian refugees and host communities in Lebanon. Conflicting reports of adherence during individual phone interviews with study participants and adherence described during FGDs is consistent with the limitations of a single question measure of adherence to capture sporadic, short-term non-adherence, as well as with the reasons for nonadherence raised during FGDs. Utilizing multiple methods of data collection, including qualitative components, more effectively captures components and occurrences of non-adherence that can be missed by quantitative instruments for individual self-report. Alternatively, quantitative scales that include more specific content focused on the appropriate type of and contributors to non-adherence are likely to yield more reliable estimates of the prevalence of medication adherence in similar contexts.

Results show an association between participation in subsidized medication programs, housing stability, and lower education attainment and a reduced risk of interrupted medication adherence. Knowledge of complications of hypertension and diabetes were also found to possibly influence adherence behaviors. Though further information is needed regarding medication availability and its influence on patient adherence to prescribed medication(s), these results, coupled with emergent themes during FGDs with patients and health providers identify areas in which targeted interventions may reduce gaps in medication use.

Effective interventions to improve medication adherence build on applied research, understanding patient and provider behaviors, and a systems model of pharmaceutical management. Suggested strategies from the present research include continued efforts to scale-up employment of CHWs and/or ROVs to provide health education, monitoring, care, and referral services to vulnerable populations in Lebanon; consideration of diabetes distress in ongoing programming; enhanced pharmaceutical inventory management utilizing electronic health records where available to link patient health records with dispensary stock; and physician training and support for prescribing practices that consider availability and cost.

	Hypertension Only	Type 2 Diabetes Only	Hypertension & Type 2 Diabetes	Total
Syrian Refugees	325 (51%)	85 (13%)	227 (36%)	637
Lebanese Host Community	129 (39%)	35 (11%)	166 (50%)	330
Other Nationalities	16 (37%)	6 (14%)	21 (49%)	43
Total	470 (47%)	126 (12%)	414 (41%)	1,010

Table 7-1. Enrolled Sample by Population Group and Diagnosed Condition(s)

Presented as N (% of respective population group)

	HYPERTENSION		DIAB	ETES	
	Syrian	Host	Syrian	Host	
	Refugees	Community	Refugees	Community	
	(N=463) % (95% CI)	(N=248) % (95% CI)	(N=280) % (95% CI)	(N=188) % (95% CI)	
Madication Prosprintion	/0 (/// 0 01)	/0 (/// 0 01)	/0 (/// 001)	/0 (/// 001)	
	100 (00 0 100)	100 (00 5 100)	100 (00 7 100)	100 (00 1 100)	
Ever prescribed medication	100 (99.2-100)	100 (98.5-100)	100 (98.7-100)	100 (98.1-100)	
Prescribed in Syria	55.9 (51.3-60.5)		54.6 (48.6-60.6)		
Prescribed in Lebanon'	44.1 (39.5-48.7)		45.4 (39.4-51.4)		
	( <i>n</i> =462)	(n=248)	(n=280)	(n=188)	
Currently taking medication	98.1 (96.3-99.1)	98.4 (95.9-99.6)	96.8 (94.0-98.5)	97.3 (93.9-99.1)	
	P = 0	0.751	P = 0	).730	
Medication Adherence <sup>†</sup>	(n=463)	(n=248)	(n=280)	(n=188)	
Stopped taking medicines for 2+ weeks in the past 6 months	13.2 (10.2-16.6)	2.0 (0.7-4.6)	10.0 (6.7-14.1)	2.7 (0.9-6.1)	
ľ	P < 0.001		P = 0	0.002	
Stopped taking medicines for 2+ weeks in the past 6 months against medical advice	12.8 (9.9-16.2)	1.6 (0.4-4.1)	10.0 (6.7-14.1)	1.6 (0.3-4.6)	
	P < 0	.001	<i>P</i> < 0.001		
When medication was stopped <sup>‡</sup>	(n=59)	(n=0)	(n=28)	(n=0)	
Stopped taking in Syria	13.6 (6.0-25.0)		21.4 (8.3-41.0)		
Stopped in Lebanon	49.2 (35.9-62.5)		57.1 (37.2-75.5)		
Started in Lebanon but stopped	37.3 (25.0-50.9)		21.4 (8.3-41.0)		
Reason for stopping medication <sup>‡</sup>	(n=58)	(n=4)	(n=28)	(n=3)	
HH could not afford medication	72.4 (59.1-83.3)	50.0 (6.8-93.2)	78.6 (59.0-91.7)	66.7 (9.4-99.2)	
Could not find pharmacy with the medication	8.6 (2.9-19.0)	0.0	14.3 (4.0-32.7)	0.0	
Symptoms improved/felt better	3.4 (0.4-11.9)	50.0 (6.8-93.2)	0.0	0.0	
Did not like available medications	5.2 (1.1-14.4)	0.0	7.1 (0.9-23.5)	0.0	
Did not know where to get the medication	5.2 (1.1-14.4)	0.0	0.0	0.0	
Too far to travel to obtain medication	1.7 (0.0-9.2)	0.0	0.0	0.0	
Other	3.4 (0.4-11.9)	0.0	0.0	33.3 (0.8-90.6)	
	P = 0.032		P = 0.018		

Table 7-2. Hypertension and Type 2 Diabetes Medication Prescription and Adherence

HH = household. P-value for group comparisons using Pearson's chi-square. Statistical significance indicated in bold (*P*<0.05) and bold italics (*P*<0.001). \* As percent of patients with condition diagnosis † As percent of patients prescribed medication \* As percent of patients that stopped taking medication in the past six months without instructions from a doctor

	Crude Odds OR (95% CI)	P-value	Adjusted Odds OR (95% CI)	P-value
	HYPERTENSION	N		
Patient Characteristics				
Age	0.93 (0.90-0.96)	<0.001	0.96 (0.93-0.99)	0.025
Female	1.40 (0.75-2.61)	0.287	1.26 (0.60-2.62)	0.539
Completed $\geq$ primary education	2.07 (1.18-3.61)	0.011	2.48 (1.26-4.88)	0.008
Above median monthly HH expenditures*	0.70 (0.40-1.22)	0.206	0.97 (0.52-1.79)	0.913
In current residence $\leq 1$ year	2.59 (1.47-4.55)	0.001	2.70 (1.46-4.99)	0.001
<b>Clinical Characteristics</b>				
Diabetes comorbidity	0.78 (0.44-1.40)	0.406	1.03 (0.54-1.95)	0.928
Time since diagnosis ( <i>ref:</i> < 5 years)				
5 - 9 years	1.04 (0.57-1.89)	0.909	1.12 (0.58-2.14)	0.734
$\geq 10$ years	0.26 (0.11-0.65)	0.004	0.39 (0.15-1.03)	0.058
Enrolled in YMCA program	0.31 (0.14-0.70)	0.005	0.35 (0.14-0.86)	0.023
Knowledge of stroke as a complication of HT	0.48 (0.27-0.84)	0.010	0.53 (0.28-1.02)	0.058
	DIABETES			
Patient Characteristics				
Age	0.93 (0.88-0.98)	0.005	0.92 (0.87-0.98)	0.011
Female	1.00 (0.43-2.31)	1.000	0.94 (0.35-2.51)	0.894
Completed $\geq$ primary education	1.72 (0.77-3.85)	0.190	2.09 (0.78-5.59)	0.141
Above median monthly HH expenditures*	1.52 (0.68-3.38)	0.304	1.86 (0.76-4.55)	0.172
In current residence $\leq 1$ year	3.11 (1.40-6.91)	0.005	3.46 (1.44-8.34)	0.006
<b>Clinical Characteristics</b>				
HT comorbidity	1.00 (0.42-2.37)	1.000	1.52 (0.56-4.15)	0.412
Time since diagnosis ( <i>ref:</i> < 5 years)				
5 - 9 years	1.80 (0.68-4.80)	0.239	3.03 (1.03-8.87)	0.043
$\geq 10$ years	1.58 (0.58-4.28)	0.374	3.59 (1.14-11.35)	0.030
Enrolled in YMCA program	0.44 (0.15-1.32)	0.144	0.49 (0.14-1.73)	0.267
Knowledge of $\geq 1$ complication of diabetes <sup>†</sup>	0.58 (0.26-1.28)	0.177	0.41 (0.16-1.05)	0.064

 Table 7-3. Odds of Interrupted Adherence to Medication for Hypertension and Type 2

 Diabetes Among Syrian Refugee Care-Seekers

HH = household; HT = hypertension. Statistical significance indicated in bold (P < 0.05) and bold italics (P < 0.001). Interrupted medication adherence defined as having stopped medication for hypertension/diabetes for two weeks or longer

in the past six months without instructions from a doctor

\* Relative to median monthly household expenditures reported by Syrian refugees

<sup>†</sup> Able to identify at least one complication of diabetes, including eye problems, kidney problems, foot ulcers, and heart problems. Reference: not able to identify any complication.

	Overall	Interrupted Adherence	Uninterrupted Adherence	<i>P</i> -value
	Point (95% CI)	Point (95% CI)	Point (95% CI)	
	HYPER	TENSION		
Identification of HT complications <sup>*</sup>	(n=735)	(n=64)	(n=671)	
Stroke	59.0% (55.6-62.3%)	42.2% (29.9-55.2%)	64.5% (60.8-68.2%)	<0.001
None/No risk factors	1.8% (1.1-3.0%)	1.6% (0.0-8.4%)	0.4% (0.1-1.3%)	0.247
Don't know	8.2% (6.5-10.2%)	28.1% (17.6-40.8%)	6.3% (4.5-8.4%)	<0.001
Other	30.9% (27.9-34.1%)	28.1% (17.6-40.8%)	28.8% (25.4-32.4%)	0.914
	DIA	BETES		
Identification of specific diabetes complications <sup>†</sup>	(n=491)	(n=33)	(n=458)	
Eye Problems	47.2% (42.9-51.6%)	36.4% (20.4-54.9%)	49.3% (44.7-54.0%)	0.150
Kidney Problems	31.3% (27.4-35.5%)	18.2% (7.0-35.5%)	31.9% (27.6-36.4%)	0.100
Foot Ulcers	28.1% (24.3-32.1%)	6.1% (0.7-20.2%)	31.0% (26.8-35.5%)	0.002
Heart Problems	15.9% (12.9-19.3%)	15.2% (5.1-31.9%)	16.8% (13.5-20.6%)	0.805
No complications	3.2% (1.9-5.1%)	0.0% (0.0-10.6%)	1.3% (0.5-2.8%)	0.508
Don't know	28.1% (24.3-32.1%)	33.3% (18.0-51.8%)	27.3% (23.3-31.6%)	0.454
Number of correctly identified complications <sup>‡</sup>				
Cannot identify any complications	39.8% (35.6-44.2%)	54.5% (36.4-71.9%)	36.9% (32.5-41.5%)	0.043
Identifies 1-2 complications	44.2% (39.9-48.6%)	42.4% (25.5-60.8%)	46.3% (41.6-51.0%)	
Identifies 3+ complications	15.9% (12.9-19.3%)	3.0% (0.1-15.8%)	16.8% (13.5-20.6%)	
Mean number of complications identified	1.22 (1.12-1.33)	0.76 (0.40-1.11)	1.29 (1.18-1.40)	0.016

 Table 7-4. Knowledge of Possible Complications by Interrupted Adherence to Medication

 for Hypertension and Type 2 Diabetes Among Syrian Refugee and Lebanese Host

 Community Care-Seekers

Point = point estimate (proportion, mean, or median); HT = hypertension

Group comparison using Pearson's chi-square. Statistical significance indicated in bold (P<0.05) and bold italics (P<0.001). \* As percent of patients with hypertension diagnosis

<sup>†</sup> Each item as percent of all patients with type 2 diabetes diagnosis able to correctly identify the complication

<sup>‡</sup> As percent of patients with type 2 diabetes diagnosis

### **Chapter 8. Conclusions**

The aims of this dissertation were to assess healthcare utilization and medication adherence for hypertension and type 2 diabetes among Syrian refugees and host communities in Lebanon, and to identify factors associated with care-seeking and medication adherence for these conditions among refugees. Paper 1 assessed care-seeking and medication adherence at the population level. Papers 2 and 3 examined healthcare utilization and medication adherence, respectively, in greater depth among care-seekers at select primary level health facilities, thus eliminating questions about initial contact with the health system. Together, these papers reveal overall high levels of care-seeking and medication adherence for hypertension and diabetes in both refugee and host populations. However, they identify important differences in these behaviors between Syrian refugees and host communities. The findings highlight opportunities of focus for improving refugee and Lebanese host community health service utilization and adherence to medication for hypertension and type 2 diabetes.

### 8.1. Summary of Results

### **Overall Trends**

#### Care Utilization and Costs

Focusing on hypertension and diabetes, <u>Paper 1</u> demonstrates high care-seeking overall at the population level for both refugees and host community members, with more than half reporting that they received care for these conditions in the preceding three months. Despite overall high care-seeking in both populations, host community cases of hypertension and diabetes were more likely to seek care than refugees, and to have done so within the past six months. Cost was a priority motivator for refugees' care-seeking decisions. Conversely, host community cases primarily utilized private clinics, citing perceived quality of care/continuity of care from the family doctor(s) as their predominant motivation for doing so. Greater overall care-seeking and out-of-pocket spending were significantly higher in the host community than among refugees, reflecting the host community's greater use of private sector facilities, differential financial support available to the two groups, and potentially, varying financial resources for affording care.

The majority of refugee and host community care-seekers incurred out-of-pocket cost for their most recent hypertension/diabetes care visit. The average reported consultation costs among refugees who received care at primary level health facilities exceed the standard subsidized cost of US\$2 – US\$3. The large proportion of primary level care-seekers reporting costs above the standard subsidized rate likely indicates care being sought at facilities outside the Ministry of Public Health's (MoPH) primary healthcare center (PHCC) network or not supported by the United Nations High Commissioner for Refugees (UNHCR) or non-governmental organizations (NGOs).

Paper 2 also provides evidence that hospitalization was uncommon for either condition, but that care utilization was consistently high among patients who had sought care at select primary level health facilities at least one time in the six months preceding study enrollment. Although general practitioner (GP) and specialist care are more accessible in Lebanon than in nearly any other humanitarian setting, findings from focus group discussions (FGDs) with patients and providers revealed that many patients make health facility follow-up visits solely to obtain prescribed medication refills. Patient FGD participants reported problems with facilities having stockouts and did not see the value in visiting a doctor if medication is not available at the health facility. Additional uncertainty about the quality of care at primary level facilities was revealed in provider FGDs where GPs also raised concerns about the limits of their training and ability to treat patients with hypertension and/or diabetes. For both hypertension and diabetes, refugees were more likely to seek care from GPs and report more frequent GP visits while Lebanese patients tended to rely more on specialists' care (cardiologist for both hypertension and diabetes, and endocrinologist for diabetes).

### Medication Prescription and Adherence Interruption

Evidence from <u>Paper 1</u> demonstrates that nearly all hypertension and diabetes cases had been prescribed medication for their condition and of those patients, few reported having stopped medication for two weeks or longer in the preceding year. When there was an interruption, cost was the primary reason among both population groups and both conditions, which confirms the role of financial burden in healthcare decisions.

Paper 3 contained relatively low rates of reported interrupted medication adherence among Syrian refugee and host community patients for both hypertension and type 2 diabetes. However, the actual rates may be higher since qualitative findings indicated that non-adherence was often reported for individual doses or a few days at a time, far shorter durations than the two weeks or longer specified in the question used to quantify adherence. This reveals a fundamental weakness of quantitative measurement of adherence interruption for longer timespans. Additional qualitative findings include unreliable availability of medication in accessible dispensaries, and discordance in patient-provider understanding of complications and consequences related to these conditions.

Results from <u>Paper 1</u> also identified higher incidence of interrupted medication use (i.e., stopping for two weeks or longer) among refugees than among host community cases. For both hypertension and diabetes, interrupted medication use was reported by more than one-quarter of refugees, which is more than three times the interruption rate reported by host community cases.

This disparity also held in **<u>Paper 3</u>**, showing that among patients who had visited a primary health facility in the preceding six months, a substantially smaller proportion of host community patients reported interrupted medication adherence as compared to refugees.

### Characteristics Associated with Care-Seeking and Interrupted Medication Use

Few household level predictors of care-seeking or interrupted medication adherence were identified among refugees in **Paper 1**. Care-seeking for hypertension in the preceding three months, the only individual level variable retained in its regression analyses, was among the few factors significantly associated with the [decreased] odds of interrupted medication adherence among hypertension cases. The otherwise null findings illustrate the pitfalls of assuming the impact of household characteristics on individual members' care-seeking and medication use.

In <u>Paper 2</u>, negative binomial hurdle regression analyses revealed several individual level characteristics associated with utilization of GP and specialist care for hypertension and type 2 diabetes, and of the number of GP and specialist visits conditioned upon having any care visits in the preceding six months. <u>Paper 3</u> similarly identified individual patient level factors associated with interrupted adherence to medication for these conditions. Papers 2 and 3 showed that older age and having lived in their current residence for more than one year were associated with higher care-seeking and lower odds of interrupted medication adherence among patients with type 2 diabetes. While longer time in their current residence was also associated with higher care-seeking and decreased odds of medication interruption among patients with hypertension, associations between patient characteristics and health behaviors were less consistent for hypertension. For example, for patients with hypertension, older age was associated with decreased odds of specialist care-seeking but increased number of GP care visits and decreased odds of interrupted medication adherence at the decreased odds of interrupted number of GP care visits and decreased odds of interrupted medication adherence. Conversely, having completed at least primary

education was predictive of increased odds of GP care-seeking, and increased odds of interrupted adherence to medication. Enrollment in the Young Men's Christian Association (YMCA) medication program was associated with decreased odds of interrupted medication adherence, yet lower number of GP visits for hypertension.

Although not statistically significant in regression analyses, descriptive and qualitative findings suggest that knowledge of available services at subsidized rates likely influence refugees delaying or not seeking care for hypertension and diabetes, and that knowledge of complications of hypertension and diabetes may improve adherence behaviors.

### 8.2. Strengths and Limitations

A key strength of this dissertation is that it provides an assessment of care-seeking and health behaviors from a multi-level perspective: first, by understanding larger trends at the population level (Paper 1), then by focusing at the individual level (Papers 2 and 3) to understand challenges facing patients after they initiate care in Lebanon. Papers 2 and 3 study individuals seeking care in a sample of health facilities, which limits representativeness to the subset of the population while providing important information about barriers to continued care This dissertation is also limited by its use of data collected four years prior to publication. This may have implications on the relevance of findings given subsequent changes in the context and the introduction of new projects. However, most programmatic changes have been relatively smallscale and meeting the needs of Syrian refugees and vulnerable host communities remains an immense challenge.

### 8.3. Programming Recommendations

# 1. Increase refugee knowledge of services available to them and how these services can be accessed through continued communication efforts

Continued communication efforts are recommended to increase refugees' understanding of accessible support and improve utilization of affordable care. Refugees' difficulty distinguishing between PHCCs in the MoPH network, primary care facilities supported by UNHCR or NGOs, and private clinics, combined with reports of seeking care at private clinics for cost-related reasons suggest inadequate awareness of the support available to them and where and how it can be accessed. Confusion or limited knowledge of subsidized health services and medication may play a role in cost being the predominant reason for refugees' delaying or avoiding care-seeking. The existence of this knowledge gap is also supported by UNHCR's annual Health Access and Utilization Survey (HAUS), which found that in 2014, immediately prior to the time of data collection for this dissertation, just over half of refugees knew they could access consultations at PHCCs for approximately US\$2-US\$ and fewer than one-quarter were aware that medication for chronic conditions is available for approximately US\$0.66.71 Communication efforts have improved refugees' knowledge of available health services and associated costs, but in the 2018 HAUS, 40% of refugees still were not aware of subsidized consultation costs.<sup>432</sup> These efforts should be expanded to facilitate refugees' ability to locate and access nearby health facilities offering subsidized services, minimizing the impact of geographic access and cost on delayed or avoided care-seeking.

2. Facilitate standard, predictable costs to patients through alternative payment arrangements such as bundled service packages or a flat fee model

Findings from this dissertation demonstrate a need for minimal and predictable out-ofpocket payments for health services. Lebanon's fragmented health system generates wide variations in base costs for services, especially diagnostic testing, across facilities. These variations contribute to patients' misunderstanding of cost and interferes with their ability to predict out-of-pocket costs prior to seeking care. One consequence of unpredictable costs is delayed or avoided care-seeking by patients with limited financial resources. Such deferred careseeking may be prevented by providing bundled services at predetermined rates, and effectively communicating them to refugees and vulnerable Lebanese prior to their seeking care.

A 2017 stakeholder acceptability study conducted in Lebanon showed strong public and civil society sector support for a health benefits package and numerous ongoing projects such as the Emergency Primary Healthcare Restoration Project (EPHRP) and Reducing Economic Barriers to Accessing Health Services in Lebanon (REBAHS) are currently piloting alternative approaches to out-of-pocket costs, including a subsidized essential healthcare package and a flat fee capitation approach.<sup>418,419,518</sup> Pending outcome results and feasibility analyses, these approaches should be considered for implementation at scale to mitigate the consequences of current unpredictable fee schedules across facilities.

### 3. Improve quality of care for hypertension and diabetes through large-scale training of health providers, particularly GPs, on treatment standards and guidelines, integration of collaborative care models, and improved referral system(s)

Universal delivery of quality care for hypertension and diabetes in Lebanon is hindered by provider knowledge and adherence to standard treatment guidelines, public-private sector and specialist-generalist physician divides, and discontinuity of care across the health sector. Many GPs in primary level health facilities rely on specialist referrals to manage patients with hypertension and diabetes, impeding efficient long-term management of these conditions. Increased GP capacity to treat patients with hypertension and diabetes is critical to provision of affordable, quality care to refugees and other vulnerable populations in Lebanon. Programs such as the MoPH's initiative for cardiovascular services in the national PHCC network and the EPHRP can provide useful experience and lessons regarding the feasibility, implementation, and overall effectiveness of healthcare provider capacity building. Improvements based upon these experiences and expanding targeted clinical training for primary level health workers is recommended to improve the quality of patient care for better health outcomes.

In addition, integration of a collaborative care approach within and between health facilities could further benefit care quality, cost, and long-term control of chronic health conditions. Collaborative care approaches have already proved advantageous in Lebanon, with notable benefits stemming from increased communication and partnership between general and specialist physicians and from overall intra-facility cooperation.<sup>470</sup> Expansion of referral system linkages between facilities in the MoPH-PHCC network with public hospitals to include facilities throughout the Lebanese health system would enhance the continuity of care required for managing chronic conditions.

# 4. Scale up CHW and ROV use to provide health education, monitoring, care, and referral services to vulnerable populations

Increased use of community health workers (CHWs) and/or refugee outreach volunteers (ROVs) via a range of activities including health education and awareness raising, basic condition monitoring, and referral to relevant higher-level care providers when appropriate can leverage investments and contribute to realizing Lebanon's health system goals. Community-driven, cost effective, and sustainable interventions are essential in this context in view of the expectation that

Syrian refugees will remain in Lebanon for the foreseeable future. Community-based interventions that employ CHWs and ROVs have shown great potential for improving chronic disease care in Lebanon as well as other humanitarian and development contexts.<sup>494-502</sup> Expanding current use of CHWs and ROVs to provide health education, more continuous monitoring, basic care, and service referrals for Syrian refugees and vulnerable Lebanese with chronic health conditions address impediments to long-term control of hypertension and diabetes.

### 8.4. Recommendations for Future Research

Findings from this research suggest that quantitative self-reported medication adherence measures have unstable reliability among Syrian refugees and vulnerable populations in Lebanon. Conflicting reports of adherence during individual patient phone interviews and adherence disclosed during FGDs demonstrate the limitations of evaluating medication adherence with single-question measures. Adherence reports from previous research in which such measures are used should be interpreted with caution given these methodological differences and shortcomings.

Future research in unstable or limited resource settings should utilize more sensitive instruments distinguished by the ability to capture and differentiate between types of nonadherence (e.g., non-fulfillment, shorter periods of non-adherence, and episodic non-confirming including skipped/missed or altered doses). In the context of displaced and vulnerable populations in Lebanon, most previously validated adherence measures do not sufficiently evaluate the reasons for non-adherence, such as those conveyed by FGD participants, which included fear of medication availability for future refills, undesirable side effects, and misunderstanding how and why to take prescribed medications. Of the available instruments validated for assessing multiple chronic conditions, the Adherence to Refills and Medications scale (ARMS) is likely to provide actionable evidence of the contributors to non-adherence among Syrian refugees in Lebanon, though its 14-question length requires adaptation and further testing for feasible use outside of studies focused exclusively on chronic conditions to minimize administration time.<sup>265</sup> The Hill-Bone Compliance to High Blood Pressure Therapy Scale (HB-HBP) and the Hill-Bone Medication Adherence Scale (HB-MAS) are also worth exploring within this context; however, with 14 and 9 items, respectively, these scales require similar administration time and the HB-HBP's focus on hypertension hinder its utility for more general use.<sup>252-256</sup> This research and previous studies with Syrian refugees in neighboring countries also indicate the substantial benefit of mixed-methods approaches, which provide a deeper understanding of the context-specific nuances motivating and characterizing medication adherence and related health behaviors. Given the difficulties in accurately quantifying medication adherence, triangulating data from multiple sources, including qualitative data, is recommended to reduce the risk of mischaracterizing results.<sup>426</sup>

Findings from this dissertation suggest several areas to be explored in future research. While relatively high care utilization rates were identified, uncertainties about whether this represents rational use of the various types of healthcare providers remain. Frequent specialist care-seeking may in some cases be appropriate, representing patients who receive care commensurate to the complexity of their condition, the presence of complications, and/or overall condition control. In other patients, however, it may be unnecessary, more costly, and an unnecessary use of specialty resources when GP care could be appropriate.

There is little documented evidence concerning the quality of care provided for hypertension and diabetes at primary level facilities. What constitutes rational use of generalist versus specialist care is dependent upon an understanding of the extent and quality of care provided by each type of provider. It will also be influenced by their relative cost and productivity within overall health sector service demands, as well as financial and personnel constraints. Future research examining rational provider utilization and dimensions of quality care at primary level facilities is needed to most effectively plan and deliver interventions. Targeted research should investigate and assess both Syrian and Lebanese patients' perceptions and beliefs regarding generalist versus specialist care for these conditions and, in turn, whether GP capacity building could be a viable near-term improvement.

These study results also indicate a need for further investigation of service/commodity availability and cost on the supply side at facilities, as well as on the demand side with patients. Questions remain about the nature of medication availability, resilience of medications' supply chain, and accessibility of specialist care at primary level facilities.

### Appendix A. *Household Survey of Syrian Refugee Health Status and Access to Care in Lebanon*: Survey Design and Implementation Methods

A survey of Syrian refugees and Lebanese host communities was conducted in March and April 2015 to characterize health-seeking behaviors and health service access. A cluster design with probability proportional to size sampling was used to attain a nationally representative sample of Syrian refugees living outside of camps. The planned sample was increased from the minimum identified size of 900 refugee households to 1400 refugee households and 700 Lebanese host community households to provide increased precision of point estimates and additional power.

### **Sample Size Calculations**

Sample size calculations were based on the study objectives of assessing health status and access to health care among Syrian refugees and host communities in the region. A moderate level of precision in point estimates was required given that the primary purpose of the study was to inform humanitarian programming. Given this and the challenges of data collection in urban Syrian refugee populations, a modest sample size was identified. The sample size calculations were based on the most conservative prevalence of 50% and assumed 80% power  $(1-\beta)$  and a design effect of 2.0 to account for a cluster sample design. The minimum and maximum planned sample sizes were increased to account for a 10% non-response rate and the possibility of incomplete reporting. The minimum sample size identified was 900 Syrian refugee households, which would allow for the characterization of prevalence rates for health access and status with  $\pm 5\%$  precision. Increased precision of point estimates and additional power for comparisons between registered and unregistered Syrian refugees, Syrian refugees in different sub-national regions, and between Syrian refugee and host community households were considered desirable

and a decision was made to increase the sample size. Data collection was planned for 1,400 Syrian refugee households and 700 host Lebanese households (2:1 ratio of refugee vs. host communities) with a final target sample of 2,100 households. The planned sample size was sufficient to allow for the detection of differences greater than 11% between Syrian refugees in different regions and differences greater than 8% between Syrian refugee and Lebanese host community households for dichotomous variables.

### Sample Design

A multi-stage cluster survey design with probability proportional to size (PPS) sampling was used to attain a nationally representative sample. A 100 cluster x 21 household (14 Syrian refugee households and 7 host Lebanese households per cluster) design was chosen due to the relatively low costs for visiting many locations given the small geographic size of Lebanon and the concentration of the Syrian refugee population. PPS sampling was used to assign the number clusters to sub-districts using United Nations High Commissioner for Refugees (UNHCR) registration data, assuming that non-registered Syrian refugees had similar housing patterns as those registered with UNHCR. Lebanese host community households were sampled using a neighborhood approach (i.e., households were selected based on proximity to included Syrian households) so that the sample reflected Lebanese households from communities most affected by the influx of Syrian refugees. It is important to note that sample of Lebanese host community households was not designed to be nationally representative of the Lebanese population as a whole, but rather as representative of communities whose health services access was most likely to be affected by the crisis.

A multi-stage cluster design was used: clusters were first allocated by governorate, then by district, and then by cadastral (similar to municipality and the lowest level administrative unit where UNHCR registration data was available). An overview of the registered Syrian refugee population and the final cluster allocation by governorate is summarized in Supplementary Table A-1, A-2, and A-3. The original sample was planned using the UNHCR registered population and assumed that all cadastrals were accessible.

The research team was unable to attain permission to conduct the survey in certain security sensitive areas as planned, which necessitated a re-draw of 28 clusters that were originally assigned to 22 inaccessible cadastrals. Clusters were re-assigned using PPS sampling methods based on a revised population of accessible areas. Supplementary Figure A-1 presents the administrative units that were accessible and included in the survey. Detailed information on the UNHCR registered population, cluster allocation, and sampling by cadastral are presented in Supplementary Figures A-2 and A-3. The final sample encompassed all five governorates, 18 of 26 districts, and 76 of 126 cadastrals; according to UNHCR registration data used for survey planning, 52.8% of registered refugees resided in cadastrals included in the survey coverage area (inclusive of two clusters in two cadastrals in the South which were later excluded from the analysis).

ArcGIS software was used to randomly allocate cluster start points within cadastrals. Coordinates in populated areas were used and the nearest intersection to the start point, usually within a half kilometer, was used as the starting survey location. Teams were provided with coordinates and satellite imagery maps and were instructed to navigate to start points using mapping software such as Google Maps. At the start location, interviewer pairs were sent in different directions to locate households; they approached the nearest business likely to be used by refugees and asked to be referred to nearby Syrian households. Other key informants, notably community residents, were used when there were no nearby shops. Verbal informed consent was sought at the beginning of the interview; only consenting households proceeded with interviews. When interviewers reached a household that consented to participate, the first interview in the cluster was conducted; upon completion, respondents were asked for a referral or introduction to the nearest Syrian household. This referral process was used until 14 Syrian refugee interviews were completed. Following every two interviews completed with Syrian refugee households, the nearest Lebanese household was approached to complete an interview. To improve representativeness and geographic coverage of the sample, no more than three households within the same apartment building were included.

To sample informal settlements, the team estimated the settlement's overall size and area by walking transects and/or the perimeter. When necessary, the settlement was divided into subareas of similar size that were assigned to different interviewers. Interviewers located the middle of the settlement/area, spun a pen to select a direction randomly, and then walked in the indicated direction counting the number of shelters passed before reaching the edge of the settlement/area. A randomly selected number between one and the total number of shelters passed was used to identify the starting household. This process was repeated until the necessary number of interviews was complete; referrals were not requested in informal settlements to reduce the potential for bias.

Only Syrian households arriving in Lebanon in 2011 or later were eligible to participate, as the aim was to capture the experiences of those displaced by the conflict, so the one approached household that arrived in Lebanon before 2011 was not included in the analysis. Families with both Lebanese and Syrian members were considered Syrian refugees if they arrived in Lebanon in 2011 or later and lived in Syria before this time; families who had never lived in Syria were considered Lebanese host community households for the survey.

### **Questionnaire Design**

The questionnaire was initially developed for use in Jordan by consensus between the World Health Organization (WHO), UNHCR, and Johns Hopkins Bloomberg School of Public Health (JHSPH) with the aim of providing a comprehensive assessment of the health of Syrian refugees to inform humanitarian assistance planning at local, national and regional levels. To the extent possible, existing content from WHO surveys, UNHCR assessments, and other surveys of Syrian refugee populations were adapted for use to improve the validity of the tool and comparability of results. The Jordan questionnaire was adapted to the Lebanese context by consensus between JHSPH, Médecins du Monde (MdM), International Medical Corps, UNHCR, and European Civil Protection and Humanitarian Aid Operations (ECHO). Arabic translation of the Jordan questionnaire was adapted for Lebanon and a formal pilot test conducted before implementation in Lebanon. The final questionnaire focused on four key domains: health service utilization, access and barriers to care, children's health, and non-communicable diseases (NCDs).

To obtain information on access to health services and medications for NCDs, respondents were asked about the five conditions reported to be most common among the Syrian refugee population in Lebanon: hypertension, cardiovascular disease (including heart failure, angina, arrhythmias/irregular heartbeats, a previous heart attack, or previous stroke), diabetes, chronic respiratory diseases (including asthma, chronic bronchitis, emphysema, and chronic obstructive pulmonary disease), and arthritis.<sup>72,519</sup> Diagnosis was self-reported; no documentation was required to verify reported conditions. Respondents were asked a series of questions about each of these conditions, beginning with the number of people in the household diagnosed with the condition organized into four age groups: 17 years and under, 18–39 years, 40–59 years, and 60 years and over. A series of questions regarding care-seeking, access, and utilization of health

services were asked about the experiences of one randomly selected household member who had been diagnosed with each of the five conditions. If more than one person in the household had the same condition, the person whose birthday was closest to the date of the interview was asked the series of questions about care-seeking.

### **Survey Implementation**

The survey was conducted by faculty at JHSPH, MdM staff, and hired Lebanese interviewers. Interviewers received two days of classroom training that focused on the questionnaire, e-data collection, interview techniques, basic principles of human subjects' protections, and sampling, after which two additional days of practical field training were completed. To protect the anonymity of respondents, no unique identifiers were recorded, and verbal consent was obtained.

Data were collected electronically on tablets using the Magpi mobile data platform by DataDyne LLC (Washington, DC) between March 12 and April 15, 2015 by three teams supervised by study team members from MdM and the JHSPH Field Coordinator. Interviews were conducted with either the head of household or the caretaker/health decision maker. The household head was prioritized as the respondent for some sections of the questionnaire; however, questions about hospitalizations and chronic diseases were asked directly to the afflicted individual selected, if that person was available, or, if not, another household member familiar with the person's condition or hospitalization. If households were encountered that were child-headed or had a child caretaker/health decision maker, the individual was interviewed so that this vulnerable population sub-group was not excluded. Because these individuals are acting as adults, the same informed consent process was used as in other households. If no one was home in an identified household, a second referral from the previously interviewed household was approached. If no interview could be conducted due to the absence of an appropriate household decision maker, refusal to participate, or if the household was already interviewed, this household was recorded with the appropriate reason for not completing an interview and referral to another Syrian household was requested. Interviews lasted an average of 40 minutes and typically ranged from 30 to 60 minutes depending on the household size, number of children, and number of individuals with chronic medical conditions.

JHSPH and MdM study team members actively supervised interviewers in the field to ensure adherence to data collection procedures and data quality standards. Team leaders reviewed all data records for completion and quality before uploading them to Magpi and leaving the cluster location. Data quality control included daily uploads from the tablets and overnight quality control reviews by the JHSPH field coordinator, with next day feedback to the on-site team for clarification and/or correction where data were missing or ambiguous.

Governorate	District	Cadastral*	% Refugee Population	Clusters Allocated N (%)	Clusters Sampled N
Beirut				3	3
	Beirut	Bachoura	0.7%	1 (1%)	1
		Mazraa	1.1%	1 (1%)	1
		Moussaytbeh	0.3%	1 (1%)	1
Bekaa				35	24
	Baalbek	Al-Nabi Chite	0.3%	1 (1%)	0
		Al-Qa El-Benjakie	0.9%	1 (1%)	1
		Arsale	3.6%	4 (4%)	0
		Baalbek	2.0%	2 (2%)	0
		Bednayel	0.3%	1 (1%)	0
		Brital	0.6%	1 (1%)	0
		Douress	0.3%	1 (1%)	0
	El-Hermel	Hermel	0.5%	1 (1%)	0
	Rachaya	Dahr El-Ahmar	0.2%	1 (1%)	1
	West Bekaa	Al-Marje	1.3%	1 (1%)	1
		Al-Sawireh	0.5%	1 (1%)	1
		El-Karaoun	0.3%	1 (1%)	1
		Ghazzeh	1.2%	1 (1%)	1
		Haouche-el-Harimeh	0.4%	1 (1%)	1
		Jib Jehnine	0.7%	1 (1%)	1
	Zahle	Bar-Elias	3.0%	3 (3%)	3
		Chtaura	0.4%	1 (1%)	1
		Delhamieh	0.5%	1 (1%)	1
		Jditah	0.3%	1 (1%)	1
		Kab Elias	2.4%	2 (2%)	2
		Kfar Zabed	0.9%	1 (1%)	1
		Maallaka (Terres)	0.5%	1 (1%)	1
		Mejdel-Anjar	1.5%	1 (1%)	1
		Rayak	0.6%	1 (1%)	1
		Saeid Neil	1.4%	1 (1%)	1
		Talabaya	1.0%	1 (1%)	1
		Zahleh Maallaka Kerek	0.5%	1 (1%)	1
		Zahleh Midan	1.3%	1 (1%)	1
Mt. Lebanon				24	18
	Aley	Aley	0.6%	1 (1%)	2
	-	Aramoun	0.9%	1 (1%)	1
		Chouaifat Amroussyat	1.7%	2 (2%)	2
		Chouaifat Qobbat	0.5%	1 (1%)	1
	Baabda	Borge el Baragenat	2.1%	2 (2%)	0
		Chiah	4.4%	4 (4%)	1
		Haret Horaeik	0.4%	1 (1%)	0
		Laylaki	0.3%	1 (1%)	0

## Supplementary Table A- 1. Initial Cluster Allocation by Governorate, District, and Cadastral

Chouf         Barja         0.7%         1 (1%)         1           Damour         0.3%         1 (1%)         1           Damour         0.3%         1 (1%)         1           El Jiych         0.2%         1 (1%)         1           Naamat         0.5%         1 (1%)         1           El Meten         Baouchariat         0.6%         1 (1%)         1           Borge Hammoud         1.6%         2 (2%)         2           Dekouanet         0.3%         1 (1%)         1           Kesrwane         Djounich Ghadir         0.2%         1 (1%)         1           North         Z5         25         25           North         Akkar         Akroum         0.5%         1 (1%)         1           Al-Khraibeh         0.2%         1 (1%)         1         1           Al-Khraibeh         0.2%         1 (1%)         1         1           Behnine         0.5%         1 (1%)         1         1           Berkayel         0.3%         1 (1%)         1         1           El Baroun         Batroune         0.4%         1 (1%)         1           Halba         0.9%	Governorate	District	Cadastral*	% Refugee Population	Clusters Allocated N (%)	Clusters Sampled N
$ \begin{array}{c c c c c c c c c c c c c c c c c c c $		Chouf	Barja	0.7%	1 (1%)	1
Damour         0.3%         1 (1%)         1           El Jiych         0.2%         1 (1%)         1           Naamat         0.5%         1 (1%)         1           Borge Hammoud         1.6%         2 (2%)         2           Dekouanet         0.3%         1 (1%)         1           Senn el Fil         0.3%         1 (1%)         1           Kesrwane         Djounich Ghadir         0.2%         1 (1%)         1           North         ZS         25           Akkar         Akroum         0.5%         1 (1%)         1           Al-Khraibch         0.2%         1 (1%)         1           Behnine         0.5%         1 (1%)         1           Bekayel         0.3%         1 (1%)         1           Dei-Daloum         0.2%         1 (1%)         1           Halba         0.9%         1 (1%)         1           Deir-Daloum         0.2%         1 (1%)         1           Halba         0.9%         1 (1%)         1           Ouadi Khaled         1.4%         1         1           El Batroun         Batroune         0.4%         1 (1%)         1 <t< td=""><td></td><td></td><td>Chehime</td><td>0.5%</td><td>1 (1%)</td><td>1</td></t<>			Chehime	0.5%	1 (1%)	1
El Jiych         0.2%         1 (1%)         1           Naamat         0.5%         1 (1%)         1           El Meten         Baouchariat         0.6%         1 (1%)         1           Borge Hammoud         1.6%         2 (2%)         2           Dekouanet         0.3%         1 (1%)         1           Kesrwane         Djounieh Ghadir         0.2%         1 (1%)         1           North         25         25         3         1 (1%)         1           Akkar         Akroum         0.5%         1 (1%)         1         1           Al-Mchamara         0.6%         1 (1%)         1         1         1           Berkayel         0.3%         1 (1%)         1			Damour	0.3%	1 (1%)	1
$ \begin{array}{ c c c c c c c c c c c c c c c c c c c$			El Jiyeh	0.2%	1 (1%)	1
El Meten         Baouchariat         0.6%         1 (1%)         1           Borge Hammoud         1.6%         2 (2%)         2           Dekouanet         0.3%         1 (1%)         1           Kesrwane         Djounich Ghadir         0.2%         1 (1%)         1           North         25         25           Akkar         Akroum         0.5%         1 (1%)         1           Al-Mchamra         0.6%         1 (1%)         1           Al-Mchamra         0.6%         1 (1%)         1           Berkayel         0.3%         1 (1%)         1           Halba         0.9%         1 (1%)         1           Halba         0.9%         1 (1%)         1           Ouadi Khaled         1.4%         1 (1%)         1           El Batroun         Batroune         0.4%         1 (1%)         1           El Koura         Ras Maska         0.2%			Naamat	0.5%	1 (1%)	1
Borge Hammoud         1.6%         2 (2%)         2           Dekouanet         0.3%         1 (1%)         1           Senn el Fil         0.3%         1 (1%)         1           North         Z         25         25           Akkar         Akroum         0.5%         1 (1%)         1           Al-Khraibeh         0.2%         1 (1%)         1           Al-Mehamra         0.6%         1 (1%)         1           Bebnine         0.5%         1 (1%)         1           Berkayel         0.3%         1 (1%)         1           Deir-Daloum         0.2%         1 (1%)         1           Berkayel         0.3%         1 (1%)         1           Halba         0.9%         1 (1%)         1           Ouadi Khaled         1.4%         1 (1%)         1           El Batroun         Batroune         0.4%         1 (1%)         1           El Koura         Ras Maska         0.2%         1 (1%)         1           El Koura         Ras Maska         0.2%         1 (1%)         1           Tripoli         Al-Kalmoune         0.3%         1 (1%)         1           Al-Minich		El Meten	Baouchariat	0.6%	1 (1%)	1
$\begin{tabular}{ c c c c c c c c c c c c c c c c c c c$			Borge Hammoud	1.6%	2 (2%)	2
$\begin{tabular}{ c c c c c c c c c c c c c c c c c c c$			Dekouanet	0.3%	1 (1%)	1
Kesrwane         Djounieh Ghadir         0.2%         1 (1%)         1           North         25         25           Akkar         Akroum         0.5%         1 (1%)         1           Al-Mchamra         0.6%         1 (1%)         1           Al-Mchamra         0.6%         1 (1%)         1           Bebnine         0.3%         1 (1%)         1           Berkayel         0.3%         1 (1%)         1           Deir-Daloum         0.2%         1 (1%)         1           Halba         0.9%         1 (1%)         1           Machta Hammoud         0.2%         1 (1%)         1           Ouadi Khaled         1.4%         1 (1%)         1           El Batroun         Batroune         0.4%         1 (1%)         1           El Koura         Ras Maska         0.2%         1 (1%)         1           El Koura         Ras Maska         0.2%         1 (1%)         1           Tripoli         Al-Scidaoui         1.5%         2 (2%)         2           Al-Mina Jardins         0.4%         1 (1%)         1           Tripoli Al-Kabmoune         0.3%         1 (1%)         1 <tr< td=""><td></td><td></td><td>Senn el Fil</td><td>0.3%</td><td>1 (1%)</td><td>1</td></tr<>			Senn el Fil	0.3%	1 (1%)	1
North         25         25           Akkar         Akroum $0.5\%$ $(1\%)$ 1           Al-Khraibeh $0.2\%$ $(1\%)$ 1           Al-Mehamra $0.6\%$ $1(1\%)$ 1           Berkayel $0.3\%$ $1(1\%)$ 1           Berkayel $0.3\%$ $1(1\%)$ 1           Deir-Daloum $0.2\%$ $1(1\%)$ 1           El-Birch $0.5\%$ $1(1\%)$ 1           Halba $0.9\%$ $1(1\%)$ 1           Machta Hammoud $0.2\%$ $1(1\%)$ 1           Machta Hammoud $0.2\%$ $1(1\%)$ 1           Chekka $0.3\%$ $1(1\%)$ 1           El Batroun         Batroune $0.4\%$ $1(1\%)$ 1           El Koura         Ras Maska $0.2\%$ $1(1\%)$ 1           El Minich-Dennic         Al-Beddaoui $1.5\%$ $2(2\%)$ $2$ Sir $0.7\%$ $1(1\%)$ $1$ $1$ $1$ Tripoli         Al-Kalmoune $0.3\%$		Kesrwane	Djounieh Ghadir	0.2%	1 (1%)	1
Akkar         Akroum         0.5%         1 (1%)         1           Al-Khraibeh         0.2%         1 (1%)         1           Al-Mchamra         0.6%         1 (1%)         1           Bebnine         0.5%         1 (1%)         1           Berkayel         0.3%         1 (1%)         1           Deir-Daloum         0.2%         1 (1%)         1           El-Birch         0.5%         1 (1%)         1           Halba         0.9%         1 (1%)         1           Ouadi Khaled         1.4%         1 (1%)         1           El Batroun         Batroune         0.4%         1 (1%)         1           El Koura         Ras Maska         0.2%         1 (1%)         1           El Minich-Dennie         Al-Beddaoui         1.5%         2 (2%)         2           Sir         0.7%         1 (1%)         1           Tripoli         Al-Kalmoune         0.3%         1 (1%)         1           Tripoli Al-Kobbeh         0.9%         1 (1%)         1         1           Tripoli Al-Kalmoune         0.3%         1 (1%)         1         1           Marbaizeheh         0.9%         1 (1%) <td>North</td> <td></td> <td></td> <td></td> <td>25</td> <td>25</td>	North				25	25
Al-Khraibeh         0.2%         1 (1%)         1           Al-Mehamra         0.6%         1 (1%)         1           Bebnine         0.5%         1 (1%)         1           Berkayel         0.3%         1 (1%)         1           Deir-Daloum         0.2%         1 (1%)         1           Deir-Daloum         0.2%         1 (1%)         1           Deir-Daloum         0.2%         1 (1%)         1           Halba         0.9%         1 (1%)         1           Machta Hammoud         0.2%         1 (1%)         1           Ouadi Khaled         1.4%         1 (1%)         1           El Batroun         Batroune         0.4%         1 (1%)         1           El Koura         Ras Maska         0.2%         1 (1%)         1           El Koura         Al-Mineh         1.5%         2 (2%)         2           Sir         0.7%         1 (1%)         1           Tripoli Al-Kalmoune         0.3%         1 (1%)         1           Tripoli Al-Kobbeh         0.9%         1 (1%)         1           Tripoli Al-Kobbeh         0.9%         1 (1%)         1           Tripoli Al-Kobbeh		Akkar	Akroum	0.5%	1 (1%)	1
$ \begin{array}{c c c c c c c c c c c c c c c c c c c $			Al-Khraibeh	0.2%	1 (1%)	1
Bebnine         0.5%         1 (1%)         1           Berkayel         0.3%         1 (1%)         1           Deir-Daloum         0.2%         1 (1%)         1           El-Birch         0.5%         1 (1%)         1           Halba         0.9%         1 (1%)         1           Ouadi Khaled         1.4%         1 (1%)         1           El Batroun         Batroune         0.4%         1 (1%)         1           El Muria         Ras Maska         0.2%         1 (1%)         1           El Koura         Ras Maska         0.2%         1 (1%)         1           El Minich-Dennie         Al-Binia         1.5%         2 (2%)         2           Sir         0.7%         1 (1%)         1           Tripoli         Al-Kalmoune         0.3%         1 (1%)         1           Tripoli Al-Kabbeh         0.9%         1 (1%)         1         1           Tripoli Al-Kalmoune         0.3%         1 (1%)         1         1           Tripoli Al-Kabbeh         0.9%         1 (1%)         1         1           Bent Jbeil         Bint Jbail         0.1%         1         1           Mabatich </td <td></td> <td></td> <td>Al-Mehamra</td> <td>0.6%</td> <td>1 (1%)</td> <td>1</td>			Al-Mehamra	0.6%	1 (1%)	1
Berkayel         0.3%         1 (1%)         1           Deir-Daloum         0.2%         1 (1%)         1           El-Birch         0.5%         1 (1%)         1           Halba         0.9%         1 (1%)         1           Machta Hammoud         0.2%         1 (1%)         1           Ouadi Khaled         1.4%         1 (1%)         1           El Batroun         Batroune         0.4%         1 (1%)         1           El Koura         Ras Maska         0.2%         1 (1%)         1           El Minich-Dennie         Al-Beddaoui         1.5%         2 (2%)         2           Al-Minich         1.5%         2 (2%)         2         Sir         0.7%         1 (1%)         1           Tripoli         Al-Kalmoune         0.3%         1 (1%)         1         Tripoli Al-Kobbeh         0.9%         1 (1%)         1           Tripoli Al-Kobbeh         0.9%         1 (1%)         1         Tripoli Al-Kobbeh         0.9%         1 (1%)         1           Tripoli Al-Kobbeh         0.9%         1 (1%)         1         Tripoli Al-Kobbeh         0.9%         1 (1%)         0           Mehriata         0.2%         1 (1%) <td></td> <td></td> <td>Bebnine</td> <td>0.5%</td> <td>1 (1%)</td> <td>1</td>			Bebnine	0.5%	1 (1%)	1
$ \begin{array}{c c c c c c c c c c c c c c c c c c c $			Berkayel	0.3%	1 (1%)	1
$\begin{tabular}{ c c c c c c c c c c c c c c c c c c c$			Deir-Daloum	0.2%	1 (1%)	1
Halba         0.9%         1 (1%)         1           Machta Hammoud         0.2%         1 (1%)         1           Ouadi Khaled         1.4%         1 (1%)         1           El Batroun         Batroune         0.4%         1 (1%)         1           El Batroun         Batroune         0.4%         1 (1%)         1           El Koura         Ras Maska         0.2%         1 (1%)         1           El Minich-Dennie         Al-Beddaoui         1.5%         2 (2%)         2           Al-Minieh         1.5%         2 (2%)         2         2           Sir         0.7%         1 (1%)         1         1           Tripoli         Al-Kalmoune         0.3%         1 (1%)         1           Al-Mina Jardins         0.4%         1 (1%)         1         1           Tripoli Al-Tabbanch         0.6%         1 (1%)         1         1           Tripoli Al-Tabbanch         0.6%         1 (1%)         1         1           South         Impoli Zeitoun         1.6%         2 (2%)         2           Zgharta         Mehriata         0.2%         1 (1%)         0           Nabatiyeh El-Faouka         0.2% </td <td></td> <td></td> <td>El-Bireh</td> <td>0.5%</td> <td>1 (1%)</td> <td>1</td>			El-Bireh	0.5%	1 (1%)	1
$\begin{tabular}{ c c c c c c c c c c c c c c c c c c c$			Halba	0.9%	1 (1%)	1
$\begin{tabular}{ c c c c c c } \hline U(1) & U($			Machta Hammoud	0.2%	1 (1%)	1
$ \begin{array}{c c c c c c c c c c c c c c c c c c c $			Ouadi Khaled	1.4%	1 (1%)	1
$\begin{tabular}{ c c c c c c c c c c c c c c c c c c c$		El Batroun	Batroune	0.4%	1 (1%)	1
$ \begin{array}{c c c c c c c c c c c c c c c c c c c $			Chekka	0.3%	1 (1%)	1
$\begin{tabular}{ c c c c c c c c c c c c c c c c c c c$		El Koura	Ras Maska	0.2%	1 (1%)	1
$\begin{tabular}{ c c c c c c c c c c c c c c c c c c c$		El Minieh-Dennie	Al-Beddaoui	1.5%	2 (2%)	2
$\begin{tabular}{ c c c c c c c c c c c c c c c c c c c$			Al-Minieh	1.5%	2 (2%)	2
$ \begin{array}{c c c c c c c c c c c c c c c c c c c $			Sir	0.7%	1 (1%)	1
Al-Mina Jardins $0.4\%$ $1(1\%)$ $1$ Tripoli Al-Kobbeh $0.9\%$ $1(1\%)$ $1$ Tripoli Al-Tabbaneh $0.6\%$ $1(1\%)$ $1$ Tripoli Zeitoun $1.6\%$ $2(2\%)$ $2$ Zgharta       Mehriata $0.2\%$ $1(1\%)$ $1$ South       Table $1.6\%$ $2(2\%)$ $2$ Bent Jbeil       Bint Jbail $0.1\%$ $1(1\%)$ $0$ El Nabatieh       Kfar Remmane $0.2\%$ $1(1\%)$ $0$ Nabatiyeh El-Faouka $0.2\%$ $1(1\%)$ $0$ Marjaayoun       El-Khiam $0.2\%$ $1(1\%)$ $0$ Saida       Bissariat $0.4\%$ $1(1\%)$ $0$ Saida       Bissariat $0.4\%$ $1(1\%)$ $0$ Sarafend $0.3\%$ $1(1\%)$ $1$ $1$ Abbassyat $0.2\%$ $1(1\%)$ $0$ $1$ Marjaayoun       El-Khiam $0.2\%$ $1(1\%)$ $0$ Ghazyat $0.5\%$ $1(1\%)$ $0$ $0$ Borg		Tripoli	Al-Kalmoune	0.3%	1 (1%)	1
$ \begin{array}{c c c c c c c c c c c c c c c c c c c $		1	Al-Mina Jardins	0.4%	1 (1%)	1
$\begin{tabular}{ c c c c c c c c c c c c c c c c c c c$			Tripoli Al-Kobbeh	0.9%	1 (1%)	1
$\begin{tabular}{ c c c c c c c c c c c c c c c c c c c$			Tripoli Al-Tabbaneh	0.6%	1 (1%)	1
Zgharta         Mehriata $0.2\%$ $1(1\%)$ $1$ South         I3 $2$ Bent Jbeil         Bint Jbail $0.1\%$ $1(1\%)$ $0$ El Nabatieh         Kfar Remmane $0.2\%$ $1(1\%)$ $0$ Nabatiyeh El-Faouka $0.2\%$ $1(1\%)$ $0$ Hasbaya         Chabaaa $0.3\%$ $1(1\%)$ $0$ Marjaayoun         El-Khiam $0.2\%$ $1(1\%)$ $0$ Saida         Bissariat $0.4\%$ $1(1\%)$ $0$ Saida         Bissariat $0.4\%$ $1(1\%)$ $0$ Babassyat         O.5\% $1(1\%)$ $0$ Sarafend $0.3\%$ $1(1\%)$ $0$ Barge El-Chehmali $0.2\%$ $1(1\%)$ $0$ Borge El-Chehmali $0.2\%$ $1(1\%)$ $0$ Borge El-Chehmali $0.2\%$ $1(1\%)$ $0$ Borge El-Chehmali $0.2\%$ $1(1\%)$ $0$			Tripoli Zeitoun	1.6%	2 (2%)	2
South       13       2         Bent Jbeil       Bint Jbail $0.1\%$ $1 (1\%)$ $0$ El Nabatieh       Kfar Remmane $0.2\%$ $1 (1\%)$ $0$ Nabatiyeh El-Faouka $0.2\%$ $1 (1\%)$ $0$ Mastiyeh El-Tahta $0.3\%$ $1 (1\%)$ $0$ Hasbaya       Chabaaa $0.3\%$ $1 (1\%)$ $0$ Marjaayoun       El-Khiam $0.2\%$ $1 (1\%)$ $0$ Saida       Bissariat $0.4\%$ $1 (1\%)$ $0$ Saeida Ville $1.3\%$ $1 (1\%)$ $0$ Sarafend $0.3\%$ $1 (1\%)$ $0$ Berge El-Chehmali $0.2\%$ $1 (1\%)$ $0$ Sour (Tyr) $0.8\%$ $1 (1\%)$ $0$		Zgharta	Mehriata	0.2%	1 (1%)	1
Bent Jbeil         Bint Jbail         0.1%         1 (1%)         0           El Nabatieh         Kfar Remmane         0.2%         1 (1%)         0           Nabatiyeh El-Faouka         0.2%         1 (1%)         0           Nabatiyeh El-Tahta         0.3%         1 (1%)         0           Hasbaya         Chabaaa         0.3%         1 (1%)         0           Marjaayoun         El-Khiam         0.2%         1 (1%)         0           Saida         Bissariat         0.4%         1 (1%)         0           Saida         Bissariat         0.4%         1 (1%)         0           Saeida Ville         1.3%         1 (1%)         1           Abbassyat         0.2%         1 (1%)         1           Abbassyat         0.2%         1 (1%)         0           Sarafend         0.3%         1 (1%)         1           Abbassyat         0.2%         1 (1%)         0           Borge El-Chehmali         0.2%         1 (1%)         0           Borge El-Chehmali         0.2%         1 (1%)         0           Borge El-Chehmali         0.2%         1 (1%)         0	South	0			13	2
El Nabatieh       Kfar Remane $0.2\%$ $1$ (1%) $0$ Nabatiyeh El-Faouka $0.2\%$ $1$ (1%) $0$ Nabatiyeh El-Tahta $0.3\%$ $1$ (1%) $0$ Hasbaya       Chabaaa $0.3\%$ $1$ (1%) $0$ Marjaayoun       El-Khiam $0.2\%$ $1$ (1%) $0$ Saida       Bissariat $0.4\%$ $1$ (1%) $0$ Saida       Bissariat $0.4\%$ $1$ (1%) $0$ Saeida Ville $1.3\%$ $1$ (1%) $1$ Abbassyat $0.2\%$ $1$ (1%) $1$ Borge El-Chehmali $0.2\%$ $1$ (1%) $0$	South	Bent Jbeil	Bint Jhail	0.1%	1 (1%)	0
In Nabatiyeh El-Faouka $0.2\%$ $1 (1\%)$ $0$ Nabatiyeh El-Faouka $0.3\%$ $1 (1\%)$ $0$ Hasbaya       Chabaaa $0.3\%$ $1 (1\%)$ $0$ Marjaayoun       El-Khiam $0.2\%$ $1 (1\%)$ $0$ Marjaayoun       El-Khiam $0.2\%$ $1 (1\%)$ $0$ Saida       Bissariat $0.4\%$ $1 (1\%)$ $0$ Saida       Bissariat $0.4\%$ $1 (1\%)$ $0$ Saeida Ville $1.3\%$ $1 (1\%)$ $1$ Abbassyat $0.2\%$ $1 (1\%)$ $0$ Borge El-Chehmali $0.2\%$ $1 (1\%)$ $0$ Bour (Tyr) $0.8\%$ $1 (1\%)$ $0$		El Nabatieh	Kfar Remmane	0.2%	1 (1%)	0
Nabatiyeh El-Tahta $0.3\%$ $1 (1\%)$ $0$ Hasbaya       Chabaaa $0.3\%$ $1 (1\%)$ $0$ Marjaayoun       El-Khiam $0.2\%$ $1 (1\%)$ $0$ Marjaayoun       El-Khiam $0.2\%$ $1 (1\%)$ $0$ Saida       Bissariat $0.4\%$ $1 (1\%)$ $0$ Saida       Bissariat $0.4\%$ $1 (1\%)$ $0$ Saeida Ville $1.3\%$ $1 (1\%)$ $1$ Sarafend $0.3\%$ $1 (1\%)$ $1$ Abbassyat $0.2\%$ $1 (1\%)$ $0$ Borge El-Chehmali $0.2\%$ $1 (1\%)$ $0$ Sour (Tyr) $0.8\%$ $1 (1\%)$ $0$			Nabativeh El-Faouka	0.2%	1(1%)	Ő
Hasbaya       Chabaaa $0.3\%$ $1 (1\%)$ $0$ Marjaayoun       El-Khiam $0.2\%$ $1 (1\%)$ $0$ Saida       Bissariat $0.4\%$ $1 (1\%)$ $0$ Saeida Ville $1.3\%$ $1 (1\%)$ $1$ Sarafend $0.3\%$ $1 (1\%)$ $1$ Abbassyat $0.2\%$ $1 (1\%)$ $0$ Borge El-Chehmali $0.2\%$ $1 (1\%)$ $0$ Sour (Tyr) $0.8\%$ $1 (1\%)$ $0$			Nabativeh El-Tahta	0.3%	1 (1%)	Ő
Interstruct       Christian $0.2\%$ $1 (1\%)$ $0$ Marjaayoun       El-Khiam $0.2\%$ $1 (1\%)$ $0$ Saida       Bissariat $0.4\%$ $1 (1\%)$ $0$ Ghazyat $0.5\%$ $1 (1\%)$ $0$ Saida       Bissariat $0.4\%$ $1 (1\%)$ $0$ Saida       Bissariat $0.4\%$ $1 (1\%)$ $0$ Saida       Bissariat $0.4\%$ $1 (1\%)$ $0$ Saida       Bissariat $0.2\%$ $1 (1\%)$ $1$ Abbassyat $0.2\%$ $1 (1\%)$ $0$ Borge El-Chehmali $0.2\%$ $1 (1\%)$ $0$ Sour (Tyr) $0.8\%$ $1 (1\%)$ $0$		Hashava	Chabaaa	0.3%	$\frac{1}{1}(1\%)$	0
Nalifacional       Di Ninani       0.2%       1 (1%)       0         Saida       Bissariat       0.4%       1 (1%)       0         Ghazyat       0.5%       1 (1%)       0         Saida       Saida       Saida       0.4%       1 (1%)       0         Saida       Saida       Saida       0.5%       1 (1%)       0         Saida       Saida       0.3%       1 (1%)       1         Saida       0.3%       1 (1%)       0         Abbassyat       0.2%       1 (1%)       0         Borge El-Chehmali       0.2%       1 (1%)       0         Sour (Tyr)       0.8%       1 (1%)       0		Mariaavoun	Fl-Khiam	0.2%	$\frac{1(1\%)}{1(1\%)}$	0
Saida       Dissaria       0.770       1 (170)       0         Ghazyat       0.5%       1 (1%)       0         Saeida Ville       1.3%       1 (1%)       1         Sarafend       0.3%       1 (1%)       1         Abbassyat       0.2%       1 (1%)       0         Borge El-Chehmali       0.2%       1 (1%)       0         Sour (Tyr)       0.8%       1 (1%)       0		Saida	Rissariat	0.2%	$\frac{1(1\%)}{1(1\%)}$	0
Saeida Ville       1.3%       1 (1%)       1         Saeida Ville       1.3%       1 (1%)       1         Sarafend       0.3%       1 (1%)       1         Abbassyat       0.2%       1 (1%)       0         Borge El-Chehmali       0.2%       1 (1%)       0         Sour (Tyr)       0.8%       1 (1%)       0		Janua	Ghazvat	0.470	1(1%)	0
Sarafend     0.3%     1 (1%)     1       Abbassyat     0.2%     1 (1%)     0       Borge El-Chehmali     0.2%     1 (1%)     0       Sour (Tyr)     0.8%     1 (1%)     0			Saeida Ville	1 3%	1 (1%)	1
Abbassyat     0.3%     1 (1%)     1       Abbassyat     0.2%     1 (1%)     0       Borge El-Chehmali     0.2%     1 (1%)     0       Sour (Tyr)     0.8%     1 (1%)     0			Sarafend	0.20%	1 (1%)	1
Aboussyal         0.2%         1 (1%)         0           Borge El-Chehmali         0.2%         1 (1%)         0           Sour (Tyr)         0.8%         1 (1%)         0			Abbassvat	0.570	1(170)	0
Borge El-Chenman         0.2%         1 (1%)         0           Sour (Tyr)         0.8%         1 (1%)         0			Rorge Fl_Chehmali	0.270	1(170) 1(196)	0
Total 100 72			Sour (Tyr)	0.270	1(1%)	0
	Total				100	

Supplementary Table A-1 (continued)

\*Lightly shaded and italicized cadastrals were excluded from data collection

	#			% Refugee	%	#
Governorate	Clusters	District	Cadastral	Population in	Clusters	Clusters
	Allocated			Permitted Areas	Allocated	Sampled
Beirut	1			3.8%	4%	1
		Beirut	Moussaytbeh	0.4%	4%	1
Bekaa	10			33.7%	36%	10
		West Bekaa	Haouche-el-	0.6%	4%	1
			Harimeh			
			Ghazzeh	1.7%	4%	1
			Kherbet Kanafar	0.1%	4%	1
		Zahle	Delhamieh	0.7%	4%	1
			Kfar Zabed	1.3%	4%	1
			Mejdel-Anjar	2.1%	4%	1
			Saeid Neil	2.0%	4%	1
			Talabaya	1.4%	4%	1
			Tanaeil	0.4%	4%	1
			Zahleh Midan	1.9%	4%	1
Mt. Lebanon	7			25.1%	25%	7
		Aley	Aley	0.8%	4%	1
		5	Bhamdoun	0.3%	4%	1
			(Village)			
		Chouf	Baakline	0.1%	4%	1
			Chehime	0.8%	4%	1
		El Meten	Jal-el-Dib	0.1%	4%	1
			Senn el Fil	0.4%	4%	1
		Kesrwane	Faraya	0.2%	4%	1
North	10			35.3%	36%	10
		Akkar	Akkar El-Atika	0.2%	4%	1
			Bebnine	0.7%	4%	1
			Deir-Daloum	0.3%	4%	1
			Tikrite	0.1%	4%	1
		El Batroun	Tannourine Foka	0.1%	4%	1
		El Koura	Enfeh	0.2%	4%	1
		El Minieh-	Bakhoune	0.3%	4%	1
		Dennie				
			Sir	1.0%	4%	1
		Tripoli	Al-Kalmoune	0.5%	4%	1
		-	Tripoli Jardins	0.3%	4%	1
South	0			2.2%	0%	0
Total				100.0%	100.0%	28

Supplementary Table A- 2. Allocation of 28 Replacement Clusters in Permitted Areas by Governorate, District, and Cadastral

Conomanata	District	Cadastual	% Refugee	% Clusters	% HHs	# Clusters	
Governorate	District	Cauastral	Population	Allocated	Sampled	Sampled	
Beirut	-		2%	4%	4%	4	
	Beirut	Bachoura	1%	1%	1%	1	
		Mazraa	1%	1%	1%	1	
		Moussaytbeh	0%	2%	2%	2	
Bekaa		,	20%	34%	34%	34	
	Baalbek	Al-Qa El-Benjakie	1%	1%	1%	1	
	Rachaya	Dahr El-Ahmar	0%	1%	1%	1	
	West Bekaa	Al-Marje	1%	1%	1%	1	
		Al-Sawireh	0%	1%	1%	1	
		El-Karaoun	0%	1%	1%	1	
		Ghazzeh	1%	2%	2%	2	
		Haouche-el-Harimeh	0%	2%	2%	2	
		Jib Jehnine	1%	1%	1%	1	
		Kherbet Kanafar	0%	1%	1%	1	
	Zahle	Bar-Elias	3%	3%	3%	3	
		Chtaura	0%	1%	1%	1	
		Delhamieh	0%	2%	2%	2	
		Iditah	0%	1%	1%	1	
		Kab Elias	2%	2%	2%	2	
		K far Zabed	1%	2%	2%	2	
		Maallaka (Terres)	1%	1%	1%	1	
		Meidel-Aniar	1%	2%	2%	2	
		Ravak	1%	1%	1%	1	
		Saeid Neil	1%	2%	2%	2	
		Talahaya	1%	2%	2%	2	
		Tanaeil	0%	1%	1%	1	
		Zahleh Maallaka Kerek	0%	1%	1%	1	
		Zahleh Midan	1%	2%	2%	2	
Mt Labanan		Zamen witdan	1/0	270	270	2	
WIL LEDAHON	Alex	Alex	14/0	2370	23/0	23	
	Alcy	Aramoun	1%	1%	1%	1	
		Rhamdoun (Village)	0%	1%	1 70	1	
		Chousifat Amroussyst	2%	20%	2%	1	
		Chouaifat Oobbat	270	1%	270	1	
	Raabda	Chieh	1 /0	10/2	1 70	1	
	Chouf	Bookline	470	1 /0	1 /0	1	
	Ciloui	Daakiiiic	10/	1 /0	1 /0	1	
		Chahima	1 70	1 /0	170	1	
		Damour	1 70	270 10/	2.70 1.0/	2	
		El Livoh	0%	1 70	170	1	
		Noomot	070 10/	170	170	1	
	El Matan	Naamat De see de suise	1 70	170	170	1	
	El Meten	Baouchariai	1%	1%	1%	1	
		Borge Hammoud	<u>ک%</u>	۷%0 ۱0/	۷% ۱۹/	<u>/</u>	
			U%0	1 70	1 %0	1	
		Jai-el-Dib	U%	1%0	1%		
		Senn el Fil	U%	۷%0 ۱۵	۷% ۱۵	2	
	Jbeil	Jbeil	0%	1%	1%	1	

Supplementary Table A- 3. Final Allocation of Survey Clusters by Governorate, District, and Cadastral

Governorate	District	Cadastral	% Refugee	% Clusters	% HHs	# Clusters
			Population	Allocated	Sampled	Sampled
	Kesrwane	Djounieh Ghadir	0%	1%	1%	1
		Faraya	0%	1%	1%	1
North			15%	35%	35%	35
	Akkar	Akkar El-Atika	0%	1%	1%	1
		Akroum	1%	1%	1%	1
		Al-Khraibeh	0%	1%	1%	1
		Al-Mehamra	1%	1%	1%	1
		Bebnine	0%	2%	2%	2
		Berkayel	0%	1%	1%	1
		Deir-Daloum	0%	2%	2%	2
		El-Bireh	0%	1%	1%	1
		Halba	1%	1%	1%	1
		Machta Hammoud	0%	1%	1%	1
		Ouadi Khaled	1%	1%	1%	1
		Tikrite	0%	1%	1%	1
	El Batroun	Batroune	0%	1%	1%	1
		Chekka	0%	1%	1%	1
		Tannourine Foka	0%	1%	1%	1
	El Koura	Enfeh	0%	1%	1%	1
		Ras Maska	0%	1%	1%	1
	El Minieh-	Al-Beddaoui	1%	2%	2%	2
	Dennie	Al-Minieh	2%	2%	2%	2
		Bakhoune	0%	1%	1%	1
		Sir	1%	2%	2%	2
	Tripoli	Al-Kalmoune	0%	2%	2%	2
	-	Al-Mina Jardins	0%	1%	1%	1
		Tripoli Al-Kobbeh	1%	1%	1%	1
		Tripoli Al-Tabbaneh	1%	1%	1%	1
		Tripoli Jardins	0%	1%	1%	1
		Tripoli Zeitoun	2%	2%	2%	2
	Zgharta	Mehriata	0%	1%	1%	1
South			2%	2%	2%	2
	Saida	Saeida Ville	1%	1%	1%	1
		Sarafend	0%	1%	1%	1
Total			53%		100%	100

Supplementary Table A- 3 (continued)



Supplementary Figure A-1. Survey Coverage Area by Cadastral





	Registered	Clu	sters
	Refugees (%)	Ν	%
Beirut	3%	4	4%
Bekaa	35%	34	34%
Mt Lebanon	25%	25	25%
North	25%	35	35%
South	12%	2	2%

Supplementary Figure A- 3. Cluster Allocation by Governorate
# Appendix B. Treatment Guidelines for Hypertension and Type 2 Diabetes in Syrian Refugees and Host Communities in Lebanon: Study Design and Methods

The Treatment Guidelines for Hypertension and Type 2 Diabetes in Syrian Refugees and

Host Communities in Lebanon study was a longitudinal cohort study implemented from

September 2014 through September 2016 in primary health care settings in Lebanon serving both

Syrian refugees and host communities with two research aims:

- 1. To develop, adapt, and test existing standards and guidelines for treatment, including counseling, of persons with hypertension and type 2 diabetes (or both).
- 2. To evaluate the effectiveness of an mHealth tool that includes a patient-controlled health record (PCHR), which have the potential to improve quality of care, continuity of care, health literacy, and health outcomes for patients. This objective focused on supporting provider and patient compliance and improving disease control through the introduction of the mHealth tool and PCHRs.

#### **Study Design**

The study used a phased introduction of two interventions over a period of two years with longitudinal measurement of outcomes. While randomized control trials are considered the gold standard research design, they are often not possible in humanitarian emergencies. In the case of this study, randomized and quasi-experimental designs were not feasible at the facility level because there are few participating facilities and important underlying differences between the facilities and patient populations served. Patient randomization was not possible because of likely contamination between groups and difficulties associated with asking providers to manage patients differently. A study that included fewer health facilities but provided a more in-depth assessment of outcomes from multiple perspectives was preferable to a design that incorporated more facilities so that more comprehensive evidence could be generated with a better understanding of causal pathways and added value of the interventions. Longitudinal study designs are generally preferable to cross-sectional assessments and provide more analysis options. This study design followed the cohort monitoring approach used by United Nations Relief and

Works Agency for Palestine Refugees in the Near East (UNRWA) to evaluate non-communicable

disease (NCD) management in Palestinian refugees and proved feasible in this context. 520,521

Study Interventions

The Treatment Guidelines for Hypertension and Type 2 Diabetes in Syrian Refugees and

Host Communities in Lebanon study evaluated two interventions with a phased implementation

design:

- Guidelines for Treatment of Hypertension and Type 2 Diabetes in Primary Care Facilities were developed based on adaptations to relevant guidelines from international sources such as the World Health Organization's Package of Essential Noncommunicable Disease Interventions (WHO PEN), standards from professional societies and authorities such as the National Institute for Health and Care Excellence clinical guidelines, and the recently updated treatment guidelines by the Lebanese Ministry of Public Health (MoPH).<sup>522,523</sup> The adapted guidelines are congruent with the Lebanese context, applicable beyond the participating health facilities, and generally applicable to other humanitarian organizations and crisis settings.
- 2. The mHealth intervention is a tablet-based open source software for clinical management of hypertension and type 2 diabetes that serves as both electronic medical record and a decision support tool for providers with key clinical milestones and tracking of what physicians prescribe. The mHealth application also produced a PCHR, exportable in paper format and abbreviated SMS format to be provided to patients. The PCHR contains a limited disease history, updated every visit with information such as fasting blood sugar, blood pressure, medications prescribed, and date of next follow up, as well as a risk assessment summary for biometrics and lifestyle (adapted from existing resources such as the World Health Professions Alliance Health Improvement Card).<sup>523,524</sup> Basic elements of the record were printed off and given to the patient or transmitted via SMS to the patient's cell phone for an electronic record, which could help patients understand and monitor their condition or can provide medical history if the patient unexpectedly needs to access care outside their usual providers. In summary, the mHealth tool is best conceptualized as tablet-based decision support tool used by medical providers that can store patient medical information; an output of the system is a summary of the patient's condition and prescriptions to be provided at each visit either in paper or SMS format.

#### Participants and Sample Size Calculations

Study participants consisted of care-seekers at ten primary health facilities in Lebanon supported by the International Organization for Migration (IOM) and International Medical Corps (IMC) in the South, Bekaa, Beirut, and Mount Lebanon governorates (Supplementary Figure B-1). Care-seekers at these locations include Syrian refugees, Lebanese populations, and in smaller number, Iraqi refugees and Armenian populations. Individuals without a hypertension or type 2 diabetes diagnosis, those less than 40 years of age, and adults lacking the capacity to participate in interviews independently were excluded from the study.

The final sample size was dependent on the caseload of diabetes and hypertension patients seen at study health facilities. Planned sample sizes were based on the total estimated caseload and projected newly diagnosed cases for each study health facility. Initial enrollment figures at IOM facilities were substantially below target enrollment numbers, so five additional facilities supported by IMC were brought on to participate in the study and participants from these sites were recruited. The total initially estimated caseload, as well as the anticipated proportion that could be reached by phone (estimated at 80%) and proportion that would consent to participate (estimated at 80%) for each facility are presented in Supplementary Table B-1. The planned and maximum samples to be enrolled in each facility are also presented; the maximum sample size was increased to allow for anticipated community outreach activities that were expected to generate additional cases beyond sample size projections from facility information.

Sample size calculations were based on the main study objective of improving quality of care, specifically the proportion of providers who adhere to treatment guidelines. Sample size calculations assumed a baseline prevalence rate of 50% for adherence to guidelines, which is the most conservative prevalence rate from a statistical perspective that would ensure the ability to detect significant differences from all other rates. This is a reasonable assumption given that the

proposed guidelines do not differ substantially from other best practice guidelines, thus, some providers may already have been adhering to guidelines. Further, sample size calculations assumed  $\alpha = 0.05$ ,  $\beta = 0.20$  (power = 0.80) and one-sided calculations based on the supposition that quality of care would not decrease as a result of the study interventions. Sample size calculations were performed using Stata 13. The final sample size in each study phase is presented by health facility in Supplementary Table B-2 and by diagnosed condition in Supplementary Figure B-2.

#### Recruitment and Enrolment Process

Potential participants were identified using patient lists provided to IOM by the participating health facilities. At the beginning of the study, lists of diabetes and hypertension patients who visited each facility within the past six months were provided. These lists covered most of the existing caseload and served as the patient population initially approached for enrollment. Each facility submitted updated patient lists for study recruitment purposes weekly through the end of the enrollment period. Enrollment of additional patients continued until the first intervention was implemented in the facility. These patients included: 1) those newly diagnosed with hypertension and diabetes, 2) those that were unreachable by telephone, and 3) those not included in the initial lists but later identified as potentially eligible for enrollment.

Identified patients were called by interviewers using the primary contact number provided, or an alternate number when necessary and available. Interviewers began by reading a brief script introducing the reason for the call and providing information about the study and the patient's rights to decline participation. During this call, informed consent was obtained by interviewers trained in human subjects research and data collection practices, including the data collection tools used for the study.

#### Data Collection

This study was designed using a mixed-methods approach with both qualitative and quantitative data collection. A timeline of study intervention implementation and data collection is provided in Supplementary Figure B-3.

#### Quantitative Data Collection

<u>Health facility assessments</u> were performed at baseline to collect information about available equipment, drug supplies, and facility conditions. They also included observation of the physical space; numbers of providers by type and facility operating hours; records of patients seen for the target conditions and related diagnoses and referral; equipment for diagnosis and management of hypertension and diabetes; and medicines for the conditions and recent stock outs.

In addition to a facility assessment conducted at the start of the study, a total of four instruments were used to collect patient data throughout the study: (i) enrollment interview, (ii) patient record review, (iii) exit interviews, and (iv) end of study phase interviews.

<u>Enrolment interviews</u> were conducted with every patient. These were structured interviews conducted by phone at baseline for all participants. In addition to providing consent for study participation, key indicators collected through these interviews included patient demographic and migration information; medical history and recent care seeking behaviors; and knowledge, attitudes, and practices related to diabetes and/or hypertension.

<u>Medical record reviews</u> were conducted for each patient following enrollment, retrospectively at the end of Phase 2, and finally with information from both the mHealth application and facility records at the end of Phase 3. Key indicators included in the record reviews were related to provider compliance with guidelines and quality of care; frequency of visits; generic patient outcomes (death and loss to follow-up), and disease-specific patient outcomes (complications and adverse events of hypertension and diabetes).

<u>Patient exit interviews</u> were conducted on a subset of enrolled patients that sought care at study facilities throughout the study period. Phone interviews with these patients were conducted within ten days of a visit to the facility. Key indicators relate to provider trust, counseling received, and satisfaction and perceptions of care received during the most recent visit.

End of study phase interviews consisted of a shortened combination of questions from enrollment and exit interviews and were conducted at the end of Phases 2 and 3. Key indicators included recent care seeking behaviors; knowledge, attitudes, and practices related to diabetes and/or hypertension; and counseling, satisfaction, and perceptions of care received during the most recent visit to a study facility.

All patient interviews were conducted by phone to ensure confidentiality and reduce the gratuity bias of interviews performed at health facilities. The approach has been successfully used by the United Nations High Commissioner for Refugees (UNHCR) for surveys of Syrian refugees in Lebanon with reduced implementation costs and loss to follow-up compared to in-person interviews.<sup>71,117</sup> Interview and record review data were collected on tablets using the Magpi mobile data platform by DataDyne LLC (Washington, DC).

#### Qualitative Data Collection

In addition to quantitative data collected via phone interviews, a total of 19 focus group discussions (FGDs) were conducted with Syrian refugees and Lebanese host community members enrolled in the study, as well as health care providers working at study health facilities. Interview content focused on care-seeking and medication adherence, providing more nuanced information regarding barriers to care-seeking, treatment, and medication adherence from both patient and provider perspectives. Two key informant interviews (KIIs) were also conducted with staff from humanitarian organizations providing services or programming for NCDs among Syrian refugees in Lebanon.

Qualitative data was collected by local IOM staff with one note-taker and one interviewer at each focus group. Oral informed consent was obtained from each participant before initiating the group discussion. FGDs were facilitated using semi-structured interview guides and lasted between 30 and 90 minutes, depending upon time participants had available and interest in participation.

Separate focus group discussions were conducted for Syrian refugees and Lebanese host community members in each geographic region. Groups were then further separated based upon whether the participant sought care for hypertension and/or type 2 diabetes in the six months prior to FGDs. Supplementary Table B-3 presents the number of FGD participants by location and participant group.

Focus groups were recorded to allow facilitators to more fully engage in discussions without compromising documentation. Following each discussion, the interviewer and note-taker discussed participants' contributions, interactions within the group, and how group composition or other factors may have influenced participants' responses. Detailed notes were typed using recordings to expand upon notes taken during focus groups, then reviewed by data collection team members and translated to English. FGD facilitators also debriefed with the Johns Hopkins Bloomberg School of Public Health (JHSPH) field coordinator throughout data collection to discuss questions, concerns, challenges faced, as well as strengths and weaknesses of each discussion. In addition to FGDs, individual and group KIIs were conducted with staff from various humanitarian organizations involved in the provision of services for NCDs to Syrian refugees in Lebanon. Interviews with humanitarian actors were semi-structured and conducted by the JHSPH field coordinator and the local IOM study coordinator who facilitated FGDs.

FGD and KII summaries and field notes were analyzed using content analysis methods to identify key themes, consensus viewpoints, and viewpoints of a minority within groups, in addition to views that were unique to particular contexts or locations. FGD notes were analyzed separately for each participant group, after which findings were analyzed across groups to examine common themes further.

#### Preliminary Data Cleaning

A sequenced process-based classification used patient records, clinical data, and prescriptions to assign a uniform diagnosis category to patients in cases where reporting was inconsistent. Eight patients remained with an unclassified diagnosis and were subsequently dropped from the final analysis to ensure reliable reporting by condition. A similar process was used to classify population group (i.e., Syrian refugee, Lebanese host community, or other nationalities) among participants with conflicting reporting across data sources; all participants were successfully classified.

#### Limitations

Limiting the study sample to individuals seeking care at study health facilities, while necessary for the main study objectives, is a limitation of this research in that it restricts representativeness to a small subset of the population of Syrian refugees and host communities in Lebanon who sought care in these locations. The prevalence of hypertension and type 2 diabetes is likely to be much higher in the community than only those recruited for the study without additional screening of the general population, and persons receiving care from private clinics, pharmacies, or Syrian doctors may well have different findings. As such, results are not necessarily applicable to all individuals with hypertension or diabetes who are not receiving care or who receive care at different types of health facilities or in other geographic areas of Lebanon. This is limiting because outcomes among patients not receiving care could presumably be far worse than in patients receiving some level of care; however, results from this research can neither confirm nor preclude those assumptions.

Health Facility	Current Caseload	New Cases <sup>*</sup>	Estimated Total Cases	# estimated to be reachable <sup>†</sup>	Estimated Sample <sup>‡</sup>
IOM Supported Facilitie	25				
Tyre	123	74	197	158	142
Msayleh	193	116	309	247	223
Nabatiyeh	140	84	224	179	161
Bar Elias	N/A	N/A	125	100	90
Taalabaya	16	18	34	27	25
IMC Supported Facilitie	25				
Saadnayel	324		324	259	233
Tayouneh	183	NT-4	183	146	132
Fanar	50	INOL	50	40	36
Mrayje	72	applicable	72	58	52
Karagheusian	715		715	572	515
Maximum Planned San	nple	-	-		1,609

Supplementary Table B- 1. Sample Size and Power Calculations

\*estimated by taking 10% of the current caseload as newly identified cases monthly and extrapolating this out for a 6-month period during Phase 1; and <sup>†</sup> 80% of the estimated cases; and <sup>‡</sup> estimated at 80% of the reachable cases

Health Facility (Supporting Organization)	Enrollment (N=1,010)	End Phase 2 (N=830)	End Phase 3 (N=963)	Complete Follow-Up* (N=804)
South Governorate				
Msayleh (IOM)	116	93	113	88
Nabatiyeh (IOM)	67	62	64	62
Tyre (IOM)	83	65	81	64
Bekaa Governorate				
Bar Elias (IOM)	105	86	92	81
Taalabaya (IOM)	193	163	185	158
Saadnayel (IMC)	95	88	91	83
Beirut/Mt. Lebanon Govern	orates			
Tayouneh (IMC)	9	8	9	8
Fanar (IMC)	12	9	11	9
Mrayje (IMC)	49	50	48	48
Karagheusian (IMC)	281	206	269	203
Total	1.010	830	963	804

# Supplementary Table B- 2. Final Study Sample by Health Facility and Study Phase

\* Complete follow-up indicates data collected from at least one instrument (i.e. participant interview and/or record review) in each study phase

Participant Type	Beirut / Mt. Lebanon	Bekaa	South	Total
Health Care Providers				
Physicians	2	3	6	11
Nurses	3	4	4	11
Pharmacists	0	0	2	2
Total Provider FGD Sample	5	7	12	24
Patients				
Syrian Refugees				
Recently sought care	11	9	3	23
Did not recently seek care	12	8	8	28
Lebanese Host Community				
Recently sought care	8	3	2	13
Did not recently seek care	4	3	4	11
Total Patient FGD Sample	35	23	17	75

Supplementary Table B- 3. Focus Group Discussion Participants by Location and Participant Group

Supplementary Figure B-1. Study Facilities by Geographic Area





# Supplementary Figure B-2. Final Study Sample by Condition and Study Phase

## Supplementary Figure B- 3. Data Collection and Study Intervention Timeline

Year		20	)14							20	15									20	16			
Month	9	10	11	12	1	2	3	4	5	6	7	8	9	10	11	12	1	2	3	4	5	6	7	8
Study Intervention I	mp	ler	nen	tati	ion																			
Treatment guidelines																								
mHealth app																								
Data Collection		-	_		-				-	-	_		_		-	-		-	-	-	_			
Facility assessments																								
Enrollment interviews																								
Record reviews																								
Exit interviews																								

# **Appendix C. Explanatory Variables**

Multicollinearity among explanatory variables was explored in each dataset using variance inflation factor (VIF) scores, which measure the extent of inflation in a regression coefficient's variance due to multicollinearity in the model. In the case of models in all three papers, VIF scores were all below 1.75, indicating no multicollinearity concerns relative to conventional thresholds.

## Paper 1

Explanatory variables used in analyses are summarized in Supplementary Table C-1 below and included: (i) any care visit for the condition of interest in the three-month period prior to interview (no/yes; only included in models for odds of interrupted medication adherence); (ii) region of residence (Beirut or Mt. Lebanon/Bekaa/North); (iii) female-headed household (no/yes); (iv) highest level of education completed by the household head (less than primary/primary or higher); (v) household expenditure category (measured as below/above the median monthly household expenditures reported by Syrian refugees); (vi) year of arrival in Lebanon (2011-2012/2013-2015); and (vii) receipt of any cash/voucher assistance from a United Nations agency, non-governmental organization (NGO), or other religious or community group in the month preceding interview (no/yes). Distributions of explanatory variables are provided in Supplementary Table C-2 stratified by households with members diagnosed with hypertension and those with diabetes.

## Paper 2

Explanatory variables used in analyses are summarized in Supplementary Table C-3 below. Patient demographic characteristics in this analysis include: (i) age (40-50 years/51-60 years/older than 60 year); (ii) sex (male/female), (iii) highest level of education completed (less

than primary/primary or higher), (iv) household expenditure category (below/above the median monthly household expenditures reported by refugees); and (v) duration of time in current residence location (longer than one year/one year or less). Age was categorized into wider intervals due to imprecision in self-report.

Clinical characteristics include: (i) comorbid hypertension and diabetes diagnoses (no/yes); (ii) time since diagnosis (less than 10 years/10 years ago or longer); (iii) patient enrollment in the YMCA chronic medications program (no/yes); and (v) knowledge of complications of the condition of interest (hypertension and/or type 2 diabetes). As with age, time since diagnosis is analyzed as a dichotomous variable because of imprecise patient reporting of disease duration; the division of 10 year disease duration for categories was selected based upon the distribution of reported continuous time since diagnosis, and to reflect distinctions between patients likely to have had established care and treatment routines prior to the start of the Syrian conflict versus those either diagnosed after the start of the crisis or close enough that they are not expected to have acclimated to the diagnosis and settled into a care routine. A descriptive overview of explanatory variables stratified by condition is provided in Supplementary Table C-4.

# Paper 3

Explanatory variables used in analyses are summarized in Supplementary Table C-5 below. Patient demographic characteristics in this analysis include: (i) age (in years); (ii) sex (male/female), (iii) highest level of education completed (less than primary/primary or higher), (iv) household expenditure category (below/above the median monthly household expenditures among refugees); and (v) duration of time in current residence location (longer than one year/one year or less). Clinical characteristics include: (i) diagnosed hypertension and diabetes comorbidity (no/yes); (ii) time since diagnosis (10 years or fewer /more than 10 years); (iii) patient enrollment in the YMCA chronic medications program (no/yes); and (v) knowledge of complications of the condition of interest (hypertension or type 2 diabetes; no/yes).

Distributions of explanatory variables stratified by diagnosed condition are provided in Supplementary Table C-6.

Supplementa	ary Table C- 1. Ir	ndividual and	Household	<b>Characteristics</b>	Included as
Explanatory	Variables in Pap	er 1 Regressi	on Analyses	8	

Variable	Variable Type	Description
Individual Character	ristics	
Recent care visit	Dichotomous	Defined as any care received for hypertension/diabetes in the three months preceding interview (no/yes)
Household Characte	ristics	
Year of arrival in Lebanon	Categorical	Categorized as: 2011-2012/2013-2015
Region of residence	Categorical	Defined as the region of current residence. Categorized as: Beirut/Mt Lebanon, South, or Bekaa
Female-headed household	Dichotomous	Categorized as: no/yes
Highest education level completed	Categorical	Defined as highest level of education completed by the household head. Categorized as: less than primary/primary or higher
Monthly household expenditure category	Dichotomous	Defined as having self-reported monthly household expenditures below/above the median amount reported by Syrian refugees (Median = 986,750 LBP/US\$654.5)
Receipt of any cash/voucher assistance	Dichotomous	Defined as receipt of any cash or voucher assistance received from a United Nations agency, NGO, or other religious or community group in the month preceding interview (no/yes)

	1+ HH Member with Hypertension <sup>*</sup>	1+ HH Member with Diabetes <sup>*</sup>
	(N=282)	(N=136)
Any care visit for condition in past 3 months	145 (51.4%)	84 (61.8%)
Year of arrival in Lebanon		
2011 - 2012	123 (43.6%)	68 (50.0%)
2013 - 2015	159 (56.4%)	68 (50.0%)
Region of residence		
Beirut/Mt. Lebanon	68 (24.1%)	35 (25.7%)
Bekaa	97 (34.4%)	45 (33.1%)
North	117 (41.5%)	56 (41.2%)
Female-headed household	45 (16.0%)	23 (16.9%)
Household head completed primary education or higher	216 (76.6%)	113 (83.1%)
Above median monthly household expenditures <sup><math>\dagger</math></sup>	168 (59.6%)	73 (53.7%)
Receipt of cash/voucher assistance <sup>‡</sup>	219 (77.7%)	104 (76.5%)

Supplementary Table C- 2. Paper 1 Explanatory Variable Distributions by Household Members Diagnosed with Hypertension and/or Diabetes

Presented as frequency (%). HH = household

\* Condition classification not mutually exclusive; households with any member(s) diagnosed with both conditions are included in both condition groups

<sup>†</sup> Relative to median monthly expenditures reported by Syrian refugee households

<sup>‡</sup> Includes cash or voucher assistance received from a United Nations agency, NGO, or other religious or community group in the month preceding interview

Variable	Variable Type	Description
Demographic Charac	teristics	
Age	Categorical	Categorized as: 40-50 years / 51-60 years / older than 60 years
Sex	Dichotomous	Male/female
Highest education level completed	Categorical	Defined as highest level of education completed by the patient. Categorized as: less than primary/primary or higher
Monthly household expenditure category	Dichotomous	Defined as having self-reported monthly household expenditures below/above the median amount for Syrian refugee patients. (Median = 932,000 LBP/US\$618)
Time in current residence location	Binary	Defined as having lived in current residence for one year or less (no/yes)
<b>Clinical Characterist</b>	ics	
Hypertension / Diabetes comorbidity	Dichotomous	Defined as formal diagnosis of both hypertension and diabetes (no/yes)
Time since diagnosis	Dichotomous	Defined as the amount of time since initial condition diagnosis Categorized as: less than 10 years / 10 years or longer
Medication assistance	Dichotomous	Defined as enrollment in the YMCA chronic medications program, which provides medications for chronic conditions at a nominal cost through select dispensaries/primary health facilities throughout the country (no/yes)
Condition knowledge	Dichotomous	For patients with hypertension, defined as reported knowledge of stroke as a complication of hypertension (no/yes) For patients with diabetes, defined as reported knowledge of at least one complication of diabetes including eye problems, kidney problems, heart problems, and/or foot ulcers (no/yes)

Supplementary Table C- 3. Clinical and Demographic Characteristics Included as Explanatory Variables in Paper 2 Regression Analyses

	Hypertension (N=552)	Type 2 Diabetes (N=312)
Patient Characteristics		
Age		
40 – 50 years	167 (30.8%)	96 (31.4%)
51 - 60 years	176 (32.4%)	103 (33.7%)
> 60 years	200 (36.8%)	107 (35.0%)
Female	370 (67.0%)	216 (69.2%)
Completed $\geq$ primary education	160 (29.5%)	87 (28.6%)
Above median monthly household expenditures*	273 (51.4%)	152 (50.8%)
Lived in current residence location $\leq 1$ year	151 (28.7%)	93 (31.7%)
Clinical Characteristics		
Hypertension/diabetes comorbidity	227 (41.5%)	227 (73.2%)
>10 years since diagnosis	129 (27.7%)	79 (30.0%)
Enrolled in YMCA Program	148 (27.3%)	79 (25.9%)
Knowledge of complication(s) of condition <sup><math>\dagger</math></sup>	281 (51.8%)	161 (52.8%)

Supplementary Table C- 4. Distribution of Paper 2 Explanatory Variables by Diagnosed Condition Among Syrian Refugees

Presented as frequency (%)

Condition classification not mutually exclusive; participants with dual diagnoses included in both condition groups

\* Relative to median monthly household expenditures reported by Syrian refugees

<sup>†</sup> Defined for hypertension patients as identifying stroke as a complication and for diabetes patients as identifying at least one complication of diabetes, including eye problems, kidney problems, foot ulcers, and heart problems. Reference: not able to identify any complication of diabetes

Variable	Variable Type	Description
Demographic Charac	teristics	
Age	Ordinal	In years
Sex	Dichotomous	Male/female
Highest education level completed	Categorical	Defined as highest level of education completed by the patient. Categorized as: less than primary/primary or higher
Monthly household expenditure category	Dichotomous	Defined as having self-reported monthly household expenditures below/above the median amount Syrian refugee patients. (Median = 932,000 LBP/US\$618)
Time in current residence location	Binary	Defined as having lived in current residence for one year or less (no/yes)
Clinical Characterist	ics	
Hypertension / Diabetes comorbidity	Dichotomous	Defined as formal diagnosis of both hypertension and diabetes (no/yes)
Time since diagnosis	Categorical	Defined as the amount of time since initial condition diagnosis Categorized as: less than five years / five to nine years / ten years or longer
Medication assistance	Dichotomous	Defined as enrollment in the YMCA chronic medications program, which provides medications for chronic conditions at a nominal cost through select dispensaries/primary health facilities throughout the country (no/yes)
Condition knowledge	Dichotomous	For patients with hypertension, defined as reported knowledge of stroke as a complication of hypertension (no/yes) For patients with diabetes, defined as reported knowledge of at least one complication of diabetes including eye problems, kidney problems, heart problems, and/or foot ulcers (no/yes)

Supplementary Table C- 5. Clinical and Demographic Characteristics Included as Explanatory Variables in Paper 3 Regression Analyses

	Hypertension	Type 2 Diabetes
	(N=552)	(N=312)
Patient Characteristics		
Age (years)	57.2 (9.9)	56.6 (9.2)
Sex		
Male	182 (33.0%)	96 (30.8%)
Female	370 (67.0%)	216 (69.2%)
Completed $\geq$ primary education	160 (29.5%)	87 (28.6%)
Above median monthly household expenditures*	273 (51.4%)	152 (50.8%)
Lived in current residence location $\leq 1$ year	151 (28.7%)	93 (31.7%)
Clinical Characteristics		
Hypertension / diabetes comorbidity	227 (41.5%)	227 (73.2%)
Time Since Diagnosis		
< 5 years	201 (43.1%)	106 (40.3%)
5 - 9 years	136 (29.2%)	78 (29.7%)
$\geq 10$ years	129 (27.7%)	79 (30.0%)
Enrolled in YMCA Program	148 (27.3%)	79 (25.9%)
Knowledge of complication(s) of condition <sup>†</sup>	281 (51.8%)	161 (52.8%)

# Supplementary Table C- 6. Distribution of Paper 3 Explanatory Variables by Diagnosed Condition Among Syrian Refugees

Presented as mean (standard deviation) for continuous variables and frequency (%) for dichotomous/categorical variables Condition classification not mutually exclusive; participants with dual diagnoses included in both condition groups

 $^{\ast}$  Relative to median monthly expenditures reported among those in the same population group

<sup>†</sup> For hypertension: Defined as able to identify stroke as a complication of hypertension.

For diabetes: Defined as able to identify at least one complication of diabetes, including eye problems, kidney problems, foot ulcers, and heart problems.

Supplementary Table D-1. Ot	it-of-Pocket Consul	tation Costs for Hy	pertensio	on and Diabetes Care	in Lebanon by Facili	ty Type
	Ĥ	ypertension			Diabetes	
	<b>Syrian Refugees</b> Point (95% CI)	Host Community Point (95% CI)	<i>P</i> -value	Syrian Refugees Point (95% CI)	Host Community Point (95% CI)	<i>P</i> -value
Out-of-Pocket Cost of All Care Vi	isits $n=195$	n=196		n=I02	n=126	
All cases Median	3	33		5	33	
Mean	14.4 (9.8-18.9)	29.5 (24.8-34.2)	< 0.001	12.0 (8.2-15.7)	31.6 (26.7-36.5)	< 0.001
% with any payment	66.7% (59.2-73.4%)	77.0% (70.7-82.3%)	0.017	70.6% (62.3-77.7%)	82.5% (74.5-88.4%)	0.025
Among cases with Median	10	33		10	33	
payment Mean	21.7 (14.9-28.5)	38.4 (33.3-43.5)	< 0.001	17.1 (12.0-22.2)	38.7 (33.3-44.0)	< 0.001
Cost by Facility Type						
<b>Primary-Level Health Facility</b>	n=107	n=38		n=62	n=22	
All cases Median	3	10		4	8	
Mean	7.4 (3.3-11.4)	18.8 (10.1-27.5)	0.012	10.6 (5.3-16.0)	12.7 (6.2-19.2)	0.623
% with any payment	73.8% (63.7-82.0%)	86.8% (71.7-94.5%)	0.115	79.0% (66.4-87.8%)	77.3% (55.2-90.4%)	0.866
Among cases with Median	5	10		L	10	
payment Mean	10.0 (4.6-15.4)	21.7 (12.1-31.2)	0.023	$13.5 \ (6.8-20.1)$	16.5 (9.0-24.0)	0.533
Private Clinic	n=42	n=116		n=2I	u=75	
All cases Median	23	33		20	33	
Mean	28.5 (17.5-39.4)	32.3 (28.0-36.7)	0.506	24.2 (16.3-32.1)	41.8 (35.7-47.8)	0.001
% with any payment <sub> </sub>	85.7% (71.8-93.4%)	82.8% (74.6-88.7%)	0.657	90.5% (69.5-97.5%)	94.7% (86.6-98.0%)	0.480
Among cases with Median	27	33		23	33	
payment Mean	33.5 (21.5-45.5)	38.6 (34.7-42.5)	0.426	26.9 (19.7-34.1)	44.2 (38.2-50.2)	0.001
Hospital	9l=u	n=3I		n=49	n=20	
All cases Median	20	33		0	25	
Mean	48.8 (11.0-86.6)	42.3 (22.0-62.7)	0.764	2.2 (-1.4-5.8)	30.0 (15.8-44.3)	< 0.001
% with any payment <sub> </sub>	62.5% (38.9-81.4%)	64.5% (45.6-79.8%)	0.897	50.0% (12.0-88.0%)	80.0% (56.4-92.5%)	0.211
Among cases with Median	27	50		L	33	
payment Mean	81.4 (29.5-133.2)	69.8 (47.1-92.4)	0.680	9.9	38.6 (23.1-54.1)	
All costs reported in in US\$; exchange r Group comparison using Pearson's chi-s	ate = $1,570.5$ LBP / US\$1 square for proportions and t	-test for means. Statistical	significance	: indicated in bold $(P<0.05)$	and bold italics ( <i>P</i> <0.001).	

Appendix D. Paper 1 Additional Results

# **Appendix E. Paper 2 Care Utilization Model Comparison and Selection Methods**

Physician utilization outcome variables in these analyses are count data (i.e., nonnegative integers). Overdispersion, or greater variability than would be expected relative to the mean, is common in count data due to excess zeros relative to standard distributions, and/or from unexplained heterogeneity.<sup>455</sup> This violates the assumption of equidispersion necessary for the Poisson model; however, the negative binomial regression model (NB) includes a parameter for dispersion and thus is able to account for over-dispersion resulting from unobserved heterogeneity and/or temporal dependency.<sup>525</sup>

In the case of overdispersion due to excess zeros, zero-inflated and hurdle models are most often utilized.<sup>526</sup> These models frequently produce comparable fit statistics, but conceptually, they contain related yet different reports of excess zero concerns. Zero-inflated models are commonly used for data with both structural and sampling excess zeros, while hurdle models are used in data that contain only sampling excess zeros. Use of hurdle models has gained favor in health research, mainly for their ability to facilitate interpretations that reflect the "dual decision structure" of health service utilization.<sup>527</sup>

Model selection for Paper 2 began by assessing equidispersion using the Lagrange Multiplier test, which identified overdispersion both in the number of visits to a general practitioner (GP) and in visits to a relevant specialist (endocrinologist and/or cardiologist).<sup>410</sup> To identify the analytical technique best suited to the data structure, Poisson and NB models were compared, along with zero-inflated Poisson (ZIP), zero-inflated negative binomial (ZINB), Poisson hurdle (PH), and negative binomial hurdle (NBH) models for each of the utilization outcome variables included in this analysis. Both the Akaike (AIC) and Bayesian information criterion (BIC) were considered in determining the best-suited model for the data, though qualitative consideration was also given to assumptions about excess zeros in the data and interpretation of model results. Goodness of fit statistics comparing the tested models are provided in Supplementary Table E-1.

Both AIC and BIC indicated a preference for NBH models in all outcome variables. Moreover, excess zeros in the data are believed to contain only sampling zeros rather than both sampling and structural zeros, further supporting the conclusion that hurdle models are better suited to these data than zero-inflated models. Because study participants were recruited using lists of patients who had received care at any of the ten study health facilities in the six months prior to enrollment, it is assumed that all study participants are "at risk" or capable of having one or more visits to any given provider type in the same period of time used as a reference period during interviews. Although patients were placed on recruitment lists regardless of whether they visited a study health facility to receive care from a physician or a nurse, to have laboratory tests performed, or simply to refill a prescription, it is assumed that by virtue of having visited a facility, all enrolled patients were "at risk" for visiting any given type of health provider in the future, particularly at the study health facilities. Consequently, the final analyses employed four distinct NBH models: (i) GP care utilization among patients with hypertension, (ii) specialist care utilization among patients with hypertension, (iii) GP care utilization among patients with type 2 diabetes, and (iv) specialist care utilization among patients with type 2 diabetes.

	Poisson	NB	ZIP	ZINB	РН	NBH	
HYPERTENSION							
GP Visits							
AIC	2075.59	1766.54	1956.45	1788.06	1922.64	1745.24	
BIC	2157.73	1852.79	2120.73	1956.45	2004.78	1831.49	
Specialist Visi	ts						
AIC	1968.87	1788.44	1926.23	1797.81	1887.53	1777.78	
BIC	2051.01	1874.69	2090.51	1966.20	1969.67	1864.03	
TYPE 2 DIABETES							
GP Visits							
AIC	1064.89	941.09	1027.90	952.39	989.75	937.29	
BIC	1135.15	1014.87	1168.44	1096.44	1060.02	1011.07	
Specialist Visi	ts						
AIC	1251.92	1115.56	1225.33	1125.63	1186.57	1099.20	
BIC	1322.19	1189.34	1365.87	1269.68	1256.84	1172.98	

## Supplementary Table E-1. Multivariate Models of Care Utilization by Syrian Refugee Patients: Goodness of Fit Comparisons for All Utilization Outcome Models

AIC = Akaike Information Criterion; BIC = Bayesian Information Criterion Poisson = Poisson regression model; NB = negative binomial regression model; ZIP = zero-inflated Poisson model; ZINB = zero-inflated negative binomial model; PH = Poisson hurdle model; NBH = negative binomial hurdle model

#### **Appendix F. Validity of Single-Question Medication Adherence Measure**

The single-question measure of interrupted medication adherence used in this paper ("Within the last six months, have you had to stop taking [medicines prescribed for hypertension/diabetes] for two weeks or more?") has been used previously in research with refugee populations; however, its validity as an informative measure in these settings was not previously evaluated.<sup>72</sup> Consequently, in the final two follow-up data collection periods of the *Treatment Guidelines for Hypertension and Type 2 Diabetes in Syrian Refugees and Host Communities in Lebanon* study, the four-item Morisky Medication Adherence Scale (MMAS-4) was included in survey instruments to evaluate the validity of the single-question adherence measure reference period was three months preceding interview, whereas the question referred to the prior six months in the enrollment interview. In all data collection periods, the single-question measure asked about medication interruption of two weeks or longer. The validity of the MMAS-4 and the original eight-item version (MMAS-8) have been established in multiple international settings and are among the most widely accepted and utilized measures of medication adherence, particularly among those with chronic health conditions.<sup>222,528,529</sup>

Paper 3 used baseline data from the *Treatment Guidelines* study to assess and model (i) medication adherence, (ii) group differences in adherence, and (iii) factors associated with adherence. The validity of the single-question adherence measure was first assessed using responses to this question and to the MMAS-4 adherence classifications collected in subsequent cohort study data collection periods. Most patients were classified as having high medication adherence according to the MMAS-4 regardless of medical condition or study phase. Ranging from zero to four with higher values indicating lower medication adherence, the mean MMAS-4 score among patients with hypertension was 0.19 (CI: 0.15-0.23) following the guidelines phase

and 0.15 (CI: 0.12-0.18) following the mHealth phase.<sup>530</sup> Similar mean MMAS-4 scores were observed among patients with type 2 diabetes (0.17, 95: CI: 0.12-0.21 following the guidelines phase and 0.12, CI: 0.08-0.15 after the mHealth phase). Of the individual items on the MMAS-4, sometimes forgetting to take medication was the most commonly reported item in all study phases for both conditions. The three remaining MMAS-4 items (carelessness in taking mediation, stopping when the patient felt better, and stopping when the patient felt worse) were reported by a similar proportion of patients in both study phases for hypertension and type 2 diabetes.

One or more of the individual MMAS-4 items were reported by a larger proportion of individuals than was interrupted adherence as measured by the single question "Have you stopped taking your hypertension/diabetes medication for two weeks or longer in the past three months?" in both study phases for both conditions.

An overview of MMAS-4 results are presented in Supplementary Table F-1 stratified by report of interrupted medication use in the single-question adherence measure. The sensitivity and specificity of the single-question medication adherence measure against the MMAS-4 are also provided in Supplementary Table F-2.

#### Hypertension

Following implementation of the treatment guidelines, 64.6% (CI: 49.5-77.8%) of patients with hypertension who reported interrupted adherence were nonetheless also classified as having high adherence using the MMAS-4 as compared to 84.1% (CI: 80.8-87.1%) among patients who did not report interrupted adherence (P<0.001). Following implementation of the mHealth application, high MMAS-4 scores were observed in 60.0% (CI: 42.1-76.1%) of patients

with hypertension who reported interrupted adherence versus 78.2% (CI: 73.7-82.3%) of those who did not report interrupted adherence (P < 0.001).

Among patients with hypertension, the single-question measurement of interrupted adherence in the prior three-month period had 16.2% (CI: 9.7%-24.7%) sensitivity and 93.8% (CI: 91.3%-95.7%) specificity compared to the validated MMAS-4 scale. These calculations consider patients with low or medium medication adherence based upon MMAS-4 scores as "non-adherent" and are based on data collected following guideline implementation. Relying on data collected after implementation of the mHealth application, the single-question measure had 14.6% (CI: 8.2%-23.3%) sensitivity and 93.4% (CI: 90.0%-95.8%) specificity among patients with hypertension.

#### **Type 2 Diabetes**

Among patients with type 2 diabetes, high medication adherence (measured using the MMAS-4) was observed in 64.3% (CI: 44.1-81.4%) of those reporting interrupted adherence and 86.1% (CI: 82.1-89.6%) of those not reporting interrupted adherence following guideline implementation (P <0.001). After mHealth implementation, 64.3% (CI: 35.1-87.2%) of those with interrupted adherence to their type 2 diabetes medication were classified as having high adherence according to the MMAS-4 versus 82.0% (CI: 76.7-86.6%) of those who did not report interrupted adherence (P <0.001).

Among patients with type 2 diabetes, the single-question measurement of interrupted adherence had 16.9% (CI: 8.4%-29.0%) sensitivity and 94.4% (CI: 91.3%-96.7%) specificity compared to the validated MMAS-4 scale following guideline implementation. After mHealth implementation, the single-question measure had 10.2% (CI: 3.4%-22.2%) sensitivity and 95.7% (CI: 92.0%-98.0%) specificity among patients with type 2 diabetes.

Adherence Scale (MMAS-4)						
	<b>Guideline Implen</b>	<u>nentation (Study Pha</u>	se II)	<u>mHealth Implem</u>	<u>entation (Study Phas</u>	<u>e III)</u>
_	Interrupted Adherence <sup>*</sup>	Uninterrupted Adherence <sup>*</sup>	P-value <sup>†</sup>	Interrupted Adherence <sup>*</sup>	Uninterrupted Adherence <sup>*</sup>	P-value <sup>†</sup>
	Point (95% CI)	Point (95% CI)		Point (95% CI)	Point (95% CI)	
		HYPERTENSION				
<b>MMAS-4 Scale Items</b>	(n=44)	(n=536)		(n=34)	(n=373)	
Sometimes forgets to take medication	34.9% (21.0-50.9%)	13.9% (11.1-17.1%)	< 0.001	32.4% (17.4-50.5%)	18.5% (14.7-22.8%)	0.052
Careless about taking medication	18.6% (8.4-33.4%)	1.9% (0.9-3.4%)	< 0.001	20.6% (8.7-37.9%)	2.9% (1.5-5.2%)	< 0.001
Stops taking medicine if feel worse	11.6% (3.9-25.1%)	1.7% (0.8-3.1%)	< 0.001	8.8% (1.9-23.7%)	2.1% (0.9-4.2%)	0.022
Stops taking medicine if feel better	14.0% (5.3-27.9%)	1.9% (0.9-3.4%)	< 0.001	14.7% (5.0-31.1%)	3.2% (1.7-5.6%)	0.001
Mean MMAS-4 Score	0.71 (0.35-1.06)	0.19(0.15 - 0.23)	< 0.001	0.74(0.34-1.15)	0.27 (0.21-0.32)	< 0.001
MMAS-4 Category						
High adherence (0)	64.6% (49.5-77.8%)	84.1% (80.8-87.1%)	< 0.001	60.0% (42.1-76.1%)	78.2% (73.7-82.3%)	< 0.001
Medium adherence (1 - 2)	25.0% (13.6-39.6%)	15.0% (12.1-18.2%)		28.6% (14.6-46.3%)	20.4% (16.5-24.9%)	
Low adherence (3 - 4)	10.4% (3.5-22.7%)	0.9% (0.3-2.1%)		11.4% (3.2-26.7%)	1.3% (0.4 - 3.1%)	
		<b>TYPE 2 DIABETE</b>	S			
<b>MMAS-4 Scale Items</b>	(n=44)	(n=536)		(n=34)	(n=373)	
Sometimes forgets to take medication	33.3% (15.6-55.3%)	11.8% (8.6-15.6%)	0.003	28.6% (8.4-58.1%)	15.8% (11.5-21.1%)	0.212
Careless about taking medication	16.7% (4.7-37.4%)	0.9% (0.2 - 2.5%)	< 0.001	14.3% (1.8-42.8%)	0.8% (0.1 - 3.0%)	< 0.001
Stops taking medicine if feel worse	8.3% (1.0-27.0%)	1.7% (0.6-3.7%)	0.031	14.3% (1.8-42.8%)	1.2% (0.3 - 3.6%)	0.001
Stops taking medicine if feel better	16.7% (4.7-37.4%)	1.7% (0.6-3.7%)	< 0.001	21.4% (4.7-50.8%)	2.1% (0.7 - 4.8%)	0.001
<b>Mean MMAS-4 Score</b>	0.64 (0.23-1.05)	0.16(0.11 - 0.20)	< 0.001	0.79(0.00-1.61)	0.20 (0.14-0.25)	< 0.001
<b>MMAS-4</b> Category						
High adherence (0)	64.3% (44.1-81.4%)	86.1% (82.1-89.6%)	< 0.001	64.3% (35.1-87.2%)	82.0% (76.7-86.6%)	< 0.001
Medium adherence (1 - 2)	28.6% (13.2-48.7%)	13.6% (10.2-17.6%)		21.4% (4.7-50.8%)	17.1% (12.6-22.5%)	
Low adherence (3 - 4)	7.1% (0.9-23.5%)	0.3% (0.0-1.6%)		14.3% (1.8-42.8%)	0.8% (0.1-2.9%)	
* Interrupted vs uninterrupted adherence measur	ed using single question "Wi	thin the last three months, h	ave you had	to stop taking [medicines pr	escribed for hypertension/d	[abetes] for
two weeks or more?" <sup>†</sup> Group comparison using Pearson's chi-square f	for proportions and t-test for	means. Statistical significan	nce indicated	in bold ( $P$ <0.05) and bold it	alics ( <i>P</i> <0.001).	

Supplementary Table F-1. Hypertension and Type 2 Diabetes Medication Adherence Using the Four-Item Morisky Medication

	Sensitivity (95% CI)	Specificity (95% CI)
Hypertension		
Guideline Implementation (Study Phase II)	16.2% (9.7-24.7%)	93.8% (91.3-95.7%)
mHealth Implementation (Study Phase III)	14.6% (8.2-23.3%)	93.4% (90.0-95.8%)
Type 2 Diabetes		
Guideline Implementation (Study Phase II)	16.9% (8.4-29.0%)	94.4% (91.3-96.7%)
mHealth Implementation (Study Phase III)	10.2% (3.4-22.2%)	95.7% (92.0-98.0%)

Supplementary Table F- 2. Sensitivity and Specificity of Single-Question Medication Adherence Measure Against the MMAS-4

MMAS-4 scores ranging from 1-4 are classified as "non-adherent" and MMAS-4 scores of 0 are classified as "adherent" for validity analyses

# **Appendix G. Paper 3 Additional Results**

#### **Medication Prescription Documented in Patient Health Records**

## Hypertension

Based on patient health records, the most frequently prescribed medications for patients with hypertension were beta blockers (48.6%, CI: 44.2-53.1%), though calcium channel blockers and angiotensin-converting-enzyme inhibitors/angiotensin II receptor blockers were each prescribed for nearly one-third of patients. Just over half (53.0%, CI: 48.5-57.4%) of all patients with hypertension were also prescribed cardiac medication, primarily Acetylsalicylic acid/Aspirin\*, though Clopidogrel/Plavix®, Molsidomine/Corvasal®, and various others were also prescribed to a smaller number of patients. The most commonly prescribed antihypertensive medications among enrolled patients were Bisoprolol Fumarate/Concor® and Amlodipine/Amlor® (Supplementary Table G-1).

#### Type 2 Diabetes

The most frequently prescribed medication for patients with type 2 diabetes reported in patient health records was Metformin/Glucophage®, which was prescribed for 84.4% (CI: 79.8-88.2%) of enrolled patients at enrollment (Supplementary Table G-2). Glimepiride/Amaryl® was the second most frequently prescribed medication for patients with type 2 diabetes, though it was only prescribed for 40.4% (CI: 34.9-46.1%) of all patients with diabetes. Similar proportions of Syrian refugees and Lebanese host community members were prescribed each of these medications.

<sup>\*</sup> The original spelling of medication names in the Lebanese context is retained in the current work

	<u> </u>	~ <b>. . . .</b>		
	Overall	Syrian Refugees	Host Community	
	(N=718)	(N=489)	(N=229)	<i>P</i> -value
	Point (95% CI)	Point (95% CI)	Point (95% CI)	
Proportion of all hypertension				0.002
patients prescribed medication	69.9% (66.4-73.3%)	66.5% (62.1-70.6%)	//.3% (/1.3-82.6%)	0.003
	( 500)	( 225)	( 155)	
Number of	(n=502)	(n=325)	(n=1/7)	
medications reported Median	2	2	2	
in medical record Mean	1.79 (1.71-1.86)	1.70 (1.61-1.79)	1.95 (1.81-2.09)	0.002
Proportion of patients with any newly prescribed medication <sup>*</sup>	30.3% (26.3-34.5%)	38.8% (33.4-44.3%)	14.7% (9.8-20.8%)	< 0.001
Prescribed medication class <sup>†</sup>	(n=502)	(n=325)	(n=177)	
Beta Blockers	48.6% (44.2-53.1%)	46.8% (41.2-52.4%)	52.0% (44.4-59.5%)	0.265
Calcium Channel Blockers	32.7% (28.6-37.0%)	29.8% (24.9-35.1%)	37.9% (30.7-45.4%)	0.068
ACEi/ARBs <sup>‡</sup>	30.9% (26.9-35.1%)	32.6% (27.5-38.0%)	27.7% (21.2-34.9%)	0.253
Diuretics	3.8% (2.3-5.8%)	5.5% (3.3-8.6%)	0.6% (0.0-3.1%)	0.005
Cardiac <sup>§</sup>	53.0% (48.5-57.4%)	48.6% (43.1-54.2%)	61.0% (53.4-68.2%)	0.008
Other	0.8% (0.2-2.0%)	0.9% (0.2-2.7%)	0.6% (0.0-3.1%)	0.666
Prescribed antihynertensive	· · · · · · · · · · · · · · · · · · ·	· · · · · ·	, ,	
medication <sup>†</sup>				
Bisoprolol Fumarate/Concor	41.8% (37.5-46.3%)	39.7% (34.3-45.2%)	45.8% (38.3-53.4%)	0.188
Amlodipine/Amlor	32.3% (28.2-36.6%)	29.8% (24.9-35.1%)	36.7% (29.6-44.3%)	0.115
Captopril/Capoten	9.8% (7.3-12.7%)	9.8% (6.8-13.6%)	9.6% (5.7-14.9%)	0.931
Ramipril/Tritace	8.4% (6.1-11.1%)	8.0% (5.3-11.5%)	9.0% (5.3-14.3%)	0.688
Andesart	8.4% (6.1-11.1%)	10.8% (7.6-14.7%)	4.0% (1.6-8.0%)	0.008
Atenolol/Tenormin	6.4% (4.4-8.9%)	7.4% (4.8-10.8%)	4.5% (2.0-8.7%)	0.209
Valsartan/Diovan	4.8% (3.1-7.0%)	4.6% (2.6-7.5%)	5.1% (2.4-9.4%)	0.814
Esidrex	3.8% (2.3-5.8%)	5.5% (3.3-8.6%)	0.6% (0.0-3.1%)	0.005
Propranolol/Inderal	0.8% (0.2-2.0%)	0.0%	2.3% (0.6-5.7%)	0.007
Diltiazem/Tildiem	0.6% (0.1-1.7%)	0.0%	1.7% (0.4-4.9%)	0.019
Other	0.8% (0.2-2.0%)	0.9% (0.2-2.7%)	0.6% (0.0-3.1%)	0.666
Prescribed cardiac medication <sup>†</sup>				
Acetylsalicylic acid/Aspirin	49.8% (45.3-54.3%)	46.2% (40.6-51.7%)	56.5% (48.9-63.9%)	0.027
Clopidogrel/Plavix	5.2% (3.4-7.5%)	3.1% (1.5-5.6%)	9.0% (5.3-14.3%)	0.004
Molsidomine/Corvasal	4.8% (3.1-7.0%)	2.8% (1.3-5.2%)	8.5% (4.8-13.6%)	0.004
Digoxin/Lanoxin	0.8% (0.2-2.0%)	1.2% (0.3-3.1%)	0.0%	0.138
Acenocoumarol/Sintrom	0.2% (0.0-1.1%)	0.0%	0.6% (0.0-3.1%)	0.175
Isosorbide Dinitrate/Isordil	0.2% (0.0-1.1%)	0.0%	0.6% (0.0-3.1%)	0.175
Amiodarone/Cordarone	0.0%	0.0%	0.0%	

Supplementary Table G- 1. Hypertension Medication Prescription Extracted from Patient Records of Enrolled Syrian Refugee and Lebanese Host Community Care-Seekers at Study **Primary Health Facilities** 

Point = point estimate (proportion, mean, or median)

Group comparison using Pearson's chi-square for proportions and t-test for means. Statistical significance indicated in bold (P<0.05) and bold italics ( $P \le 0.001$ ).

\* Among patients with a prescription recorded

 <sup>†</sup> Each as a proportion of all patients with hypertension and a prescription recorded
 <sup>‡</sup> ACEi = angiotensin-converting-enzyme inhibitor; ARB = angiotensin II receptor blockers
 <sup>§</sup> Including Acetylsalicylic acid/Aspirin, Clopidogrel/Plavix, Molsidomine/Corvasal, Digoxin/Lanoxin, Acenocoumarol/Sintrom, Isosorbide Dinitrate/Isordil, and Amiodarone/Cordarone

		Overall	Syrian Refugees	Host Community		
		(N=431)	(N=277)	(N=154)	P-value	
		Point (95% CI)	Point (95% CI)	Point (95% CI)		
Proportion of all diabetes		72.4%	72.1%	72.7%		
patients prescribed med for condition	lication	(67.1-77.2%)	(65.4-78.2%)	(63.9-80.4%)	0.909	
Number of medications		(n=307)	(n=197)	(n=110)		
reported in medical	Median	1	1	1		
record*	Mean	1.43 (1.37-1.49)	1.44 (1.36-1.51)	1.41 (1.31-1.51)	0.659	
Proportion of patients with any newly prescribed medication*		26.4%	32.5%	15.5%	0.001	
		(21.5-31.7%)	(26.0-39.5%)	(9.3-23.6%)		
Prescribed medication <sup>†</sup>		(n=307)	(n=197)	(n=110)		
Metformin/Glucophage		84.4%	85.8%	81.8%	0.250	
		(79.8-88.2%)	(80.1-90.3%)	(73.3-88.5%)	0.339	
Glimepride/Amaryl		40.4%	39.1%	42.7%	0 522	
		(34.9-46.1%)	(32.2-46.3%)	(33.3-52.5%)	0.335	
Gliclazid/Diamicron		16.3%	16.2%	16.4%	0.078	
		(12.3-20.9%)	(11.4-22.2%)	(10.0-24.6%)	0.978	
Insulin		1.3%	2.0%	0.0%	0 1 2 2	
		(0.4-3.3%)	(0.6-5.1%)		0.132	
Other		0.3%	0.5%	0.0%	0.454	
		(0.0-1.8%)	(0.0-2.8%)		0.454	

Supplementary Table G- 2. Type 2 Diabetes Medication Prescription Extracted from Patient Records of Enrolled Syrian Refugee and Lebanese Host Community Care-Seekers at Study Primary Health Facilities

Point = point estimate (proportion, mean, or median)

Group comparison using Pearson's chi-square for proportions. Statistical significance indicated in bold (*P*<0.05) and bold italics (*P*<0.001).

\* Among patients with a prescription recorded

<sup>†</sup>Each as a proportion of all patients with type 2 diabetes and a prescription recorded

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## **Curriculum Vitae**

# Emily M. Lyles, MPA, MSPH

### **EDUCATION**

2019	PhD	International Health, Health Systems Johns Hopkins Bloomberg School of Public Health
2014	MSPH	International Health, Health Systems Johns Hopkins Bloomberg School of Public Health
2012	MPA	Public Policy and Administration University of Baltimore
2010	BA	English (Minor: Discourse & Technology) University of Baltimore

#### **PROFESSIONAL EXPERIENCE**

2015 - present	Research Assistant, Johns Hopkins Bloomberg School of Public Health		
	Department of International Health		
	<u>Responsibilities:</u> Technical support in design, implementation,		
	analysis, and write-up for research and evaluation in humanitarian		
	contexts with a focus on provision of research and evaluation to		
	inform humanitarian assistance planning and program		
	implementation. Specific projects include:		
	• Evaluation of multi-purpose cash transfers among Syrian		
	refugees in Jordan and Lebanon and conditional cash transfers for health in Jordan		
	• Evaluation of the effect of different cash transfer modalities on		
	nutrition and food security outcomes among pregnant and		
	lactating women and children under five in Somalia		
	• Assessment of injuries and mortality during the ISIS occupation of Mosul and its liberation		
	• Feasibility assessment for cash transfers in Southern Syria		
	• Risk assessment of vulnerable children and migrants in Greece		
	and Serbia and evaluate pilot interventions including cash		
	transfers and shelter projects, aimed at improving protection of vulnerable migrants		
2015	Research Associate, Johns Hopkins Bloomberg School of Public Health Department of International Health		
	<u>Responsibilities:</u> Support research on refugees and internally		
	displaced populations in the Middle East including surveys of		
	Syrian refugees, needs assessment of populations in Syria, and		
	technical support to organizations providing assistance.		

- 2014 2015 Field Coordinator, Johns Hopkins Bloomberg School of Public Health Department of International Health <u>Responsibilities:</u>
  - Field coordination and technical assistance in development, implementation, and evaluation of the effectiveness of primary health care guidelines and patient managed medical records among patients with diabetes and hypertension (refugee and host-community populations) in Lebanon
  - Field coordination and technical assistance in survey design, data collection, analysis, and report writing for national surveys of urban Syrian refugees focusing on health service access and utilization in Jordan and in Lebanon
  - Support development of a report for the International Federation of Red Cross and Red Crescent Societies providing an in-depth perspective on crisis, instability, and displacement in the Middle East and North Africa Zone

2013 – 2014 Research Assistant, Johns Hopkins Bloomberg School of Public Health Department of International Health *Responsibilities:* 

- Desk review of internal displacement trends in Syria from 2011-2014
- Quantitative data analysis for studies on cause of death in children under age five and traditional birth attendants in Iraq
- Support of a systematic review of the effectiveness and efficiency of cash-based approached in protracted and sudden-onset emergencies
- 2013 2014 Research Assistant, Johns Hopkins Center for Communication Programs (CCP)

<u>Responsibilities:</u> Performed a variety of activities around the development and implementation of international health communication and capacity building projects, including survey design, literature reviews, final report editing, and submission of manuscripts to peer-reviewed journals

- 2013 Intern, World Health Organization (WHO), Mental Health and Substance Abuse Department *Responsibilities:* 
  - Assess procurement and use of controlled psychotropic medicines in Interagency Emergency Health Kits
  - Analyze current regulatory policies on phenobarbital and access implications
  - A variety of other tasks including assisting development of mhGAP training and evaluation tools

#### CONSULTATIONS

- 2017 International Advisory, Products and Systems (iAPS) / Global Communities (1/2017-7/2017). Technical support; data management, quality, assurance, and analysis for a field third party monitoring assessment of program activities in Syria.
- 2016 iAPS (3/2016). Data analysis for an independent learning evaluation of Ebola Treatment Centres in Sierra Leone.
- 2015 2016 iAPS / Global Communities (12/2015-3/2016). Design, training, monitoring, analysis, and presentation of results for a comparative analysis of response modalities and cash-based response feasibility assessment in northern Syria.
- 2014 2015 iAPS / GOAL (02/2014 10/2015). Design, training, monitoring, analysis, and presentation of results for an assessment of the extent and the impact of multiple cash transfer modalities compared to in-kind distributions in Northern Syria.
- 2014 2015 International Medical Corps (10/2014 2/2015). Design, training, implementation, analysis, and presentation of results of a patient satisfaction survey of beneficiaries at International Medical Corps-supported Primary Health Care Centers in Lebanon.
- 2013 Finnish Ministry of Social Affairs and Health (1/2013-4/2013). Development of an index of international health indicators for integration with the Finnish Medicines Agency's (Fimea's) pharmaceutical specific measures to be used for monitoring and evaluation of the Medicines 2020 national strategy implementation.

# HONORS AND AWARDS

- 2014 Johns Hopkins Bloomberg School of Public Health Humanitarian Assistance Award
- 2013 Linda Jenkins-Brown Memorial Award for Outstanding MPA Student
- 2010 Helen P. Denit Honors Program Undergraduate Research Symposium Award

### PUBLICATIONS

# Journal Articles

- Doocy S, Lyles E, Fahed Z, Mkanna A, Kontunen K, Burnham G. (2018). Characteristics of Syrian and Lebanese diabetes and hypertension patients in Lebanon. *The Open Hypertension Journal*. doi: 10.2174/1876526201810010060.
- 2. Doocy S and Lyles E. (2018). Humanitarian needs in Syria: A Call to Action. *PLOS Currents: Disasters*. doi: 10.1371/currents.dis.f510b7b5f473a260a215744b4b85c38b.
- Doocy S, Paik K, Lyles E, Hei Tam H, Fahed Z, Winkler E, Kontunen K, Mkanna A, and Burnham G. (2017). Use of guidelines and mHealth to improve quality of hypertension and type 2 diabetes care for vulnerable populations in Lebanon. *JMIR mHealth and uHealth*. doi: 10.2196/mhealth.7745.
- 4. Tappis H, Lyles E, Burton A, Jordan Health Access Study Team, Lebanon Health Access Study Team, and Doocy S. (2017). Maternal health care utilization among Syrian refugees in Lebanon and Jordan. *Maternal and Child Health Journal*. doi: 10.1007/s10995-017-2315-y.
- Doocy S, Paik K, Lyles E, Hei Tam H, Fahed Z, Winkler E, Kontunen K, Mkanna A, and Burnham G. (2017). Pilot testing and implementation of a mHealth tool for noncommunicable diseases in a humanitarian setting. *PLOS Currents: Disasters*. doi: 10.1371/currents.dis.e98c648aac93797b1996a37de099be74.
- Lyles E, Hanquart B, the LHAS Study Team, Woodman M, and Doocy S. (2017). Health service access and utilization among Syrian refugees and affected host communities in Lebanon. *Journal for Refugee Studies*. doi: 10.1093/jrs/fex014.

- Doocy S and Lyles E. (2017). Humanitarian Needs among displaced and female-headed households in government controlled areas of Syria. *The American Journal of Public Health*, 107(6):950-959. doi: 10.2105/AJPH.2017.303710.
- Doocy S, Tappis H, Lyles E, Witiw J, and Aken V. (2017). Emergency food assistance in Northern Syria: an evaluation of transfer programs in Idleb governorate. *Food and Nutrition Bulletin*. 38(2):240-259. doi: 10.1177/0379572117700755.
- 9. Doocy S, Tappis H, and Lyles E. (2016). Are Cash-based interventions a feasible approach for expanding humanitarian assistance in Syria? *Journal of International Humanitarian Action*, 1:13. doi: 10.1186/s41018-016-0015-7.
- Doocy S, Lyles E, Hanquart B, the LHAS Study Team, and Woodman M. (2016). Prevalence, care seeking, and health service utilization for chronic diseases among Syrian refugees and host communities in Lebanon. *Conflict and Health*, 10:21. doi: 10.1186/s13031-016-0088-3.
- 11. Lyles E, Hanquart B, the LHAS Study Team, Woodman M, and Doocy S. (2016). Health service utilization and access to medicines among Syrian refugee and affected host community children in Lebanon. *Journal of International Humanitarian Action*, 1:10. doi: 10.1186/s41018-016-0010-z.
- 12. Doocy S, Lyles E, Akhu-Zaheya L, Burton A, and Burnham G. (2016). Health service access and utilization among Syrian refugees in Jordan. *International Journal for Equity in Health*, 15:108. doi: 10.1186/s12939-016-0399-4.
- Lafta R, Aflouk NA, Dhiaa S, Lyles E, Burnham G. (2016). Internally displaced women and children in Baghdad, Karbala, and Kirkuk. *PLoS Currents Disasters*. doi: 10.1371/currents.dis.fefc1fc62c02ecaedec2c25910442828.
- Doocy S, Lyles E, Roberton T, Akhu-Zaheya L, Oweis A, Al Ward N, and Burton A. (2016). Health service utilization among Syrian refugees with chronic health conditions in Jordan. *PLoS One*, 11(4): e0150088. doi:10.1371/journal.pone.015008.
- Doocy S, Lyles E, Akhu-Zaheya L, Burton A, and Weiss W. (2016). Health service utilization and access to medicines among Syrian refugee children in Jordan. *International Journal of Health Planning and Management*, 31(1):97-112. doi: 10.1002/hpm.2336.
- Doocy S, Lyles E, Roberton T, Akhu-Zaheya, L Oweis A, and Burnham G. (2015). Prevalence and care seeking for chronic diseases among Syrian refugees in Jordan. *BMC Public Health*, 15:1097. doi:10.1186/s12889-015-2429-3.
- 17. Doocy S, Lyles E, Delbiso T, the IOCC/GOPA Study Team, and Robinson C. (2015). Internal displacement and the Syrian crisis: an analysis of trends from 2011-2014. *Conflict and Health*, 9:33. doi:10.1186/s13031-015-0060-7.
- Kaufman MR, Massey M, Tsang SW, Kamala B, Serlemitsos E, Lyles E, and Kong X. (2014). An assessment of HIV testing in Tanzania to inform future strategies and interventions. *AIDS Care*, 1-5. doi: 10.1080/09540121.2014.963007.

#### Reports, Manuals, and Technical Guidelines

- 1. Lyles E, Tappis H, and Doocy S. (2017). Stakeholders analysis and feedback on cash based response programming in southern Syria. Submitted to the World Food Programme. Available at: http://fscluster.org/syria/document/stakeholders-analysis-and-feedback-cash-0
- 2. Doocy S, Tappis H, and Lyles E. (2017). Shelter and Access for Empowerment and Risk Reduction (SAFERR) project: a mixed methods research study. Submitted to Catholic Relief Services.

- 3. Doocy S, Tappis H, and Lyles E. (2017). Protection needs and risks for migrants in Europe: a situation analysis of five countries. Submitted to Catholic Relief Services.
- 4. **Doocy S** and Lyles E. (2016). Humanitarian needs in Syria: an assessment across ten governorates. Submitted to International Orthodox Christian Charities.
- Doocy S, Tappis H, and Lyles E. (2016). Cash-based response feasibility assessment for northern Syria. Submitted to Global Communities and the Cash-Based Response Technical Working Group. Available at: http://reliefweb.int/sites/reliefweb.int/files/ resources/Cash%2520Based%2520Response%2520Syria%25202016.pdf
- Doocy S, Tappis H, and Lyles E. (2015). Emergency transfers in northern Syria: an economic evaluation of GOAL food assistance programs in Idleb governorate. Available at: https://www.jhsph.edu/departments/internationalhealth/news/EmergencyTransfersinNorthernSyria GOAL.pdf
- Lyles E and Doocy S. (2015). Syrian refugee and affected host population health access survey in Lebanon. Submitted to the European Commission, Humanitarian Aid and Civil Protection Department and UNHCR. Available at: https://data.unhcr.org/syrianrefugees/download.php?id=9550
- 8. Lyles E. (2015). Beneficiary satisfaction in IMC-supported primary health care clinics in Lebanon. Submitted to International Medical Corps.
- 9. Doocy S, Lyles E, Roberton T, Weiss W, and Burnham G. (2014). Syrian refugee health access survey in Jordan. Submitted to the World Health Organization. Available at: http://www.jhsph.edu/departments/international-health/news/SyrianRefugeeHealth AccessSurveyJordan2014.pdf
- 10. Lyles E, Doocy S, and Robinson C. (2014). A Desk review and analysis of internally displaced populations in Syria: population estimates, movements, and trends. Submitted to International Orthodox Christian Charities.

## PRESENTATIONS

## Scientific Meetings

• International Conference on Diabetes and its Complications. Poster presentation entitled Adherence to Medication for Type 2 Diabetes Among Syrian Refugees and Host Communities in Lebanon. November 2, 2017, Baltimore, MD.

Invited Seminars

- Johns Hopkins Bloomberg School of Public Health (JHSPH). Health Emergencies in Large Populations course guest lecture entitled *Estimating Population Size*. July 16, 2019, Baltimore, MD.
- JHSPH. Pharmaceuticals Management for Under-Served Populations course guest lecture entitled *Frameworks Review*. February 12, 2018, Baltimore, MD.
- JHSPH. Health Emergencies in Large Populations course guest lecture entitled *Estimating Population Size*. July 19, 2017, Baltimore, MD.
- JHSPH. Refugee Health course guest lecture entitled *Implementing Research in Emergencies*. November 4, 2015, Baltimore, MD.
- JHSPH. Panelist in "The Syrian Refugee Crisis: Searching for Solutions" symposium. September 21, 2015, Baltimore, MD.

- The World Health Organization Jordan Country Office. Presentation entitled *Syrian Refugee Health Access Survey in Jordan: Presentation of Findings*. June 22, 2014, Amman, Jordan.
- University of Helsinki, Viiki Campus. Presentation entitled *Evaluating Health Programs*. March 2013, Helsinki, Finland

## ADDITIONAL INFORMATION

#### **Personal Statement of Research**

My research focuses on populations affected by conflict, including refugees, internally displaced populations, and communities hosting refugees. Specific interests include:

- The impact of conflict on health systems and population health
- Cash-based interventions
- Continuity of care for chronic health conditions, including access to essential medicines
- Population-based assessments, including the epidemiology of conflict and population needs
- Monitoring and evaluation, implementation, and operations research of humanitarian assistance programs

#### **Key Words**

Humanitarian Assistance, Complex Emergency, Conflict, Monitoring and Evaluation, Cash and Voucher Assistance, Chronic Health Conditions