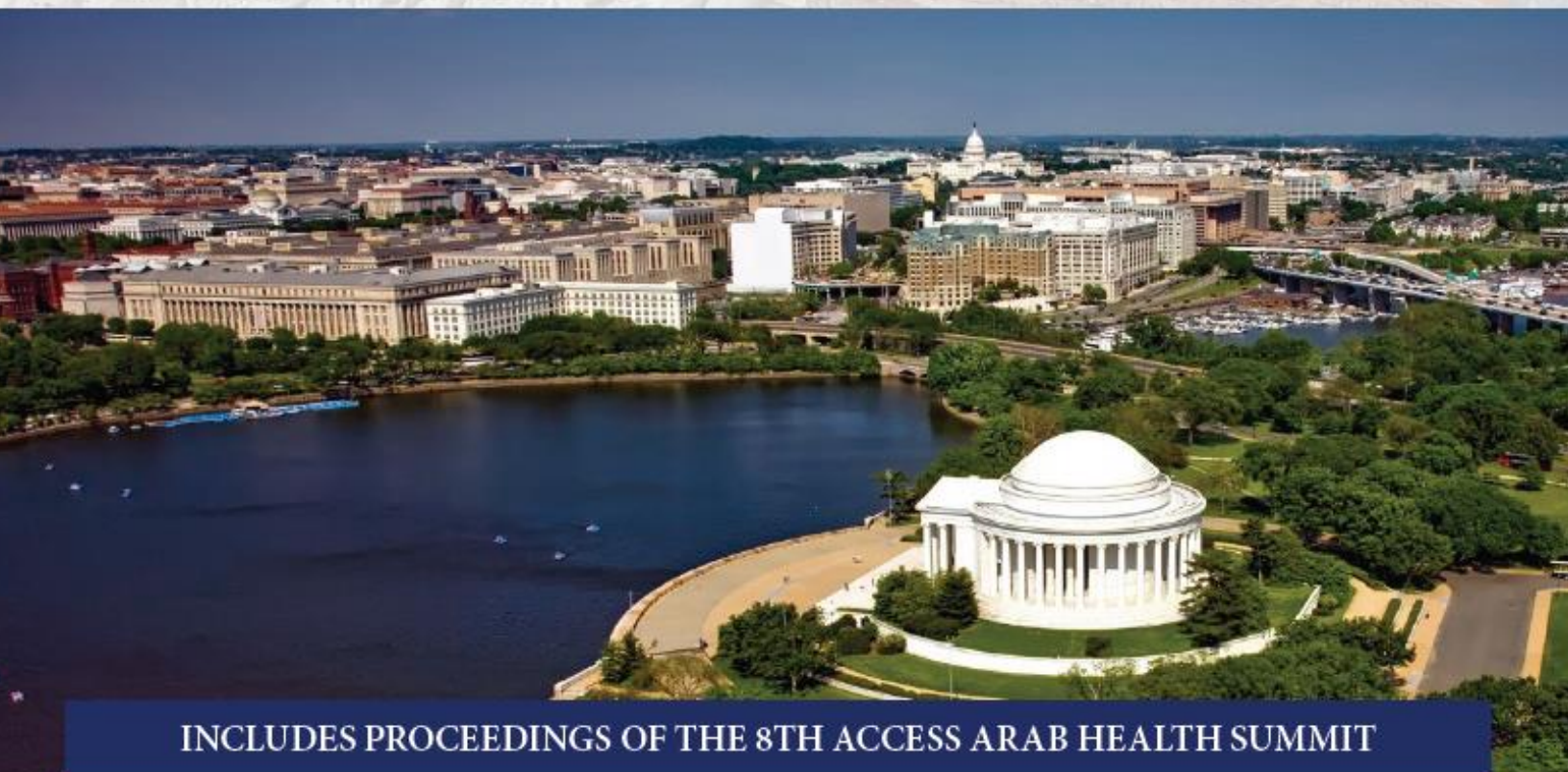




# ACCESS Health Journal

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## ACCESS

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## FROM THE EDITORS

We are proud to present the Fall 2019 edition of **ACCESS Health Journal**. This edition will also serve as the Proceedings of the **8th ACCESS Health Summit** which was held during September 2018 at the Omni Shoreham Hotel in Washington DC. This publication is the result of our commitment to the advancement of the health of Arab-American communities as well as Arab Communities in the Middle East and North Africa (MENA) Region as well as in regions of immigration across the Globe.

In the absence of a mechanism to identify the health needs and status of people of Arab descent through the census process, this summit and the ensuing publication endeavors to be an alternate vehicle to address these issues in our communities. Our eighth international summit and the ensuing documentary publications are invaluable tools in helping promote Arab health through research, clinical practice, public health initiatives, mental health promotion, human engineering and the development of collaborative efforts among academic, governmental and non-governmental entities.

This edition will also highlight the Washington Declaration on the Health Rights of Residents of the MENA Region. For too long, these rights have been ignored. Our unwavering commitment is to help our communities achieve their health rights with dignity and respect.

We will continue to advocate for meeting community health needs across the world.

**Dearborn, Michigan  
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**May 15, 2019**

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## Vaccine Knowledge, Awareness, and Utilization Among Arab-American Adults Prior to Hajj

**Abdulbaset M. Salim<sup>1</sup>, Carolyn Archer<sup>1</sup>, Madiha Tariq<sup>2</sup>, Linda Jaber<sup>1</sup>, Adnan Hammad<sup>2</sup> and Paul E. Kilgore<sup>1, 3</sup>**

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### Abstract

**Introduction:** Michigan is home to one of the largest Arab-American communities outside the Middle East and a landing point for refugee immigrants from countries in crisis. Over many years, a growing body of literature has documented health risks associated with Hajj (pilgrimage to Mecca, Saudi Arabia) travel including rapid transmission of infectious diseases (e.g., meningitis, influenza). Although much is known about immunization rates and barriers among diverse population of U.S., little information is available for Arab-American residents.

### Objectives:

- To describe knowledge, attitudes, beliefs and practices regarding Vaccine-Preventable Diseases (VPD) and adult vaccines among Arab-American residents preparing to travel for Hajj.
- To describe characteristics associated with low vaccine awareness among this population.

**Materials and Methods:** This cross-sectional study was approved by Wayne State University Institutional Review Board prior to implementation. An in-depth 88-item questionnaire was created, pilot-tested and implemented in 2012 using face-to-face interviews to collect demographic data, VPD and vaccine knowledge and awareness, and Hajj travel plans. Other survey items collected information on individual vaccines to prevent meningococcal meningitis, tetanus toxoid-reduced diphtheria toxoid-acellular pertussis (Tdap), influenza, hepatitis A and B, herpes zoster (HZ), typhoid, measles- mumps-rubella (MMR), and pneumococcal disease. Household visits by well-trained interviewers were performed in Dearborn, Michigan and survey responses were entered in a standardized MS Excel database (Microsoft, Inc., Redmond, WA) and analysis was performed using statistical analysis software (SAS Institute Inc, version 9.3, Cary, NC).

**Results:** Of 277 adult participants, 60% were female and 45% were 46 to 64 years of age. Among all participants, the majority (76.9%) had lived in the United States for more than 10 years and 25 years and (9.0%) completed a Bachelor's degree. Awareness of VPD ranged from 36.6% for typhoid vaccine to 90.6% for influenza vaccine. Previous history of vaccination was highest for meningococcal vaccine (87.9%) and influenza vaccine (60.7%). Most respondents ( $\geq 91\%$ ) had received vaccines from their primary care physician and clinics. A lack of knowledge was reported as a barrier most frequently for meningococcal (33.3%), pneumococcal (30.4%) and typhoid (35.6%) vaccines whereas low perception of risk was cited as a barrier most often for hepatitis A

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(54.1%), hepatitis B (52.4%), and Tdap (51.1%) vaccines. For Tdap vaccine, participants who were  $\geq 46$  years of age were significantly more likely to have lower awareness of the Tdap vaccine compared with younger participants (odds ratio, OR =1.69, 95% confidence interval (CI): 1.04—2.77). In contrast, participants with a Bachelor's degree or higher and  $\geq 11$  years of residence in U.S. had a significantly higher awareness for Tdap vaccine. Similar associations were observed for HZ, typhoid and pneumococcal vaccines.

**Conclusions** Knowledge and awareness for some adult vaccines varied within the study participants and appear to be higher with longer duration of residence in the U.S. and travel plans associated with Hajj. Building awareness of immunization benefits and access to vaccines among diverse populations of Middle East origin will be a key public health intervention to reduce transmission of VPD among children and adults from conflict areas around the world.

**Key words:** EMRO, Hajj, pilgrimage, pilgrims, Immunization, Vaccine.

**Running title:** Vaccines in Arab-Americans.

## Introduction

Since the 1880's, immigrants from the 22 countries and territories of the WHO Eastern Mediterranean Region (EMRO) have settled in communities across the United States with one of the largest Arab-American (AA) populations located in Southeastern Michigan near Detroit [1]. While AA residents originate from a variety of Middle East and North African countries, shared cultural values have supported growing populations in several states including California, New York, Michigan, Florida and Texas [2]. Since the 1980's, the U.S. Arab-American population has more than tripled with a 2010 analysis by the Arab American Institute estimating that there are currently 3.7 million total AA residents.

Since the 1980's, a growing body of literature has documented health risks associated with Hajj travel including environmental risks such as heat stroke as well as exacerbation of chronic diseases (e.g., heart and lung disease) and transmission of infectious (e.g., meningitis, influenza) diseases [3-7]. In the past two decades, Saudi Arabia has strengthened health-related support services and required immunization for Hajj pilgrims visiting Mecca, Medina and other sites in Saudi Arabia [8-11]. The importance of public health programs and acute care health services for pilgrims gained additional attention following the emergence of the Middle East Respiratory Coronavirus (MERS-CoV) in Saudi Arabia [12]. Although MERS-CoV has been identified among residents and travelers from Saudi Arabia, its precise origin, reservoir and modes of transmission remains unclear. In addition, it is not known if there may be risk resulting from exposure to asymptomatic carriers of the MERS-CoV [13]. As a result of the MERS-CoV outbreak and the diverse national origins of Hajj pilgrims from developed and developing countries, immunization to reduce the risk of influenza, meningococcal disease, polio, and yellow fever is strongly recommended by the Saudi Ministry of Health [14].

Arab-Americans from several U.S. states are often travelers for the annual Hajj pilgrimage to Mecca [15]. Because of the large AA population in the Metropolitan Detroit area of Michigan, there are a substantial number of Hajj pilgrims traveling from Michigan to Mecca each year. As part of routine preventive healthcare in the U.S., immunizations represent a central activity recommended by the US Centers for Disease Control and Prevention [16].



## **Objectives**

To understand current knowledge and practices with respect to Hajj immunizations among AA residents of Dearborn, Michigan.

## **Methods**

### ***Study Population***

The state of Michigan in the United States of America is home to an estimated 300,000 AA residents and is one of the largest Arabic-speaking populations located outside the Middle East and North Africa [2]. A community-based household survey was implemented by collaborative research team from Wayne State University and the Arab Community Center for Economic & Social Services during a 28-day period in 2012. ACCESS provides a wide range of social, economic and health (clinic- and community-based) services to Arab-American and other residents in Metropolitan Detroit [17]. The study was reviewed and approved by the Wayne State University Institutional Review Board.

### ***Survey design and data collection***

An in-depth 88-item questionnaire was created, pilot-tested and implemented using face-to-face interviews to collect demographic data, vaccine-preventable disease knowledge and attitudes, as well as Hajj travel plans and related vaccines. Other questions collected information on individual vaccines to prevent meningococcal meningitis, tetanus, diphtheria, pertussis, influenza, hepatitis A and B, herpes zoster, typhoid, measles, mumps, rubella and pneumococcal disease. To maximize understand and comprehension of the survey items, trained bilingual (Arabic/English) interviewers were deployed to conduct household visits in Dearborn neighborhoods with Arab-American residents. Adults aged  $\geq 18$  years, including those who were planning on traveling to Hajj, were invited to participate [18]. Advertisements for participation in this survey were distributed through several locations including Mosques, Hajj classes, households and the Islamic Center of America. For all participants, informed consent was completed prior to initiating the survey. Survey responses were recorded in a standardized fashion by each interviewer and completed paper survey forms were returned to ACCESS offices for transmittal to the research team. Study team members reviewed all survey forms for completeness, consistency and accuracy in research offices of Wayne State University, Detroit, Michigan. Responses were entered in a standardized MS Excel database (Microsoft, Inc., Redmond, WA) and analysis was performed using statistical analysis software (SAS Institute Inc, version 9.3, Cary, NC).

### ***Statistical analyses***

We performed analysis to describe the distribution of survey participants by age, gender, educational attainment, country of origin, and duration of residence in the United States. Additional analysis of responses was conducted to describe awareness of specific vaccines, locations for receipt of vaccines and the information that led to a participant's receipt of individual vaccines. Descriptive analysis was also performed to identify barriers to receipt of individual vaccines as well as to identify vaccines based on verbal report of respondents. Survey items also queried respondents regarding sources of vaccine information they have received. To evaluate responses for survey items, stratified analysis by age group and gender was performed. Categorical variables were compared the Chi-Square  $\chi^2$  test and a *P*-value of 0.05 or less was considered statistically significant. Adjusted odds ratios to identify characteristics associated with

low awareness of vaccines were calculated with 95% confidence intervals using SAS statistical software (SAS, Inc., Cary, United States of America).

## **Results**

### ***Demographic characteristics***

In this survey, a total of 277 participants were enrolled including 165 (59.6%) women. The majority (83.1%) of participants were 30--64 years of age (**Table 1**). Among all participants, the majority (76.9%) had lived in the United States for more than 10 years. Ninety-three (33.6%) participants had attended at least some high school, 53 (19.1%) had completed high school, 55 (19.9%) attended some college, 16 (5.8%) had completed an Associates college degree, 25 (9.0%) completed a Bachelor's degree and 32 (11.6%) completed college or university studies at the graduate degree level or higher. The majority of participants' fathers originated from Lebanon (55.6%; n = 154) and an additional 46 (16.6%) were from Yemen, 40 (14.4%) from Iraq and the remaining participants were from Palestine, Syria, Morocco, Jordan, Libya, Pakistan, Egypt, India and the Sudan. Among participants, 228 (82.3%) had no previous Hajj travel and a 52 (18.8%) were born in the United States.

### ***Awareness and receipt of vaccines***

The highest level of vaccine awareness was reported for influenza vaccine (90.6%), meningococcal vaccine (89.1%), and measles, mumps, and rubella (MMR) vaccine (81.1%) while the lowest awareness was found for pneumococcal vaccine (52.8%), herpes zoster (HZ) vaccine (44.9%) and typhoid fever vaccine (36.6%) (**Figure 1**). A substantial proportion of participants were aware of hepatitis A vaccine (n=210, 79.2%) and hepatitis B vaccine (n=201, 75.8%) while lower awareness was found for the pneumococcal vaccine (n=140, 52.8%).

For each vaccine, participants reported lower rates of vaccine receipt despite their awareness of the vaccines. Notably, the rate of receipt of the meningococcal vaccine, (n=217, 87.9%) was close to the level of awareness for the vaccine. Yet, for other vaccines, the difference between vaccine awareness and receipt ranged from 23--38% where the largest gap (38%) was found for Hepatitis A and the smallest gap (23%) was found in tetanus-reduced diphtheria-acellular pertussis (Tdap) vaccine. In our study population, 84.2% of participants were advised by their healthcare providers to receive meningococcal vaccine but recommendations to receive other adult vaccines were lower, notably, for typhoid fever (3.9%), HZ (11.7%), and Tdap (19.7%) vaccines.

### ***Recommendations for immunization***

A majority of respondents reported receiving recommendation from a provider for immunization with the highest proportion (84.2%) receiving a recommendation for meningococcal vaccine (**Table 2**). Other vaccines recommended with higher frequency included influenza (59.4%), MMR (40.3%), Hepatitis A (35.5%) and Hepatitis B (32.2%). Despite existing recommendations for routine immunization, Tdap (19.7%), pneumococcal (14.0%) and zoster (11.7%) vaccines were less often recommended by providers. For all vaccines, the proportion of participants considering receipt of recommended vaccine dropped sharply compared with the proportion of participants who received a professional recommendation for vaccination.

### ***Sources of vaccine information***

The most common source reported for receipt of vaccine information was the physician's office in 60 to 93% of participants (**Table 3**). Notably, participants reported that they received vaccine

information from other sites including community and neighborhood-based organizations (e.g., ACCESS), Hajj classes conducted to prepare pilgrims before the travel, and travel services that assist pilgrims with their travel arrangements. Travel services served as the source of meningococcal vaccine information for 34.2% of respondents. Other vaccine information venues such as pharmacies and the internet were the least often cited sources of vaccine information.

### ***Barriers to immunization***

For several recommended vaccines, a lack of knowledge and perceived low personal risk of disease were leading barriers cited by participating Arab-Americans (**Table 4**). A lack of knowledge was identified as a barrier most frequently for meningococcal (33.3%), pneumococcal (30.4%) and typhoid (35.6%) vaccines. A low perception of risk was cited as a barrier most often for hepatitis A (54.1%), hepatitis B (52.1%), and Tdap (51.1%) vaccines. The fear of receiving an injection and concern regarding vaccine side effects as barriers to immunization were reported in similar percentages of participants. One-third of participants feared the influenza vaccine injection while 28% worried about influenza vaccine adverse events. Interestingly, none of the participants cited concerns that vaccine components may not be Halal.

### ***Sites for receipt of vaccines***

The majority of participants received recommended vaccines in a physician's office (e.g., 91.8% received influenza vaccine in a primary care clinic) (**Table 5**). Among all vaccines, HZ (4.7%), influenza (3.8%) and pneumococcal (3.2%) vaccines were most commonly received while in-hospital. Pharmacies were infrequently reported as a source for influenza (4.4%) and meningococcal immunization (3.4%). None of participants had received pneumococcal, HZ, hepatitis A, or MMR vaccines in their local pharmacy (either a standalone independent pharmacy) or large store pharmacy.

### ***Characteristics associated with low vaccine awareness***

To identify predictors of low awareness varied by vaccine, we ran separate logistic regression models with dependent variable for low vaccine awareness (dichotomized yes, no). The resulting models for Tdap, zoster, typhoid and pneumococcal vaccines each yielded significant independent variables associated with increased or decreased vaccine awareness (**Table 6**). For Tdap vaccine, participants who were greater than or equal to 46 years of age were significantly more likely to lack awareness of the Tdap vaccine compared with younger participants (odds ratio, OR =1.69, 95% confidence interval (CI): 1.04—2.77). In contrast, participants with a higher educational degree (i.e., bachelors or higher) and  $\geq 11$  years of residence in the U.S. were significantly less likely to lack awareness of Tdap. Similar associations were observed for zoster, typhoid and pneumococcal vaccine with higher education and longer residence in the U.S. associated with a lower lack of vaccine awareness.

## **Discussion**

In the United States of America (USA), the growth in the Arabic speaking populations provide special challenges and opportunities for public health programs and acute care delivery. At present, the U.S. census bureau surveys do not collect ethnic information that allows accurate enumeration of Arab-Americans. With such limitations, health agencies (e.g., federal, state and local immunization programs) are unlikely to know the true number of persons belonging to the Arab-American community. For this reason, community organizations such as ACCESS provide a critical link to the Arab-American community to help identify leading health issues, assess the

impact of health conditions in this community and identify priorities for public health programs and health systems that serve Arab-Americans.

Globally, and in the USA, immunizations for children and adults are a recognized and essential public health good that has been proven to reduce severe, life-threatening and disability-inducing disease across all racial and ethnic groups. Despite the value of vaccines, our data suggests that a substantial segment of the Arab-American community may not have received vaccines recommended by the U.S. CDC Advisory Committee on Immunization Practices (ACIP) and some adults may also lack vaccines recommended for their Hajj-related travel. Our data shed new light on reported barriers among Arab-Americans (e.g., lack of knowledge, low perceived risk of disease) that may be impede vaccine-seeking behavior as well as demographic characteristics (e.g., lower educational attainment, older age) that may reduce awareness of recommended vaccines. These barriers have been identified in other population groups in the USA as well as other countries and suggest that educational and outreach tools that now exist should be widely adopted for use in Arab-American communities [19-21].

The Arab-American community has additional unique challenges that arise when residents choose to travel for Hajj to fulfill one of their key obligations (one of the five pillars) of Islam. Due to the growth of pilgrims traveling to the Kingdom of Saudi Arabia (KSA), Hajj is now recognized as one of the most globally significant public health events with pilgrims from over 140 countries around the world coming to revered sites within the KSA [22]. The diversity of populations that gather for Hajj, stressful living environments and the physical challenges of performing the required rituals associated with Hajj may increase pilgrims' risk of acute infectious diseases as well as potentially exacerbate underlying medical conditions (e.g., cardiovascular disease, diabetes) that are common among Arabic speaking populations [23-25]. For this reason, the health of travelers and attendees at mass gatherings around the world is now a priority in developed and developing countries [26].

Based on a range of surveys as well as analysis of surveillance data, Hajj pilgrims are exposed to a wide range of transmissible pathogens in a relatively short period of time. For example, deadly outbreaks of invasive meningococcal disease due to *N. meningitidis* have been well-documented among Hajj pilgrims [27, 28]. Also, the risk of bloodborne hepatitis B infection associated with shaving has been followed by interventions by authorities in KSA to reduce exposure to unlicensed barbers serving pilgrims [29]. Yet, even as extensive efforts to protect Hajj pilgrims are maintained, recent concern over pandemic influenza as well as the emergence of novel viral pathogens underscores the urgency for continued vigilance for diseases with epidemic potential among attendees of gatherings such as Hajj in the Kingdom of Saudi Arabia (KSA) [30]. In 2012, the emergence of Middle East Respiratory Syndrome (MERS) caused by a novel coronavirus (MERS-CoV) [31, 32] underscored the ease with which diseases cross borders and underscored the need for vigilance in public health surveillance activities in the KSA and other countries [33]. While no specific treatment is available for this disease, increased attention to surveillance for MERS and detection of MERS-CoV infection hold the prospect of more rapid disease detection and earlier access to supportive care for affected patients. Available evidence now suggests that patients suffering from underlying medical conditions that include some components of immunosuppression may be at greater risk for severe disease or death associated with MERS [34].

A limited number of studies have reported immunization rates in selected groups of Hajj pilgrims. In a report by Rashid and colleagues, only 37% of Hajj pilgrims (56 out of 150) were vaccinated against influenza [35]. In contrast, a report by Kandeel and colleagues studied Hajj pilgrims from Egypt and found that 98% (542 out of 551 pilgrims) had received the 2009 H1N1 pandemic influenza vaccine [36]. Another study reported by Memish, *et al* found that 30% of pilgrims surveyed at the King Abdulaziz International Airport had been vaccinated with pandemic H1N1 influenza vaccine [37]. In this same study, during the survey conducted upon pilgrims' arrival, 75% reported having received meningococcal vaccine, 53% reported receipt of influenza vaccine, and 3.3% reported receipt of tetanus vaccine. This and other studies documenting nasopharyngeal carriage of *N. meningitidis* strains in Hajj pilgrims after their return from Hajj suggest that greater efforts to educate and immunize Hajj pilgrims against meningitis are needed.

Despite published recommendations from the KSA that require immunizations upon entry at the border (e.g., airport), our data suggest that Arab-American Hajj pilgrims are substantially under-immunized and potentially at risk for severe disease during and after Hajj. In our study, 61% of participants planning Hajj travel were immunized against influenza, 38% were immunized against tetanus, diphtheria and pertussis while just 24% were immunized with pneumococcal vaccine. The risk for severe disease due to influenza, pertussis or pneumococcal disease (pneumonia) may be even more pronounced among pilgrims who suffer from chronic health conditions such as pulmonary disease or diabetes. In the U.S., while such vaccines are recommended by the US Advisory Committee on Immunization Practices (ACIP), our study suggests that additional educational information on vaccines is needed for healthcare providers and Hajj pilgrims.

In the Middle East, the past several months have led to exponential growth in displaced persons who have actively migrated and are now undergoing resettlement [38-40]. In cooperation with federal, state, international and local agencies, immigrants from Arabic speaking countries undergo health screenings that include review of immunizations [41, 42]. With national immunization programs under great stress in conflict areas, refugees are likely to be incompletely vaccinated and thus potentially at-risk for transmission or acquisition of vaccine-preventable diseases [43-46]. These population migrations suggest the need for highly coordinated, end-to-end immunization tracking systems that ensure migrants receive appropriate vaccines during screening and review processes. Such practices are also likely to reduce the risk of vaccine-preventable disease transmission in crowded refugee encampments or other holding locations where both young and older persons reside.

## **Conclusion**

In the U.S.A., Michigan is home to one of the largest Arab-American communities outside the Middle East and a destination for refugee immigrants from countries in crisis. At present, however, little information on education, attitudes and utilization of vaccines are available for many Arab-American communities, in part, because U.S. national health surveys and census bureau data collection methods do not comprehensively capture household-level information to describe the Arab-American population [47]. Building awareness of immunization benefits and increasing access to vaccines among Arabic speaking populations will be critical as families relocate to the US from conflict areas around the world [48]. Our findings, consistent with previous reports, suggest that additional opportunities exist for substantial immunization



education, outreach, and advocacy in Arab-American communities that will benefit large communities, Hajj pilgrims and newly-arriving immigrants across the United States [45, 49].

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**Table 1.** Demographic characteristics of Arab-American Study Participants.

| Characteristic                                      | No. of participants (n = 277) (%) | P        |
|---|-----------------------------------|----------|
| <b>Sex</b>  |                                   |          |
| Female  | 165 (59.6)                        | < 0.05   |
| <b>Age (years)<sup>a</sup></b>                      |                                   |          |
| 18--29  | 21 (7.6)                          |          |
| 30--45  | 106 (38.3)                        |          |
| 46--64  | 124 (44.8)                        |          |
| ≥ 65  | 25 (9.0)                          |          |
| <b>Years lived in US</b>                            |                                   | < 0.0001 |
| < 5   | 10 (3.6)                          |          |
| 5—10  | 46 (16.6)                         |          |
| 11—20   | 95 (34.3)                         |          |
| ≥ 21  | 118 (42.6)                        |          |
| <b>Education</b>                                    |                                   | < 0.0001 |
| Some High school (HS) or less                       | 93 (33.6)                         |          |
| Completed HS or Some College                        | 108 (39.0)                        |          |
| Associate's Degree or Bachelor's Degree             | 41 (14.8)                         |          |
| Graduate Degree or Higher                           | 32 (11.6)                         |          |
| <b>Head of household occupation</b>                 |                                   | < 0.0001 |
| Management, Business, and Financial                 | 42 (15.2)                         |          |
| Computer, Engineering and Science                   | 25 (9.0)                          |          |
| Education, Legal, Community Service, Arts and Media | 25 (9.0)                          |          |
| Healthcare  | 21 (7.6)                          |          |
| Technical Services                                  | 17 (6.1)                          |          |
| Sales and Related                                   | 25 (9.0)                          |          |
| Others  | 110 (39.7)                        |          |

<sup>a</sup>Age missing for one study participant.

**Table 2.** Recommendations & Considerations for Immunization among Arab-American study participants.

| Vaccine                           | No. recommended for vaccine by provider (%) |            |           |       | No. of those unvaccinated considering vaccine (%) |            |           |       |
|-----------------------------------|---|------------|-----------|-------|---|------------|-----------|-------|
|                                   | Yes   | No         | Not Sure  | Total | Yes   | No         | Not Sure  | Total |
| <b>Influenza</b>                  | 133 (59.4)                                  | 63 (28.1)  | 28 (12.5) | 224   | 5 (4.6)   | 62 (56.4)  | 43 (39.1) | 110   |
| <b>Hepatitis A</b>                | 86 (35.5)                                   | 123 (50.8) | 33 (13.6) | 242   | 11 (6.9)  | 84 (52.8)  | 64 (40.3) | 159   |
| <b>Hepatitis B</b>                | 76 (32.2)                                   | 126 (53.4) | 34 (14.4) | 236   | 5 (3.2)   | 87 (56.1)  | 63 (40.7) | 155   |
| <b>Meningococcal <sup>a</sup></b> | 171 (84.2)                                  | 13 (6.4)   | 19 (9.4)  | 203   | 15 (39.5)   | 6 (15.8)   | 17 (44.7) | 38    |
| <b>MMR</b>                        | 91 (40.3)                                   | 111 (49.1) | 24 (10.6) | 226   | 6 (4.8)   | 70 (56.0)  | 49 (39.2) | 125   |
| <b>Pneumococcal</b>               | 33 (14.0)                                   | 168 (71.5) | 34 (14.5) | 235   | 9 (4.4)   | 125 (61.6) | 70 (34.5) | 203   |
| <b>HZ</b>                         | 30 (11.7)                                   | 184 (71.9) | 41 (16.0) | 256   | 9 (4.1)   | 142 (64.0) | 71 (32.0) | 222   |
| <b>Tdap</b>                       | 43 (19.7)                                   | 124 (56.9) | 51 (23.4) | 218   | 8 (4.6)   | 89 (51.5)  | 76 (43.9) | 173   |
| <b>Typhoid fever <sup>a</sup></b> | 10 (3.9)                                    | 199 (78.4) | 45 (17.7) | 254   | 5 (2.1)   | 160 (68.4) | 69 (29.5) | 234   |

MMR: Measles, mumps, and rubella; HZ: Herpes zoster; Tdap: Tetanus, diphtheria, and acellular pertussis.

<sup>a</sup> Meningococcal and typhoid vaccines were recommended for those planning Hajj pilgrimage.

**Table 3. Sources of Vaccine Information Reported by Arab-American Study Participants**

| Vaccine                    | Information source No. (%) |          |                        |                              |          | Total |
|----------------------------|----------------------------|----------|------------------------|------------------------------|----------|-------|
|                            | Physician office           | Pharmacy | Community organization | Travel service or Hajj class | Internet |       |
| Influenza                  | 126 (80.3)                 | 3 (1.9)  | 8 (5.1)                | 17 (10.8)                    | 3 (1.9)  | 157   |
| Hepatitis A                | 79 (70.5)                  | 0 (0)    | 7 (6.3)                | 24 (21.4)                    | 2 (1.8)  | 112   |
| Hepatitis B                | 84 (75.7)                  | 0 (0)    | 3 (2.7)                | 22 (19.8)                    | 2 (1.8)  | 111   |
| Meningococcal <sup>a</sup> | 145 (60.4)                 | 1 (0.4)  | 11 (4.6)               | 82 (34.2)                    | 1 (0.4)  | 240   |
| MMR                        | 117 (83.0)                 | 1 (0.7)  | 3 (2.1)                | 20 (14.2)                    | 0 (0)    | 141   |
| Pneumococcal               | 54 (88.5)                  | 0 (0)    | 3 (4.9)                | 4 (6.6)                      | 0 (0)    | 61    |
| HZ                         | 38 (92.7)                  | 0 (0)    | 0 (0)                  | 3 (7.3)                      | 0 (0)    | 41    |
| Tdap                       | 80 (79.2)                  | 0 (0)    | 3 (3.0)                | 18 (17.8)                    | 0 (0)    | 101   |
| Typhoid fever <sup>a</sup> | 17 (70.8)                  | 0 (0)    | 2 (8.3)                | 4 (16.7)                     | 1 (4.2)  | 24    |

MMR: Measles, mumps, and rubella; HZ: Herpes zoster; Tdap: Tetanus, diphtheria, and acellular pertussis.

<sup>a</sup> Meningococcal and typhoid vaccines were recommended for those planning Hajj pilgrimage.

**Table 4. Barriers to Receipt of Vaccine Reported by Arab-American Study Participants**

| Vaccine                    | Participants reporting barrier to receipt of immunization, No. (%) |                           |                              |                                |                         |                             |                              |                            | Total |
|----------------------------|--|---------------------------|------------------------------|--------------------------------|-------------------------|-----------------------------|------------------------------|----------------------------|-------|
|                            | Vaccine cost   | Lacking vaccine knowledge | Felt not at risk for disease | Unsure where to obtain vaccine | Busy with work & family | Fear of receiving injection | Concern about adverse events | Believed vaccine non-Halal |       |
| Influenza                  | 5 (4.8)  | 5 (4.8)                   | 21 (20.2)                    | 1 (1.0)                        | 7 (6.7)                 | 35 (33.7)                   | 29 (27.9)                    | 0 (0)                      | 104   |
| Hepatitis A                | 14 (9.5)   | 13 (8.8)                  | 80 (54.1)                    | 3 (2.0)                        | 3 (2.0)                 | 16 (10.8)                   | 19 (12.8)                    | 0 (0)                      | 148   |
| Hepatitis B                | 12 (8.4)   | 19 (13.3)                 | 75 (52.4)                    | 5 (3.5)                        | 4 (2.8)                 | 9 (6.3)                     | 19 (13.3)                    | 0 (0)                      | 143   |
| Meningococcal <sup>a</sup> | 2 (11.1)   | 6 (33.3)                  | 1 (5.6)                      | 1 (5.6)                        | 0 (0)                   | 4 (22.2)                    | 4 (22.2)                     | 0 (0)                      | 18    |
| MMR                        | 12 (10.6)  | 17 (15.0)                 | 49 (43.4)                    | 4 (3.5)                        | 4 (3.5)                 | 13 (11.5)                   | 14 (12.4)                    | 0 (0)                      | 113   |
| Pneumococcal               | 18 (9.9)   | 56 (30.4)                 | 74 (40.2)                    | 5 (2.7)                        | 6 (3.3)                 | 9 (4.9)                     | 16 (8.7)                     | 0 (0)                      | 184   |
| HZ                         | 12 (5.9)   | 45 (22.1)                 | 91 (44.6)                    | 6 (2.9)                        | 6 (2.9)                 | 19 (9.3)                    | 25 (12.3)                    | 0 (0)                      | 204   |
| Tdap                       | 11 (7.9)   | 26 (18.7)                 | 71 (51.1)                    | 1 (0.7)                        | 8 (5.8)                 | 8 (5.8)                     | 14 (10.1)                    | 0 (0)                      | 139   |
| Typhoid fever <sup>a</sup> | 20 (8.9)   | 80 (35.6)                 | 73 (32.4)                    | 1 (0.4)                        | 5 (2.2)                 | 20 (8.9)                    | 26 (11.6)                    | 0 (0)                      | 225   |

MMR: Measles, mumps, and rubella; HZ: Herpes zoster; Tdap: Tetanus, diphtheria, and acellular pertussis.

<sup>a</sup> Meningococcal and typhoid vaccines were recommended for those planning Hajj pilgrimage.

**Table 5. Location of Immunization Reported by Arab-Americans**

| Vaccine       | Location of Immunization No. (%) |          |          | Total |
|---------------|----------------------------------|----------|----------|-------|
|               | Primary Care Clinic              | Hospital | Pharmacy |       |
| Influenza     | 146 (91.8)                       | 6 (3.8)  | 7 (4.4)  | 159   |
| Hepatitis A   | 110 (97.3)                       | 3 (2.7)  | 0 (0)    | 113   |
| Hepatitis B   | 108 (98.2)                       | 0 (0)    | 2 (1.8)  | 110   |
| Meningococcal | 227 (95.4)                       | 3 (1.3)  | 8 (3.4)  | 238   |
| MMR           | 142 (97.9)                       | 3 (2.1)  | 0 (0)    | 145   |
| Pneumonia     | 61 (96.8)                        | 2 (3.2)  | 0 (0)    | 63    |
| Zoster        | 41 (95.3)                        | 2 (4.7)  | 0 (0)    | 43    |
| Tdap          | 98 (99.0)                        | 0 (0)    | 1 (1.0)  | 99    |
| Typhoid fever | 23 (92.0)                        | 1 (4.0)  | 1 (4.0)  | 25    |

MMR: Measles, mumps, and rubella; HZ: Herpes zoster; Tdap: Tetanus, diphtheria, and acellular pertussis.

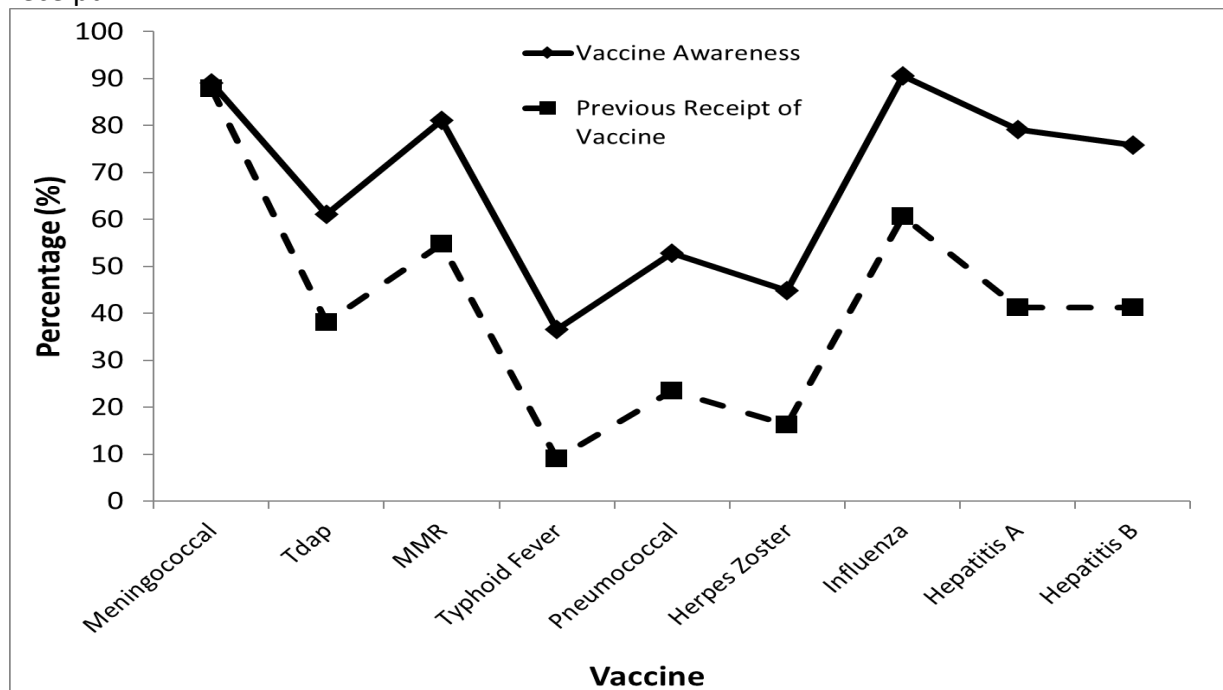
<sup>a</sup> Meningococcal and typhoid vaccines were recommended for those planning Hajj pilgrimage.



**Table 6.** Characteristics Associated with Reduced Vaccine Awareness in Arab-American participants. (CI: confidence interval; Tdap: Tetanus, diphtheria, and acellular pertussis).

| Vaccine, Independent variables | Participant No. (%) | Odds ratio (95% CI) | P      |
|--------------------------------|---------------------|---------------------|--------|
| <b>Tdap</b>                    |                     |                     |        |
| Male sex                       | 65 (58.0)           | 1.27 (0.77--2.07)   | 0.348  |
| Age ≥ 46 years                 | 83 (55.7)           | 1.69 (1.04--2.77)   | 0.037  |
| Bachelor's degree or higher    | 47 (82.5)           | 0.19 (0.08--0.40)   | 0.0001 |
| Years in US ≥ 11               | 139 (65.3)          | 0.50 (0.28--0.88)   | 0.016  |
| <b>Herpes Zoster</b>           |                     |                     |        |
| Male sex                       | 49 (43.8)           | 1.10 (0.68--1.78)   | 0.705  |
| Age ≥ 46 years                 | 65 (43.6)           | 1.14 (0.71--1.84)   | 0.588  |
| Bachelor's degree or higher    | 31 (54.4)           | 0.44 (0.22--0.86)   | 0.028  |
| Years in US ≥ 11               | 91 (42.7)           | 1.52 (0.87--2.67)   | 0.144  |
| <b>Typhoid</b>                 |                     |                     |        |
| Male sex                       | 34 (30.4)           | 1.53 (0.92-2.56)    | 0.102  |
| Age ≥ 46 years                 | 47 (31.5)           | 1.53 (0.94-2.52)    | 0.089  |
| Bachelor's degree or higher    | 28 (49.1)           | 0.39 (0.19-0.76)    | 0.024  |
| Years in US ≥ 11               | 79 (37.1)           | 0.83 (0.45-1.48)    | 0.533  |
| <b>Pneumococcal</b>            |                     |                     |        |
| Male                           | 61 (54.5)           | 0.91 (0.56-1.47)    | 0.702  |
| Age ≥ 46 years                 | 75 (50.3)           | 1.27 (0.79-2.04)    | 0.326  |
| Bachelor's degree or higher    | 37 (64.9)           | 0.48 (0.24-0.93)    | 0.099  |
| Years in US ≥ 11               | 123 (57.8)          | 0.44 (0.25-0.78)    | 0.005  |

**Figure 1.** Percentage of Arab-American participants reporting vaccine awareness and vaccine receipt.



MMR: Measles, mumps, and rubella; Tdap: Tetanus, diphtheria, and acellular pertussis.

## Reducing Mammography Disparities: Outcomes from a Religiously-Tailored, Mosque-Based Intervention

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### Abstract

**Introduction:** Faith-based health interventions adopt varied approaches to engage religious theology and faith-leaders in program design. Insights into strategies, elements, and outcomes that breed success will allow for greater theorization and model portability across faiths. This project fills a knowledge gap regarding religiously-tailored interventions to reduce mammography disparities among Muslims.

**Objective:** To describe the design of, and participant-level outcomes related to, a religiously-tailored peer-led group education program that addressed mammography-related barrier beliefs.

**Methods:** Using a community-engaged approach, including a multi-disciplinary community advisory board, we identified and subsequently intervened upon barrier beliefs impeding mammography screening among Muslim American women. Our religiously-tailored, mosque-based, peer-led intervention involved facilitated discussions and expert-led didactics conveying religious teachings about health, and information about the benefits and process of mammography. Participant surveys were collected pre-intervention, post-intervention, 6-months and one-year post-intervention. These measured changes in mammography intention, likelihood, confidence and knowledge, as well as agreement with barrier and facilitator beliefs. The structural elements and messages of the classes tackled barrier beliefs in at least one of 3 ways (i) Reprioritizing- introducing another religious belief that has greater resonance with participants such that the barrier belief is marginalized, (ii) Reframing the belief within a religious worldview such that it is consistent with the health behavior desired, and (iii) Reforming- using a religious scholar to provide “correct” interpretations of religious doctrine.

**Results:** 58 Muslim women (mean age = 50 yrs.) that had not had a mammogram in the past two years of which 18 were of Arab descent and 27 South Asian participated in the two-session course. While no changes in aggregate belief scores were observed, individuals were significantly less likely to agree with the barrier belief “Breast cancer screening is not important because God decides who will get cancer” post-intervention ( $p=0.03$ ). Self-reported likelihood of obtaining a mammogram increased significantly following the intervention ( $p=0.01$ ) as did breast cancer screening knowledge ( $p=0.0002$ ). Individuals with higher agreement with barrier beliefs pre-

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intervention had lower odds for positive change in likelihood (OR=0.80, p=0.03), while those who were married had higher odds for positive change in likelihood (OR=37.69, p=0.02). With respect to increased knowledge, Arab participants found to have increased odds of increased mammography knowledge post-intervention (OR = 4.20, p = 0.02). At one-year follow-up, 22 participants had obtained a mammogram while 20 were lost to follow-up.

**Conclusion:** Our pilot mosque-based intervention involving religiously-tailored messages demonstrated efficacy in improving Muslim women's self-reported likelihood of obtaining mammograms post-class, enhanced mammography knowledge, and indeed with receipt of mammograms over the ensuing year. Faith-based programs in mosque settings appear to have the potential to reduce disparities and improve preventive health among Muslim Americans.

## Introduction

Although decreasing, breast cancer death rates for women in the US remain second only to lung cancer deaths. (2017d) As the five-year cancer survival rate at early stages is much better than later stages, the health benefits of routine mammography are attributable to increased early-stage detection (2017c). Accordingly, the Centers for Disease Control targets that 81% of US women aged 50 to 74 receive guideline-appropriate mammograms by 2020 (2012). To reach this goal, minority communities are strategically targeted for interventions because mammography rates remain disproportionately low for many racial and ethnic minority groups (2016, 2017a, 2017b).

Studies amongst American Muslims, a racially and ethnically diverse group, describe low rates of mammography utilization (Hasnain et al. 2014, Schwartz et al. 2008). For example, a survey of 207 immigrant Muslim women in Chicago found 52% to have had a mammogram in past two years but a third never had a mammogram (Padela et al. 2014). Studies examining this screening disparity describe several types of barriers to mammography including access-related challenges, religion-related factors, and personal beliefs. Access barriers include the lack of health insurance (Padela et al. 2016, Salman 2012, Shirazi, Champeau, and Talebi 2006, 2017a), and primary care providers (Padela et al. 2016, Hasnain et al, 2012). Religion-related factors cover notions such as worship-related practices being a viable modality for disease prevention (Al-Amoudi et al. 2015, Padela et al., 2016, Salman 2012) and notions of modesty (Al-Amoudi et al. 2015, Padela et al. 2016, Bottorff et al. 1998, Salman 2012) which can deter some Muslims from receiving mammograms due to concerns about gender-concordant care (Al-Amoudi et al. 2015, Padela et al. 2016, Bottorff et al. 1998, Salman 2012). Personal beliefs such as holding mammograms to be painful (Al-Amoudi et al. 2015) and fearing positive mammography results (Bottorff et al. 1998) also problematize screening.

In order to develop interventions that effectively improve mammography rates among American Muslims, it is essential to leverage strategies that have been useful in other minority groups. These effective strategies include the delivery of culturally appropriate information to at-risk groups, and the use of peer educators (Garza et al. 2005, Crawford et al. 2015, Brownstein 1992). Research among Muslims supports the acceptability of such strategies in mosque settings (Bader et al. 2006, Banerjee et al. 2017, Rashid et al. 2014). Additionally, faith-based messaging that highlights that "Islam" encourages cancer screening may also enhance mammography uptake (Pratt et al. 2017). Our formative research amongst American Muslim women in Chicago confirmed the acceptability of using religious messages, peer educators, and the mosque for

community-based, health behavior interventions (Vu et al. 2017, Padela, Malik, and Ahmed 2017). Accordingly we crafted an intervention deploying all of these techniques to tackle barriers to mammography uptake among Muslim Americans.

We hypothesized that beliefs that were barriers to mammography intention could be addressed by a religiously-tailored approach to message design (described in the methods section). In addition to the faith-*based* tailoring described above, we incorporated a faith-*placed* approach by designating the mosque as the intervention setting, again hypothesizing that a faith-placed approach would be effective for behavioral change.

### **Objectives**

This paper describes the design of, and participant-level outcomes related to, a religiously-tailored peer-led group education program addressing barriers to screening mammography among Muslim Americans.

### **Methods**

The overall community-engaged research project involved the identification of barriers to mammography screening among Muslim women, and the design of a religiously-tailored, group education intervention to address those barrier beliefs. A multi-sectoral and multi-disciplinary community advisory board (CAB) comprising of community leaders from mosques and community organizations was formed to advise on design and implementation. CAB members and research staff collaboratively designed the intervention curriculum and messaging based on our prior data on American Muslim women's salient behavioral, normative, and control mammography-related beliefs and religious influences upon these beliefs (Padela et al. 2016). The project was approved by the Institutional Review Board of the Biological Sciences Division at the University of Chicago.

#### **Peer Educator Recruitment and Training**

We identified potential peer educators from mosques with Arab and South Asian congregations so that peer educators were religiously and ethnically concordant with the intervention population. Selection criteria included being English-speaking, Muslim, female, and over the age of 40. Peer educators were recruited via flyers and emails through mosque boards and listservs and underwent a screening phone call to assess eligibility and confirm interest. Candidates were asked to attend a two-session training course, which focused on developing skills in group facilitation and discussion moderation as well as training in research ethics. Additionally, potential peer educators learned about breast cancer screening disparities, the relationships between religion and health, and health care access.

#### **Intervention Design Elements**

The group education classes consisted of a two-session program where discussions were led by peer-educators and didactics delivered by topical experts. The intervention was conducted over a period of 7.5 hours on Saturday mornings (See Table 1 for course details).

The Theory of Planned Behavior (TPB) (Ajzen 1991) informed data collection in previous phases of our project and the measurement of behavior change. Specifically, barrier and facilitator beliefs to mammography were categorized according to the behavioral, normative, and control domains of TPB in previous phases of the project, and we set improved perceived

intention for mammography (as well as improved likelihood and confidence) as our outcome target(s). Barrier beliefs identified in previous phases of the study were addressed through the 3R model for religiously tailored messaging: (i) Reframing - introducing a new way of thinking about the belief that is consonant with the desired health behavior (ii) Reprioritizing - introducing a new “facilitative” belief that coheres with the target behavioral outcome and reinforcing this belief through repetition so that it has higher valence among participants than the barrier belief and (iii) Reforming - confronting the barrier belief head on by pointing out theological misunderstandings or logical (Padela et al. 2017). Tailored messages that addressed each of the identified barrier beliefs were delivered during the group education intervention in multiple ways over multiple sessions. For example, the barrier belief that mammograms are painful was addressed through the tailored strategies of reframing and reprioritizing. The reframing message communicated that “the pain incurred on the path to completing a good deed (e.g. caring for my body) is rewarded by God” while the reprioritization strategy introduced the importance of one’s stewardship responsibility for the body.

### **Group Education Subject Recruitment**

Participants were recruited from mosques and community organization events through flyers and recruitment tables. Inclusion criteria were (i) self-identified Muslim women, (ii) no personal diagnosis of breast cancer, (iii) no mammogram in the last two years, (iv) age between 40 and 74 years, and (v) literate in English. Classes were held at two mosque sites, with one having a predominantly South Asian population and the other having a predominantly Arab population.

### **Data Collection**

Questionnaires were used to collect participant data and were self-administered pre- and post- intervention. At six months and one year after the intervention a phone call was placed to ascertain receipt of mammogram and obtain repeat measurements of the primary outcomes (see below). The principal measures were as follows:

#### Primary outcomes:

These included measures of intention, likelihood, and confidence in obtaining a mammogram. Question stems were “I intend to get a mammogram within the next year,” “How likely is it that you will get a mammogram within the next year?” and “How confident are you that you will be able to get a mammogram within the next year?” Responses were recorded along a five-point Likert-type scale from very likely to not at all likely.

#### Secondary outcomes:

Aggregate barrier and facilitator belief scores were generated by summing participant responses to a series of belief statements rated along a 4-point Likert-type agreement scale, where completely disagree received a zero and completely agree received a four. The barrier measure comprised of six barrier belief statements drawn from prior qualitative data (Padela et al. 2016). The facilitator belief measure contained eight facilitator beliefs. Four of these were based on tailored messages (e.g. “I will be rewarded by God for the hardship I undergo to get a mammogram” and “knowing my breast cancer status outweighs my fear of the test results”), three were beliefs positively associated with mammography utilization from the prior data (Padela et al. 2016), and one was the opposite of a barrier belief (e.g. my health takes precedence



over my family's needs) [Table 2]. We assessed mammography guideline knowledge with a subset of questions from the Breast Cancer Knowledge test. (McCance et al. 1990) We used three questions related to breast cancer screening and updated them to reflect the American Cancer Society's 2016 guidelines (American Cancer Society 2016). Participants were given a score between zero and three depending on how many questions they were able to answer correctly. Change in knowledge, facilitator and barrier beliefs scores were set as additional outcomes.

Tertiary outcome: Mammography receipt at six-months and one-year post-intervention.

Predictor variables: These included fatalism, modesty, religiosity, and sociodemographic characteristics. Moreover, for some outcomes (post-intervention mammography receipt and changed likelihood) changes in level of agreement with aggregate barrier and facilitator beliefs were included as predictor variables as well.

**Fatalism:** We adapted a fatalism measure known to associate with breast cancer screening practices, the Religious Health Fatalism Questionnaire (RHFQ) (Franklin, Schlundt, and Wallston 2008). Items from the Divine Provision and Destined Plan subscales of the RHFQ were rephrased to include the word "Allah". For example, question stems included "Allah can bring healing without human intervention," "I trust in Allah to provide good health," and "If I become ill, Allah has intended that to happen." We discarded one item based on cognitive pre-testing.

**Modesty:** We used a modesty measure comprising of 10 items that assesses attitudinal and behavioral aspects of Islamic modesty. This measure was an enhanced version of our previously validated pilot measure (Vu et al. 2016, Padela et al. 2015). Sample question stems included "I always look for a female doctor for myself," and "My clothing demonstrates a commitment to Islamic modesty." Responses were recorded along a 4-point Likert-type agreement scale.

**Religiosity Measures:**

**Religiosity:** The Duke University Religion Index (DUREL) measure was used with slight modifications to question stems; replacing references to the Divine with the word Allah, and the word religion to Islam (Koenig and Bussing 2010).

**Positive religious coping:** This aspect of religiosity was measured using the positive religious coping subscale of the Psychological Measure of Islamic Religiousness (PMIR). (Raiya et al. 2008) We changed question stems such that they referred to facing "a health problem" instead of life stressor. For example, the original PMIR question of "When I face a problem in life, I look for a stronger connection with God (Allah)" was changed to "When facing a health problem, I look for a stronger connection with God (Allah)." A four-point Likert-type agreement scale assessed responses.

**Negative religious coping:** This aspect of religiosity was measured using the PMIR-Punishing Allah Reappraisal subscale which assesses the belief that obstacles in life are a result of God's punishment (Raiya et al. 2008). Question stems were rephrased to refer to facing a health problem. For example, the original question of "When I face a problem in life, I feel punished by Allah for my lack of devotion" to "When I face a health problem, I feel punished by Allah for my lack of devotion," Responses were collected along a four-point Likert-type scale of agreement.

Sociodemographic variables: Conventional descriptors including marital status, income level, educational status, race/ethnicity, and insurance status were collected.

### **Statistical Analyses**

#### **Data Transformation**

For ease of analysis, and to avoid statistical error, response categories were collapsed into an adjacent category when they contained less than five percent of total observations. For ease of interpretation and due to small numbers of observations in certain categories, marital status was dichotomized to married versus those who are unmarried or widowed. The ethnicity variable was similarly dichotomized to Arab American or Other, with the “Other” category predominantly comprising of South Asian respondents.

Levels of agreement with aggregate barrier and facilitator beliefs were created by summing individual participant responses to question sets (six and eight items respectively). Single imputation was utilized to impute missing responses where participants had answered at least seventy percent of the items in the question set. Changed knowledge, barrier and facilitator belief scores were calculated by subtracting the baseline scores from post-intervention scores.

#### **Statistical Models**

A three-tiered analytic approach was used. The first set of analyses aimed at determining whether there were significant changes in levels of agreement with barrier and facilitator beliefs scores, changes in mammography knowledge, and changes in overall intention, likelihood and confidence to obtain a mammogram. These changes were evaluated using paired t-tests to determine if the post-intervention results were significantly different from the pre-intervention results. Final multivariable models were generated only when there was significant statistical change in the outcome variables.

The next analytic step sought to identify *baseline* characteristics that predict intervention success, i.e. positive change in aggregate facilitator beliefs or a negative change in aggregate barrier beliefs, as well as improvements mammography intention, likelihood and confidence. In other words, we wanted to identify characteristics that “prime” individuals for positive behavioral change. Simple ordered logistic regression models were used to evaluate the associations between the predictor variables and primary outcomes. Final, adjusted, multivariable ordered logistic regression models for changed intention, likelihood, and confidence contained any *baseline* characteristic that had a p-value of less than 0.10 in the simple regression models. For changes in aggregate barrier and facilitator beliefs, model building involved bidirectional stepwise elimination, of sociodemographic characteristics that were significantly ( $p < 0.10$ ) associated with the outcome in bivariate testing, with a probability to enter of 10% and a probability to exit of 15% (Thayer 2002a) (Thayer 2002b).

The final set of analyses sought to determine whether belief structure changes contributed to a positive change in intention, likelihood or confidence in obtaining a mammogram, while controlling for other measured predictors of the outcome. Stepwise regression, which included all relevant baseline variables, was used to identify potential predictors of a positive change in outcome measures. Changed barrier and changed facilitator variables were chosen a priori to remain in the final regression models, regardless of p-value, to

satisfy the primary research questions. For all other variables, p value to enter was set at 0.10 and the p value to stay set at 0.15.

To further explore the impact of the intervention, we also examined changes in individual items within the belief domains using paired t-tests. If level of agreement with an individual belief changed significantly post-intervention, simple and multivariable ordered logistic regression modeling was performed. All analyses were performed using STATA/MP version 15 statistical software (StataCorp LLC, College Station, TX).

## **Results**

### **Baseline sociodemographic characteristics**

Fifty-eight individuals participated in the study of which most were either South Asian (56%) or Arab/Arab American (35%). The mean age of participants was 50.4 years, and most were married (89%) and had health insurance (73%). The participant pool was almost evenly split with half (29/58) never having gotten a mammogram and half (27/58) having not obtained a mammogram in the past two years [See Table 3].

### **Assessment of changes in intention, likelihood, and confidence for obtaining a mammogram**

Analyses between pre-intervention and post-intervention responses demonstrated a statistically significant increase in perceived likelihood to obtain a mammogram (0.29,  $p = 0.01$ ). At 6-month follow-up, a trend towards increased confidence was also observed (0.32,  $p = 0.08$ ) [Table 4].

### **Baseline characteristics and predictors associated with changed likelihood to receive a mammogram post-intervention**

In multivariable modeling assessing the impact of baseline belief scores, being married was a significant positive predictor of likelihood change (OR = 37.69,  $p = 0.02$ ), while having a higher baseline agreement with barrier beliefs was associated with lower odds of increased likelihood (OR = 0.80,  $p = 0.03$ ) [See Table 5].

Multivariable modeling, assessing whether changes in participant agreement with barrier and facilitator beliefs was associated with positive likelihood change post-intervention, confirmed that being married was positively associated with behavioral change (OR = 22.16,  $p = 0.02$ ). A paradoxical associative trend towards increased odds for a positive change in likelihood with increased agreement with barrier beliefs was also observed (OR = 1.14,  $P = 0.08$ ). [Table 6]

### **Assessment of changes in mammography knowledge and agreement with facilitator and barrier beliefs**

Analyses of pre-intervention and post-intervention responses revealed a statistically significant increase in mean mammography knowledge (0.53,  $p = 0.0002$ ) post- intervention. There was also a trend towards increased agreement with aggregate facilitator beliefs (0.92,  $p = 0.08$ ) [Table 7]. While there was no significant change in agreement with specific facilitator beliefs from pre- to post-intervention, there was a significant decrease in agreement with the barrier belief “Breast Cancer Screening is not important because God decides who will get cancer” (0.40,  $p = 0.03$ ) [Table 2].

### **Predictors of changes in agreement with beliefs post-intervention**

Although there was a trend towards increased level of agreement with aggregate facilitator beliefs [Table 8], multivariable modeling failed to find any significant associations between predictors and increased agreement [Table 9]. For individual barrier beliefs, multivariable modeling identified that individuals with higher scores on the PMIR Punishing Allah Appraisal subscale had higher odds of reduced endorsement of the barrier belief, “Breast cancer screening is not important because God decides who will get cancer (OR = 1.241,  $p = 0.03$ ). [Table 9].”

### **Association between sociodemographic characteristics and mammography receipt**

Of the initial 58 women, 20 were lost to follow-up at one-year post-intervention. No significant differences in demographic profile was found between those lost to follow-up and those being able to provide data at one-year. Of the remaining 38, 22 obtained a mammogram by one-year post-intervention. Being older ( $p = 0.01$ ) and having higher levels of educational attainment ( $p = 0.01$ ) were significantly associated with mammography receipt [Table 10].

### **Discussion**

Tailoring health messages to incorporate and be consistent with cultural frameworks of patient populations improve intervention efficacy and can decrease health disparities (Kreuter et al. 2003, Shirazi et al. 2015). Such messages leverage belief structures and worldviews common to individuals and shared by communities, and thus may resonate more deeply and be more persuasive than generic messages used to motivate positive behavioral change (Kreuter et al. 2005). Moreover, when certain values and beliefs appear to conflict with, or otherwise appear as barriers to, healthcare seeking confronting these ideas through tailored messaging might be a viable strategy leading to durable behavioral change.

While Muslim Americans suffer from health disparities (Padela et al. 2015), and their health frameworks, beliefs, and behaviors are strongly-informed by religion (Yosef 2008), there is scant research on religiously-tailored interventions in this community. Indeed, there are few models delineating how to design tailored messages that address religion-related barriers, and few projects that implement religiously-tailored interventions across the diversity of the Muslim American community. While, breast cancer screening interventions amongst Muslims have utilized religious leaders to deliver health messages and placed interventions in religious settings, our program is more comprehensive in scope (Pratt et al. 2017, Banerjee et al. 2017). Our paper addresses this knowledge and literature gap by confronting mammography screening disparities among Muslim Americans through a religiously-tailored, mosque-based, peer-led, educational intervention.

Before discussing our outcomes, we would like to comment on this innovative engagement with religious community, values and identity. We utilized a community-engaged approach with a CAB to facilitate community knowledge informing program design, and to enhance community receptivity to the program. We further trained and deployed ethnically and religiously concordant peer-educators to generate greater relatability and trust with the intervention population and build community capacity for health work. In terms of attending to religious values and identity, setting the project in mosques where religious identity is communicated and using the 3R model to design religiously-laden messages cohered with our

focus on religion. Moreover, we used religious scholars to deliver lectures on Islam and health and correct misinterpretations of theology, e.g. fatalism, to further embed the project within a religious context. In these ways our intervention moved messages from being simply *faith-placed* to being holistically *faith-based*. Accordingly, our work advances the intervention science and practice in this community because most disparity research among Muslim Americans ignores religion, (Padela and Raza 2015) and most breast cancer screening interventions among Muslims have focused on enhancing access and cancer screening knowledge, not on tackling barrier beliefs related to religion (Ahmad, Cameron, and Stewart 2005, Pratt et al. 2017).

With respect to our primary outcome of changed intention, likelihood, and confidence in obtaining a mammogram, there was a statistically significant increase in mean perceived likelihood (0.29,  $p = 0.01$ ) from pre- to post-intervention. While we expected positive change in all three measures, there may be conceptual reasons that likelihood and not the other related constructs significantly changed. Some social psychologists assert that measuring perceived intention records perceptions of behavioral ability without consideration of external barriers (Armitage et al. 2015). Likelihood, on the other hand, is a measure of expectation about whether an individual will “actually” change behavior and takes into consideration external factors as well as physical barriers to performing the health behavior. Although the TPB construct of intention incorporates notions of perceived behavioral control, some argue measuring likelihood does so in a more complete way (Armitage et al. 2015). Consequently, the argument goes that the likelihood is downstream from intention, and that one can intend to do an action but be still perceive themselves unlikely to actually perform the behavior. Confidence is related to both intention and likelihood as it is a measure of self-efficacy, again somewhat downstream to intention. Therefore, although an individual may have the intention to change, they might not be confident in their ability to perform the action. Thus, greater research on the relationships and measurement overlap between perceived intention, confidence and likelihood is needed. Nonetheless, our religiously-tailored intervention was effective in improving overall perceived likelihood for, and indeed receipt of, mammograms.

Notably there was a trend where individuals who increased in their level of agreement with barrier beliefs from pre- to post-intervention, paradoxically had higher odds of increasing likelihood for mammography (OR=1.14,  $p=0.08$ ). At the same time, participants with greater level of agreement with barrier beliefs at *baseline* had lower perceived likelihood of getting a mammogram (OR=0.80,  $p=0.03$ ). These results could be explained in several ways. First, the trend in increasing agreement barrier beliefs post-intervention could be an artefact as it did not reach the  $p<.05$  level of significance. On the other hand, it could be that participants became more aware of the barrier beliefs post-intervention than they were pre-intervention because the barrier beliefs were discussed during the classes. For example, the barrier belief that mammograms are painful was discussed and is indeed true, thus participants might record greater agreement with this belief (the agreement with this belief did increase from pre- to post intervention albeit non-significantly). At the same time, however the greater knowledge of barrier beliefs did not impede their improved perception of getting a mammogram because participants came to recognize the importance of, and benefits associated with, screening mammography. The finding that individuals who have greater agreement with barrier beliefs at the outset have lower odds of positive changes in likelihood makes intuitive sense, as the more problematic one interprets mammography to be the greater the resistance to behavioral change.

Secondarily, overall participant knowledge significantly increased post-intervention (0.53,  $p=0.0002$ ).

Moreover, with respect to health behavior change, further study is needed to understand the relative weight of facilitator beliefs and barrier beliefs on influencing screening mammography. It may be hypothesized that reducing barrier beliefs increases self-efficacy, which in turn increases screening mammography uptake. Alternatively, one could hypothesize that significantly enhancing facilitator beliefs leads to behavior change. On the other hand, variable effects may result based on where individuals reside on the continuum of endorsing specific barrier beliefs and/or facilitator beliefs. Greater research into how specific messages promote belief structure changes at the individual level and how these changes inform future behaviors is needed. In our study, 22 out of the 58 participants (38%; 20 individuals lost to follow-up) obtained a mammogram at one-year follow-up demonstrating effective behavioral change despite the relatively modest belief structure changes noted above. Excluding the 20 individuals unable to be reached at one-year follow-up, the percentage rises to 76%. Irrespective of the different approaches to calculating efficacy and effectiveness of this pilot intervention, 20 individuals getting a mammogram reflects intervention success.

Although our findings are encouraging, they should be interpreted with caution given the modest sample size and particularities about the sample, i.e. English-speaking, mosque-going women. Additionally, while selecting for highly religious people was purposive because we wanted to leverage religion for behavior change, the approach limits generalizability because of variances in religiosity among Muslim Americans. Additional limitations relate to measurement. We used one-item measures of intention, confidence, and likelihood and these measures may not comprehensively reflect the psychological and attitudinal changes antecedents to the target health behavior (getting a mammogram). Consequently, we recommend future research test the efficacy of our program with Muslims of different ethnicities and of varying religiosity, and that measures from other theories of behavioral change also be incorporated.

In conclusion, our religiously-tailored, mosque-based, peer-led intervention targeting barrier beliefs to mammography was effective in increasing participant likelihood to, and receipt of, mammograms. We believe there is immense potential for using religious ideas to promote health and healthcare seeking among Muslim Americans and suggest that our model provides the conceptual and evidentiary bases for developing such interventions.

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**Table 1. Caring for Body and Soul: A Workshop on Women's Health, Workshop Agenda**

| Course Content                                  | Course Description  | Educational Objectives  |
|---|---|---|
| <b>Class 1: Good Health Starts with You</b>     |   |   |
|   |   | <b>At the end of the session, participants should be able to:</b>   |
| Study Overview                                  | Didactic session led by study staff and peer educators  | 1. Identify underlying motivations for the project;   |
|   |   | 2. Be able to describe the goals of the training program in improving women's health knowledge and mammography intention; |
|   |   | 3. Become familiar with data from previous phases of the study;   |
|   |   | 4. Describe barriers to and facilitators of preventive health (targeted beliefs)  |
| Icebreaker                                      | Interactive session led by peer educators   | 1. Understand data from previous phases of the study;   |
|   |   | 2. Identify and discuss personal barriers to and facilitators of preventive health  |
| Women & Health                                  | Didactic session led by peer educators  | 1. Know peer educators and understand their motivations for joining the project;  |
|   |   | 2. Understand barriers to and facilitators of preventive health for women   |
| Health & Access                                 | Didactic session led by representative from A Silver Lining Foundation, a local organization aiming to ensure dignified and equal access to quality cancer education and services for all | 1. Identify resources for setting up mammography screening appointments and possible follow-up visits                     |
| Religious Dimensions of Health                  | Didactic session led by female religious scholar  | 1. Understand different religious dimensions of health  |
| <b>Class 2: Mammography Experiences</b>         |   |   |
| Cancer Care Story                               | Peer educator-led facilitated group discussion and debrief following the showing of a culturally-appropriate elicitation video  | 1. Identify and discuss beliefs related to mammography intention  |
| Survivorship Story                              | Didactic session led by breast cancer survivor  | 1. Identify and discuss beliefs, barriers, and personal experience with mammography                                       |
| Breast Cancer Screening Guidelines & Procedures | Didactic session led by a female physician  | 1. Distinguish myths and facts of breast cancer ;   |
|   |   | 2. Understand the benefits and process of mammography   |

| Table 2. Targeted Beliefs with Mean Change in Agreement, Pre- to Post-Intervention |  |                                  |                                   |        |         |
|--|--|----------------------------------|-----------------------------------|--------|---------|
| Belief Origin  | Belief Statement   | Pre-intervention Agreement Level | Post-intervention Agreement Level | Change | p-value |
| <b>Facilitator Beliefs</b>   |  |                                  |                                   |        |         |
| Beliefs Positively Associated with Mammography                                     | Mammograms can help detect disease and facilitate opportunities for prevention & treatment (n = 51)                                | 3.62                             | 3.69                              | 0.07   | 0.51    |
|  | My family supports my getting a mammogram (n = 52)   | 3.62                             | 3.63                              | 0.02   | 0.78    |
|  | I am comfortable talking to my friends about mammography (n = 52)  | 3.65                             | 3.58                              | -0.08  | 0.48    |
| Tailored Beliefs Resulting from Messages   | I will be rewarded by God for the hardship I undergo to get a mammogram (n = 49)   | 3.27                             | 3.13                              | -0.15  | 0.32    |
|  | Getting a mammogram is one way to meet my religious duty of caring for my body (n = 50)  | 3.31                             | 3.48                              | 0.17   | 0.19    |
|  | Knowing my breast cancer status outweighs my fear of the test results (n = 50)   | 3.23                             | 3.29                              | 0.06   | 0.64    |
|  | Although God controls disease and illness, it is my religious responsibility to care for my body and get cancer screening (n = 51) | 3.71                             | 3.71                              | 0      | 1.00    |
| Barrier Belief Reciprocals   | My health takes precedence over my family's needs (n = 51)   | 3.14                             | 3.29                              | 0.15   | 0.29    |
| <b>Barrier Beliefs</b>   |  |                                  |                                   |        |         |
| Utilization-Associated Mammography Target Beliefs                                  | Mammograms are painful (n = 51)  | 2.87                             | 2.94                              | 0.07   | 0.67    |
|  | My fear of a positive result prevents me from getting a mammogram (n = 51)   | 2.39                             | 2.46                              | 0.07   | 0.62    |
|  | My family's needs and priorities are more important than my own (n = 52)   | 2.72                             | 2.46                              | -0.26  | 0.14    |
|  | Insurance policies make getting a mammogram difficult (n = 51)   | 2.53                             | 2.64                              | 0.11   | 0.47    |
|  | Breast cancer screening is not important because God decides who will get cancer (n = 50)  | 1.90                             | 1.50                              | -0.40  | 0.03*   |
|  | I have not gotten a mammogram in the past two years because I worry about being serviced by a male technician (n = 51)             | 2.20                             | 2.53                              | 0.33   | 0.08    |

\* Statistically significant at  $p \leq 0.05$

| <b>Table 3. Sociodemographic Characteristics of Study Participants, N = 58</b> |                               |
|--|-------------------------------|
| Characteristic   |                               |
| <b>Sociodemographic Characteristics</b>  | <b>N (%)</b>                  |
| Age (n = 44)*  | Mean $\pm$ SD: 50.4 $\pm$ 8.4 |
| Less than 50   | 20 (45.5)                     |
| 50 or older  | 24 (54.6)                     |
| Race/Ethnicity (n = 52)  |                               |
| South Asian  | 29 (55.8)                     |
| Arab/Arab American   | 18 (34.6)                     |
| Marital Status (n = 55)  |                               |
| Married  | 49 (89.1)                     |
| Unmarried or Widowed   | 6 (10.9)                      |
| Country of Origin (n = 54)   |                               |
| South Asian  | 30 (55.6)                     |
| Arab World   | 14 (25.9)                     |
| United States  | 5 (9.3)                       |
| Education (n = 56)   |                               |
| Less than High School  | 7 (12.5)                      |
| High school diploma/GED  | 11 (19.6)                     |
| Associates Degree  | 11 (19.6)                     |
| Bachelor's level or equivalent   | 19 (33.9)                     |
| Advanced degree (post-baccalaureate, Masters, Doctoral)                        | 8 (14.3)                      |
| Annual Income (n = 46)   |                               |
| Less than \$20,000   | 18 (40.0)                     |
| \$20,000 - \$49,999  | 17 (37.0)                     |
| \$50,000 - \$74,999  | 6 (13.0)                      |
| \$75,000 or more   | 6 (13.0)                      |
| Health Insurance (n = 51)  |                               |
| Yes  | 37 (72.6)                     |

**Table 4. Average Change in Intention to Receive a Mammogram and its Proxy Measures (Likelihood and Confidence), Evaluated at Pre-Intervention, Post-Intervention, and 6-month Follow Up**

| Measure    | Mean Change (P-Value) |                |
|------------|-----------------------|----------------|
|            | Pre to Post           | Pre to 6-month |
| Intention  | 0.19 (0.15)           | 0.04 (0.74)    |
| Likelihood | 0.29 (0.01)*          | 0.20 (0.15)    |
| Confidence | 0.18 (0.25)           | 0.32 (0.08)    |

\* Statistically significant at  $\alpha = 0.05$

**Table 5. Ordered Logistic Regression Model for the Changed Mammography Likelihood from Pre-to Post-Intervention, N = 40**

| Predictor            | OR (95% CI)          | P-Value |
|----------------------|----------------------|---------|
| Barrier Belief Score | 0.80 (0.66, 0.98)    | 0.03*   |
| Married              | 37.69 (2.04, 695.22) | 0.02*   |
| Income               | 1.47 (0.70, 3.09)    | 0.31    |

\*Statistically significant at  $\alpha = 0.05$

**Table 6. Ordered Logistic Regression Analysis of the Change in Likelihood to Receive a Mammogram from Pre- to Post- Intervention, N = 48**

| Predictor                     | Odds Ratio (95% CI)  | P-Value |
|-------------------------------|----------------------|---------|
| Change in Barrier Beliefs     | 1.14 (0.98, 1.32)    | 0.08    |
| Change in Facilitator Beliefs | 1.09 (0.93, 1.26)    | 0.29    |
| Married                       | 22.16 (1.77, 277.07) | 0.02*   |
| Modesty                       | 1.05 (0.90, 1.22)    | 0.52    |
| Fatalism                      | 0.91 (0.76, 1.09)    | 0.32    |

\* Statistically significant at  $\alpha = 0.05$

**Table 7. Multivariable Ordered Logistic Regression Model for Predictors of Increased Level of Agreement with Facilitator Beliefs Post-Intervention, n = 45**

| Predictor                                 | Odds Ratio (95% Confidence Interval) | p-value |
|---|--------------------------------------|---------|
| Level of Modesty                          | 0.98 (0.88, 1.08)                    | 0.67    |
| PMIR Punishing Allah Reappraisal subscale | 0.88 (0.75, 1.04)                    | 0.13    |

**Table 8. Mean Change in Mammography Knowledge, Agreement with Facilitator Beliefs, and Agreement with Barrier Beliefs Post-Intervention**

| Measure (Change Scores)                      | Mean Change (p-value)     |
|--|---------------------------|
|  | Pre- to Post-Intervention |
| Aggregate Agreement with Facilitator Beliefs | 0.92 (0.08)               |
| Aggregate Agreement with Barrier Beliefs     | 0.05 (0.94)               |
| Mammography Knowledge                        | 0.53 (0.0002)*            |

**Table 9. Multivariable Ordered Logistic Regression Model for Predictors of Decreased Level of Agreement with the Barrier Belief, “Breast Cancer Screening is not Important Because God Decides Who Will Get Cancer,” n = 45**

| Predictor                                  | Odds<br>(95% Confidence Interval) | Ratio | p-value |
|--|-----------------------------------|-------|---------|
| Level of Modesty                           | 0.94 (0.84, 1.04)                 |       | 0.23    |
| PMIR Punishing Allah<br>Appraisal subscale | 1.24 (1.02, 1.50)                 |       | 0.03*   |

\* Statistically significant at  $p \leq 0.05$

**Table 10. Association Between Baseline Demographic Characteristics and Mammography Receipt After One Year of Follow-Up**

| Characteristic            | Demographic<br>Characteristics | Breast Cancer Screening |               | P-Value <sup>†</sup> |
|---------------------------|--------------------------------|-------------------------|---------------|----------------------|
|                           |                                | No (N = 16 )            | Yes (N = 22 ) |                      |
|                           | N (%)                          | N (%)                   | N (%)         |                      |
| Age (n = 44)              |                                |                         |               | 0.01*                |
| Less than 50              | 20 (45.45)                     | 10 (62.5)               | 5 (22.7)      |                      |
| 50 or Older               | 24 (54.55)                     | 3 (18.8)                | 14 (63.6)     |                      |
| Marital Status (n = 55)   |                                |                         |               | 0.13                 |
| Married                   | 49 (89.1)                      | 14 (87.5)               | 17 (77.3)     |                      |
| Unmarried                 | 6 (10.9)                       | 0 (0)                   | 4 (18.2)      |                      |
| Ethnicity (n = 52)        |                                |                         |               | 0.15                 |
| Arab/Arab American        | 18 (34.6)                      | 6 (37.5)                | 5 (22.7)      |                      |
| South Asian               | 34 (65.4)                      | 6 (37.5)                | 16 (72.7)     |                      |
| Education (n = 56)        |                                |                         |               | 0.01*                |
| Less than High School     | 7 (12.5)                       | 5 (31.3)                | 1 (4.5)       |                      |
| High School               | 11 (19.6)                      | 4 (25.0)                | 4 (18.2)      |                      |
| Associates                | 11 (19.6)                      | 1 (6.3)                 | 6 (27.3)      |                      |
| Bachelors                 | 19 (33.9)                      | 1 (6.3)                 | 9 (40.9)      |                      |
| Advanced Degree           | 8 (14.3)                       | 4 (25.0)                | 2 (9.1)       |                      |
| Income (n = 46)           |                                |                         |               | 1                    |
| Less than \$20,000        | 17 (37.0)                      | 4 (25.0)                | 8 (36.4)      |                      |
| \$20,000 - \$49,000       | 17 (37.0)                      | 4 (25.0)                | 6 (27.3)      |                      |
| \$50,000 - \$74,999       | 6 (13)                         | 2 (12.5)                | 4 (18.2)      |                      |
| Greater than \$75,000     | 6 (13)                         | 2 (12.5)                | 3 (13.6)      |                      |
| Health Insurance (n = 51) |                                |                         |               | 1                    |
| Yes                       | 37 (72.6)                      | 10 (62.5)               | 16 (72.7)     |                      |
| No                        | 14 (27.5)                      | 2 (12.5)                | 4 (18.2)      |                      |

\* Statistically significant at  $\alpha = 0.05$

<sup>†</sup> P-Values obtained from Fisher's Exact Test

## Assessing Prevalence, Knowledge, Attitude, Beliefs and Behavior of Hookah Use among Members of Arab and Chaldean Americans in Metro Detroit Area, Michigan, 2017

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### Abstract

**Background:** Previous studies have shown a high prevalence of cigarette smoking and hookah use among Arab Americans in the Metro Detroit area in Michigan. This study has used a larger sample size to be more representative for Arab and Chaldean Americans in Michigan.

**Objective:** To determine current cigarette and hookah use prevalence, knowledge, beliefs and behavior among Arab and Chaldean Americans. Also, will compare the results with a previous similar study of 2009.

**Methods:** This is a cross sectional study designed to provide a large sample size of Arab and Chaldean American adults among Metro-Detroit residents. Questions about behavior and beliefs related to hookah were asked. The survey was administered throughout ten cities which are highly populated with this community. A total of 2056 adult, 18 years and older, were surveyed between August 2016 and August 2017.

**Results:** The study revealed that current cigarette smoking rate is 18.4% while the hookah use rate is 34.1% with heavier use among males than females. Dual use rate of cigarette and hookah is 26.3%. Regarding the age groups, the data indicate that hookah use is higher among the lower age group and use decreases as age increases after 34 years of age. By educational level, hookah use starts low with lower education and use increases as educational level increases.

**Conclusion:** Arab and Chaldean Americans smoke cigarettes at a lower level compared to the 2009 study but use hookah more. This study found that there is a positive change in believe and knowledge about the harm of hookah compared to the 2009 study.

**Keywords:** Arab-Americans; Health beliefs; Smoking, Hookah

### Introduction

Tobacco use is the single most preventable cause of disease, disability, and death in the U.S. Nearly one-half million Americans still die prematurely from tobacco use each year <sup>(1)</sup>. And a growing body of evidence suggests that hookah use may expose the user to substantial amounts of smoke volume, carbon monoxide, nicotine, carcinogens, and tar <sup>(2,3,4,5)</sup>.

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It was estimated that 3.7 million Arab Americans were living in the United States in 2010. Arab Americans grew by more than 72% between 2000 and 2010. Arab Americans are found in every state, but more than two thirds of them live in just ten states: Michigan is second after California; Metropolitan Los Angeles, Detroit, and New York are home to one-third of the population <sup>(6)</sup>.

Arab and Chaldean Americans constitute the third largest minority group in Michigan after African Americans and Latinos. Chaldean Americans originated in northern Iraq, are Christian, and speak (in addition to Arabic) a modern version of Aramaic as their common language <sup>(7)</sup>.

The Michigan Department of Health and Human Services, Tobacco Control Program (MDHHS, TCP) worked collaboratively with 2 Arab American Organizations; ACCESS (Arab Community Center for Economic and Social Services) and the ACC (Arab-American and Chaldean Council) to conduct a study in 2016 as a community health survey design. The survey was conducted in the Metro Detroit Area in Michigan.

Studies on smoking and hookah use in the Arab and Chaldean American community found higher smoking rates and lower quitting rates when compared with National and Michigan data for other population groups <sup>(8,9)</sup>.

## **Objectives**

The purposes of this study are to:

1. Determine the current cigarette smoking and hookah use rates, knowledge, attitudes and behavior among Arab and Chaldean Americans in the Metro Detroit area in Michigan.
2. Study some demographic factors among Arab Americans in Metro Detroit area related to tobacco use.
3. Compare the 2017 results with those of the 2009 study.

## **Methods**

A 22-question survey was distributed to Arab and Chaldean Americans in the Metro Detroit Area in Michigan during 2016 and 2017 in both English and Arabic. About 20 staff from both organizations (ACCESS and ACC) were trained by MDHHS to conduct the survey among eligible adults 18 years and above who belong to the Arab and Chaldean Americans community. The training included sampling methodology, random selection, eligibility criteria, recruitment plans in the community, doorstep approach and safety guidance.

According to the Census, the people of Arab ancestry in Metro Detroit are residing in 10 main cities in the Metro Detroit Area. The total number of the participants who completed the survey was 2,056 participants from different areas, this number is considered a high number when compared to other studies that have been done in this community. Surveys were collected and entered into an Excel file and then data analyzed using IBM SPSS-25.

## **Results**

### *Demographic criteria:*

Male participants are 1,149 (56%) while females are 901 (44%), age group distribution of the sample shows that 29.2% of the sample fell among the (18-24 year) age group, while in 2009 this group constituted 20.4%. There are 2 age groups, that each constitutes 25% of the sample, the



(25-34 year) and the (45 and above), the fewer group is from the age group of (35-44 year). Participants from Iraq are the leading group (n=704, 34.3%) followed by Lebanese (n= 600, 25.8%), and Yemeni (n=419, 20.4%), then Syrians and Jordanians. In 2009, Lebanese participants were the highest 37% vs 30% Iraqis. About 30.8% of the participants are born in the U.S while the remaining 69.1% are born outside the U.S., compared to 2009 those who were born in the U.S. represented 19.6%. Immigration status shows that 23.8% were refugees or asylees when they entered the U.S. While 42.9% of the sample are immigrants, we also noticed that missing or refused to answer this question are 33.2% of the participants as shown in Table-1.

#### *Socioeconomic status*

We calculated 2 elements of socioeconomic status: 1) educational level and 2) household income level. We found 15% of the participants (n=308) have low educational level (less than high school). The high school graduates are (n=721, 35%) while those with some college and above constitute 46.4% (n= 954) of the participants.

For household income level, lower than one third, 29% (n=591) of the participants have a low household income level of “less than \$20,000 per year” and 25% (n=507) have \$20,000-34,000 per year. Only 5.5% (n=114) of the Arab and Chaldean participants reported a higher income level of \$75,000 and above. In the 2009 survey, the low-income level participants were 20.4% and the higher income level were 7.1%. All results are shown in Table-2.

#### *Cigarette Smoking and Hookah Use Status and Behavior*

We assessed the current cigarette smoking rate among Arab and Chaldean Americans for this survey and found it to be 18.4% versus 32.4% in 2009. Former cigarette smoking rate is 15.7% versus 7.4% in 2009. For hookah use, the current use rate is 34.1% (n=683) versus 33.5% in 2009, while the former hookah user rate is 7.3% (n=147). We assessed the dual use of both hookah and cigarettes and it is 26.3% in 2017 versus 35% in 2009.

All results are shown in Table -3.

We studied the smoking behavior related to gender, age, country of origin, location of birth, and immigration status. We found the current cigarette smoking rate among males is 77.9% compared to 21.6% among females in the 2009 survey, the smoking rate among males was 72% versus 28% among females. For hookah use, in 2017 the rate among males is 59.6% versus 40.1% among females, whereas in 2009 the rate of using hookah was 64.6% among males compared to 35.4% among females. We found in 2017 that the current cigarette smoking rate is 18.9% among 18-24 year, 27.5% among 25-34 year, 27.2% among 35-44 year and 26.4% among 45 years and older groups. For hookah use we found the rate is 34.6% among young adults 18-24, 10.5% among 45 years and above. In 2009, hookah use was almost the same among all age groups with higher use among 45 years and above. By country of origin, the current cigarette smoking rate is 37.7% among participants originally from Iraq and second is 26.7% among participants originally from Lebanon, others are listed in Table 4. With hookah use we found that 34.4% among participants originally from Iraq and 30.1% among participants originally from Lebanon. We also assessed the smoking rate by location of birth whether inside the U.S. or outside the U.S., we found that the cigarette smoking rate is 21.3% among those who were born inside the U.S. versus 78.4% among those who born outside the U.S., and same results were found in the 2009 study.

While for hookah use we found that the rate is 47.4% for those who born inside the U.S. versus 27% among those who were born outside the U.S. All results are shown in Table-4.

#### *Cigarette Smoking and Hookah Use by Educational level and Household Income levels*

We assessed cigarette smoking and hookah use in each group of education and household income in 2017 and compared it with 2009 findings. We found that cigarette smoking is 18.2% and 23% among those with less than high school and high school graduate groups respectively, while those with college and above smoke at a rate of 14.7%, whereas the 2009 study found cigarette smoking was almost similar among all educational levels. By income level, we found that the cigarette smoking rate is 21.2% among the low-income level (below \$20K) and 15.8% among high income level (of \$75K and above). In the 2009 study, cigarette smoking was similar among all income groups. For hookah use we found the rate is 21.4% among low educational level versus 35.7% among higher education level. For the household income groups, the rate of hookah use is 29.8% among low income versus 42.1% among the highest income level. Similar findings emerged in the 2009 study among income groups but a little different among education groups. All the rates are shown in table 5.

#### *Knowledge and Attitudes among Hookah users:*

The salient reason reported for using hookah in the 2017 study is to socialize with others at 73.9%; a similar finding was also found in 2009 at 55%. The second reason given was the attractive taste of the flavored tobacco at 47.9% versus 18% in 2009, third was to relieve stress at 43.7% in 2017 versus 16% in 2009. When estimating their knowledge about the harmful effects of hookah on personal health, we found that their knowledge about the harmful effect in 2017 is 86.7% versus 78.5% in 2009 study. The findings are shown in Table-6.

#### *Quitting Behavior:*

We also assessed quitting attempts and whether individuals used quit methods during their quit attempts. We found that quitting attempts in 2017 were at 39.4% while it was 5.7% in 2009. We also found that most of those who tried to quit were able to quit on their own i.e. cold turkey (29.5%) in 2017. All the findings are in table 7.

#### *Frequency, Location, Flavored, Herbal and using delivery services among Hookah users:*

We assessed how frequent hookah users use hookah, and we found that the highest rate used hookah on a weekly basis (31.6%); 28.4% use hookah twice a week; 18.1% on a daily basis. The lowest frequency is using on a monthly basis (7.2%).

Then we assessed whether they use flavored or non-flavored shisha when using hookah and found that 91.2% use flavored shisha while only 3.4% use non-flavored. We also assessed whether they use herbal shisha or tobacco shisha and found that 93.8% use tobacco while 6.2% use herbal shisha.

We assessed whether hookah users request delivery services for their sessions or not, and we found that 31.9% use delivery services. For the location where they use hookah, we found 50.4% use them at home while 40.4% use at hookah lounge; other locations are at lower rates. All findings are shown in table 8.

## Discussion

As mentioned before, the objective of this study is to assess and compare the personal cigarette smoking and hookah use behavior among a cross sectional sample of Arab and Chaldean Americans living in the Metro Detroit area in Michigan.

We found that the current cigarette smoking rate is 18.4% versus 32.4% in 2009. This difference is mostly because many of the Arab Americans switched to hookah use. Additionally, many of them quit and now are considered former smokers since the former cigarette smoker rate in the 2017 study is 15.7% versus 7.4% in 2009 and the quit attempt rates during the past 12 months for cigarette smokers is 39.4% in 2017 versus 5.7% in 2009. Another factor contributing to quit attempts is that the MDHHS TCP offered an Arabic speaking coach in the state quitline where smokers can call and talk in Arabic. The current smoking rate is lower than the average Michigan smoking rate of 20.4%, but it is higher than the national average of 17% in 2016<sup>(15)</sup>, and it is also lower than what was found in many studies among Arab Americans<sup>(16)</sup>, but like some other studies of being low<sup>(17)</sup>. Males smoke at 77.9% which is significantly higher than females at 21.6%, and this is like most of the studies among this community<sup>(9,18)</sup>.

Smoking by age groups is similar to the Michigan general population average, higher among middle age groups and lower among young adults of 18-24 years group.

By location of birth, we found that those who born outside the U.S. smoke cigarettes at a very high level (78.4%) compared with those born in the U.S. (21.3%), and this may reflect that those born in the U.S. are similar to the U. S. general population rates of smoking (20.4%).

By immigration status, we found that those with refugee status smoke cigarettes (28.8%) less than those with non-refugee immigrant status (47.5%). One of the reasons is that access and availability of cigarettes is less than the other group because of lack of fund. For the educational level, we found that the rate of cigarette smoking is less among low educational level (14.9%) and increase with level of education, this is opposite the trend among the general population, where the smoking rate is higher among low educational level and the rate decreases with higher educational level<sup>(15)</sup>.

Smoking rates by income level follow the general population trend, as they start higher among low income and decreases with higher income level. The quit method most preferred by Arab Americans smokers is cold turkey i.e. quitting on their own (29.5%).

For hookah use, the status is different; the rate in 2017 is 34.1%, a little higher than what we found in 2009 (33.5%) which can explain why the cigarette smoking rate is lower now. The former hookah user rate is 7.3% which is an indication-of a very low quit rate among hookah users. The quit attempt rates during the past 12 months for hookah users is 23.9%.

Those with dual use of hookah and cigarettes are 26.3% in the 2017 study compared to 35% in 2009. The reason could be the lower rate of cigarette smoking in 2017; this rate is the same rate that Asfar et al. found<sup>(8)</sup>. The gap between males and females who use hookah is narrower than the cigarette smoking (59.6% among males versus 40.1% among females for hookah use). By age groups, the hookah use rate decreased with older age. This can be explained by the fact that

hookah use has exploded rapidly into the youth culture, and impacts especially on or near college campuses and schools where they attract teens and young adults <sup>(19,20)</sup>

In a similar finding that we found with cigarette smoking, the hookah use rate is highest among Iraqi Americans than others. A different finding from cigarette smoking is with location of birth, as we found the opposite: a higher rate of using hookah was found among those who are born in the U.S. (47.4% versus outside U.S. 27%). This is because those who are born in the U.S. are of younger generations and hookah attracts young adults.

By educational level, hookah use is lower among low educational level (21.4%), while those with college degrees use hookah more (35.7%); this also can be explained by the spread of hookah among the younger generation near college campuses.

When we studied it with income level, we found that hookah use starts higher among low income and then decreases with higher income level, and this can be explained by those of higher income are mostly those of middle and older age groups who use hookah less than the young population.

Reasons for why they use hookah: the highest reason is to socialize with friends (73.9%), then the taste (47.9%), and relieve stress at 43.7%. Hookah users believe that hookah use is harmful to health (86.7%) and only 18% believe that it is safer than cigarettes while in Asfar et al. study they found that 46.4% believes that hookah is safer than cigarettes and this may be one of the results of the close collaboration between the MDHHS, TCP with the 2 Arab American Organizations; ACCESS and ACC which both serve the Arab and Chaldean community in the Metro Detroit area as all partners believe that lack of public knowledge about the potential health hazards of using hookah has led to this widespread misperception that hookah smoking is safe. Studies conducted in Egypt, Israel, and Syria have found that in general, people know little about its health effects and believe that it is less harmful than cigarette smoking <sup>(12,13,14)</sup>.

Frequency of using hookah is weekly and twice a week (31.4% and 28.4%) respectively.

For the type of shisha they use in hookah sessions, we found that most of the hookah users use Tobacco versus Herbal (non-tobacco) 94% versus 6%.

Regarding the use of flavored shisha, we recognize that the introduction of flavored Tobacco in the early 1990s by Egyptian tobacco companies as they introduced “Maassel”, a specially prepared mixture containing sweetened fruit flavors and mild aromatic smoke was the major reason for the growing popularity of hookah use worldwide. Maassel, known as “shisha” in the U.S., consists of about 30% of crude cut tobacco fermented with about 70% honey, molasses, and the pulp of different fruits. It provides a pleasant aroma when heated slowly with burning charcoal and comes in a variety of flavors including apple, strawberry, rose, mango, cappuccino, banana, peach, lemon, orange, mint, licorice and many others. Currently, most hookah smokers around the world use Maassel (flavored) rather than the traditional tobacco mix because it is more flavorful and makes the process of waterpipe preparation simpler because users do not need to moisten, shape, and dry the tobacco before use, as with other kinds of tobacco <sup>(10,11)</sup>. We found in our study that 96.6% of hookah users use flavored shisha. The preferred locations to use hookah we found at home (50.4%) and hookah lounge (40.4%)

Also, we inquired about a new trend which is using delivery services for shisha and hookah to homes and found that 32% of hookah users utilize this service.

## **Conclusion**

Comparing these findings with a previous similar study in 2009 can be considered a good measure of the positive impact of the public education campaign that was conducted through the partnership between MDHHS TCP with ACCESS and ACC since 2002, as noticed from the results that there is a change in beliefs about the harmful effects of hookah. Also, the current cigarette smoking rate is decreased significantly although this was associated with increase in hookah use.

## **Recommendations**

More public education about the dangers of Hookah smoking is needed to debunk the common myths that exist. It is also observed that lack of awareness even among health professionals, and decision-makers and opinion leaders on the issue hinders progress in addressing this growing public health problem.

Resources geared for a general audience that addresses the health consequences of Hookah use, risk of communicable diseases, risk of use becoming a gateway to cigarettes and other drugs, cultural practice versus social activity of youth, and occupational health & safety would contribute to an appropriate public health response. We offer the following additional recommendations about hookah use:

1. Hookah tobacco contents should be regulated and monitored by the Food and Drug Administration.
2. Hookah tobacco packages should have warning labels about its health hazards;  
Educational campaigns should be created to increase awareness among health care providers, the public (particularly youth), and lawmakers about the risk of hookah smoking.
3. Further research is needed to: find trends and epidemiology of hookah among college students; evaluate the chemical constituents of hookah tobacco in the U.S. and analyze the toxicology of the smoke from hookah use.

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**Table 1.** Demographic characteristics of the participants in 2017 Compared to 2009

| Characteristics    |                    | 2009 % (N)     | 2017 % (N)    |
|--------------------|--------------------|----------------|---------------|
| Sample size        |                    | 2025           | 2056          |
| Gender             | Male               | 52.0 % (1,053) | 56% (1,149)   |
|                    | Female             | 48.0 % (972)   | 44% (901)     |
| Age group          | 18 – 24 years      | 20.4% (412)    | 29.2 % (600)  |
|                    | 25 – 34 years      | 27.3% (553)    | 24.6% (505)   |
|                    | 35 – 44 years      | 23.3% (472)    | 20.6% (424)   |
|                    | 45 years and above | 29% (587)      | 25.3% (521)   |
| Country of origin  | Lebanon            | 37% (7530)     | 25.8% (530)   |
|                    | Iraq               | 29.6% (600)    | 34.3% (704)   |
|                    | Syria              | N/A            | 10% (205)     |
|                    | Jordan             | 2.8% (56)      | 3.9% (80)     |
|                    | Yemen              | 22% (439)      | 20.4% (419)   |
| Location of birth  | In US              | 19.6% (397)    | 30.8% (631)   |
|                    | Outside US         | 80.1% (1,622)  | 69.1% (1,416) |
| Immigration status | Refugee/Asylee     | N/A            | 23.8% (490)   |
|                    | Immigrant          | N/A            | 42.9% (883)   |
|                    | Missing            | -              | 33.2% (683)   |

**Table 2.** Socioeconomic status of the participants in 2017 compared to 2009

| Educational level      | 2009 % (N)   | 2017 % (N)  |
|------------------------|--------------|-------------|
| Less than High School  | 26.7% (528)  | 15% (308)   |
| High School Graduate   | 26.7% (528)  | 35.1% (721) |
| Some College and above | 46.6% (924)  | 46.4% (954) |
| Household Income level |              |             |
| < \$20,000             | 20.4 % (413) | 28.7% (591) |
| \$20,000 - \$34,999    | 17.9 % (362) | 24.7% (507) |
| \$35,000 - \$49,999    | 13.3 % (269) | 14.6% (300) |
| \$50,000 - \$74,999    | 8.8 % (179)  | 13.6% (280) |
| > \$75,000             | 7.1 % (143)  | 5.5% (114)  |

**Table 3.** Percentages of Cigarette Smoking and Hookah Use Status in 2017 Compared to 2009

| Cigarette smoking              | 2009 % | 2017 % |
|--------------------------------|--------|--------|
| Current                        | 32.4%  | 18.4%  |
| Former                         | 7.4%   | 15.7%  |
| Never                          | 60%    | 65.9%  |
| Hookah use                     |        |        |
| Current                        | 33.5%  | 34.1%  |
| Former                         | N/A    | 7.4%   |
| Never                          | N/A    | 58.5%  |
| Dual smoking status            |        |        |
| Use both hookah and cigarettes | 35%    | 26.3%  |

**Table 4. Cigarette and Hookah Use by Demographic Group in 2017 Compared to 2009**

| Characteristics    |                        | Cigarette smoking % |        | Hookah use % |       |
|--------------------|------------------------|---------------------|--------|--------------|-------|
|                    |                        | 2009                | 2017   | 2009         | 2017  |
| Gender             | Male                   | 72.1%               | 77.9%  | 64.6%        | 59.6% |
|                    | Female                 | 27.9%               | 21.6%  | 35.4%        | 40.1% |
| Age Groups         | 18 – 24 years old      | N/A                 | 18.9 % | 21.5%        | 34.6% |
|                    | 25 – 34 years old      | N/A                 | 27.5%  | 25.8%        | 32.7% |
|                    | 35 – 44 years old      | N/A                 | 27.2%  | 22.9%        | 21.9% |
|                    | 45 years old and above | N/A                 | 26.4%  | 28.6%        | 10.5% |
| Country of Origin  | Lebanon                | N/A                 | 26.7%  | N/A          | 30.1% |
|                    | Iraq                   | N/A                 | 37.7%  | N/A          | 34.4% |
|                    | Syria                  | N/A                 | 10.4%  | N/A          | 8.6%  |
|                    | Jordan                 | N/A                 | 4%     | N/A          | 4.8%  |
|                    | Yemen                  | N/A                 | 15%    | N/A          | 17.4% |
| Location of Birth  | Born in US             | 37.6%               | 21.3%  | N/A          | 47.4% |
|                    | Born outside US        | 62.4%               | 78.4%  | N/A          | 27%   |
| Immigration Status | Refugee/Asylee         | N/A                 | 28.8%  | N/A          | 14.5% |
|                    | Immigrant              | N/A                 | 47.5%  | N/A          | 38.6% |

**Table 5. Cigarette and Hookah Use By socioeconomic groups in 2017 compared to 2009**

| Characteristics        | Cigarette smoking % |       | Hookah use % |       |
|------------------------|---------------------|-------|--------------|-------|
|                        | 2009                | 2017  | 2009         | 2017  |
| Educational level      |                     |       |              |       |
| Less than High School  | 26%                 | 14.9% | 28.7%        | 21.4% |
| High School Graduate   | 29.5%               | 44.3% | 26.2%        | 35.9% |
| Some College and above | 44.4%               | 37.3% | 45.1%        | 35.7% |
| Household Income level |                     |       |              |       |
| < \$20,000             | 33%                 | 33.3% | 30.2%        | 25.7% |
| \$20,000 - \$34,999    | 22.5%               | 25.6% | 28%          | 28.9% |
| \$35,000 - \$49,999    | 21.9%               | 14.4% | 18.6%        | 17%   |
| \$50,000 - \$74,999    | 13.6%               | 12.5% | 10.9%        | 14.2% |
| > \$75,000             | 9.1%                | 4.8%  | 12.3%        | 7%    |

**Table 6. Rates of Knowledge and Attitude among Hookah Users in 2017 compared to 2009**

| Characteristics                                | 2009 % | 2017 % | Characteristics  | 2009 % | 2017 % |
|--|--------|--------|--|--------|--------|
| Reasons for smoking hookah                     |        |        | Do you think smoking hookah is safer than cigarette?       |        |        |
| Socialize with family and friends              | 55%    | 73.9%  | Yes  | 22.3%  | 18%    |
| Loneliness                                     | 5.4%   | 14.6%  | No   | 56%    | 64.3%  |
| Relieve Stress                                 | 16%    | 43.7%  | Do not Know  | 20.8%  | 15.1%  |
| Taste  | 18%    | 47.9%  |  |        |        |
| Do you think hookah is harmful to your health? |        |        | Do you think second hand smoke from the hookah is harmful? |        |        |
| Yes  | 78.5%  | 86.7%  | Yes  | 66.2%  | 77.4%  |
| No   | 8.1%   | 6.7%   | No   | 11%    | 8.3%   |
| Do not Know                                    | 12.3%  | 4.2%   | Do not Know  | 22.7%  | 11.9%  |



**Table 7.** Quitting behavior among current and former cigarette smokers

| Characteristics          | 2009 % | 2017 % |
|--------------------------|--------|--------|
| Quitting behavior        |        |        |
| Quit attempts            | 5.7%   | 39.4%  |
| Methods of quitting used |        |        |
| Counseling               | 0      | 4.2%   |
| Quitline                 | 0.1%   | 0.9%   |
| Quit classes             | 0.3%   | 2.5%   |
| Prescribed medications   | 0      | 2.3%   |
| OTC medications          | 1.4%   | 3.6%   |
| Cold turkey              | 3.9%   | 29.5%  |

**Table 8.** Frequency, Location, Flavored, Herbal and Using Delivery services among hookah users in 2017

| Frequency of hookah use                            | %     |
|--|-------|
| Daily  | 18.1% |
| Twice a week                                       | 28.4% |
| Weekly   | 31.6% |
| Twice monthly                                      | 12.1% |
| Monthly  | 7.2%  |
| Flavored tobacco                                   |       |
| Used flavored tobacco                              | 91.2% |
| Used non flavored tobacco                          | 3.4%  |
| Tobacco vs Herbal                                  |       |
| Used tobacco                                       | 93.8% |
| Used Herbal  | 6.2%  |
| Used Delivery services for hookah.                 |       |
| Yes  | 31.9% |
| No   | 67.9% |
| Location of Using Hookah                           |       |
| Mainly at home (and other locations)               | 50.4% |
| Mainly at hookah Lounge (and other locations)      | 40.4% |
| Mainly at restaurant/Café (and other locations)    | 9.2%  |
| Mainly at cultural clubs (and other locations)     | 4.5%  |
| Mainly near college campuses (and other locations) | 1%    |

## Understanding Substance Use among Arab Americans: A Community Assessment

*Mona Abdallah-Hijazi, Kaston D. Anderson-Carpenter, Jennifer A. Gruber, Danielle Chiaramonte, and Paige E. Haight*

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### Abstract

Substance use is a significant health-related problem affecting diverse communities globally. Among Arab Americans, opioid and heroin use are especially problematic. However, full impact of these substances on the community is unknown. Given the current limitations in the existing scientific literature, the present study has two main research questions: (1) How do Arab Americans perceive the impact of opioid and heroin use in their community? (2) What barriers and assets to substance abuse treatment and prevention exist in the Arab American community? The community-academic partnership used the ecological systems theory and a community-based participatory research approach to develop and implement a community assessment in Dearborn and Dearborn Heights, Michigan. This geographical area has one of the highest concentrations of individuals with Arab ancestry in North America. Data collection methods included surveys, focus groups, town hall meetings, and 45-60-minute semi-structured interviews with representatives across multiple community sectors such as police departments, schools, and pharmacies. Community participants identified multiple barriers and facilitators of heroin and opioid use in the community, such as cultural stereotypes, stigma, and opportunities for expanding existing services. Facilitating multisectoral collaborations with an ecological perspective can create social conditions that empower Arab Americans to support community-level changes in reducing substance abuse disparities and promote community health equity.

### Introduction

According to the United States Department of Health and Human Services ([DHHS], 2016) and the National Institute on Drug Abuse ([NIDA], 2018), heroin and opioid use have become a public health crisis in the United States. Recent prevalence data indicate that across the United States, 61% of substance use related deaths were related to opioid or heroin overdoses (Rudd, Aleshire, Zibbell, & Gladden, 2016), contributing to a daily mortality of approximately 115 individuals (Centers for Disease Control and Prevention [CDC], 2017). As recent as 2016, the greatest contributor to opioid-related deaths has been synthetic opioids (e.g., fentanyl, tramadol) with more than 6 deaths per 100,000 people, with heroin and commonly prescribed opioids contributing to about 5 deaths per 100,000 people (CDC, 2017).

In addition to contributing to years of potential life lost, opioid use places a substantial burden on the U.S. economic system. The total economic burden is estimated to be \$78.5 billion, of which more than \$19.6 billion is related to health care, substance use treatment, and criminal

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justice expenditures (Florence, Luo, Xu, & Zhou, 2016). To address the systemic and ecological burden of opioid and heroin use, the DHHS has developed a five-point strategy: (a) better prevention, treatment, and recovery services; (b) better data; (c) better pain management; (d) better availability of overdose-reversing drugs; and (e) better research (Department of Health and Human Services [DHHS], 2018). Collectively, these strategies present a comprehensive plan to empower local communities to develop assessment methods, programs, and evaluation mechanisms to monitor and eradicate the epidemic.

Although epidemiological data related to opioid and heroin use are abundant in the scientific literature, far less is known about these outcomes within the Arab American communities. One limitation is the estimated population discrepancies that exist for Arab Americans. Whereas the American Community Survey has estimated the Arab American population at more than 1.7 million persons (U.S. Census, 2011), this is believed to be substantial underestimation. Other estimates suggest the estimate is almost 3.7 million individuals (Arab American Institute, 2018), indicating a 60% difference between the estimates. A second limitation is that since the *Dow v. United States* (1915) decision, the United States has categorized Arab Americans as White, further reinforcing whiteness as the legal and social standard for rights, privileges, and access to quality services. Over time, two limitations have provided substantial challenges in obtaining accurate population estimates for Arab Americans. Furthermore, these challenges are amplified during efforts of understanding the impact of public health crises in Arab American communities.

### *Substance Use among Arab Americans*

The increase in morbidity and mortality from substance use has caused serious alarm within the Arab American community (Arfken, Arnetz, Fakhouri, Ventimiglia, & Jamil, 2011; Hunter, 2016; Jamil, Niazy, Jamil, & Arnetz, 2016). Although substantial evidence exists of heroin and opioid use at the national level (CDC, 2017a; CDC, 2017b; DHHS, 2018; Rudd, Aleshire, Zibbel, & Gladden, 2016), very little epidemiological data exist about the prevalence and scope of use in the Arab American community. Two reasons may explain the lack of existing data. First, Arab Americans are often and mistakenly classified as Caucasian/White in national surveys. Second, because substance abuse and misuse is socially unacceptable in the Arab American community, opioid and heroin use may be largely underreported when such data are available. Therefore, much of the existing knowledge of the problem in the community is drawn from anecdotal evidence or first responders' reports of overdose rescues.

Given the lack of data, it is critical to conduct a community assessment to identify the prevalence of opioid and heroin use in the Arab American community, determine the barriers to linking individuals to existing services, and highlight the existing strengths and resources present in the community. The community assessment informs the community-academic partnership's efforts in serving the community's needs and promoting a drug-free community. In a related vein, the assessment will be the impetus of selecting, adapting, and testing evidence-based strategies through a culturally competent lens.

### *The Arab American Community in Wayne County, Michigan*

Over the past 40 years, a large number of immigrants migrated to the United States, settling primarily in New York, California, and Wayne County, Michigan. Currently, a substantial portion of Arab Americans are second- or third-generation immigrants, suggesting that their

parents or grandparents immigrated to the United States from one or more of the 22 Arab Nations. Although legal and cultural prohibitions in the Arab Nations exist regarding substance use, heroin and opioid use remains a growing concern among the Arab American community in Dearborn and Dearborn Heights, Michigan. Moreover, religious beliefs and traditions have contributed to a perception that alcohol and other drugs are not a problem in their community because these substances are religiously forbidden in the Quran.

## **Objectives**

Although substance use exists among Arab Americans (Arfken, Berry, & Owens, 2009; Jamil, Niazy, Jamil, & Arnetz, 2016), little is known about the epidemiology, level, and scope of opioid and heroin use in this population. Moreover, comprehensive, ecological frameworks have not been applied widely within the Arab American context to understand the influencing factors of substance use. Given the current gaps in research and practice, we aim to address two pertinent questions: (a) How do Arab Americans perceive the impact of opioid and heroin use in their community? and (b) What are the facilitating and inhibiting factors for substance use treatment and prevention within the Arab American community?

## **Methods**

### *Theoretical Approach*

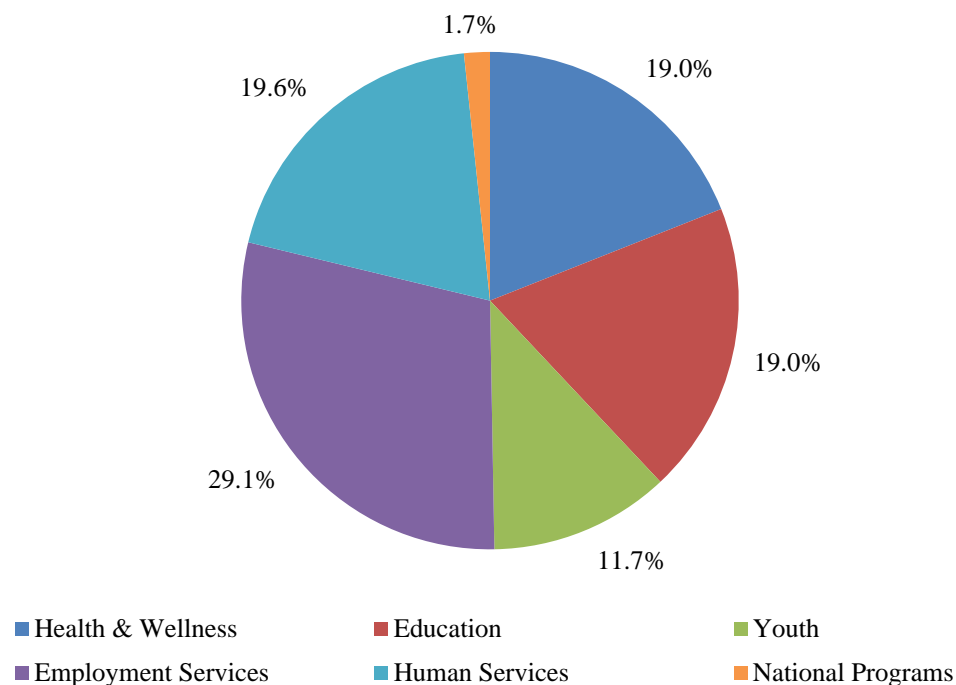
The community assessment is based on the ecological systems theory (EST) and the principles of community-based participatory research (CPBR). The EST (Bronfenbrenner, 1979, 1994) posits that individuals can be studied in the context of their social environment. Specifically, the EST, as proposed by Bronfenbrenner, describes individual behavior as *nested* within multiple levels of the social ecology. However, some scholars have argued that the EST is not necessarily nested, but rather comprises multiple *networks* of which individuals are members (Neal & Neal, 2013). According to the EST, for example, substance use affects not only the individual substance user, but also the user's family and friends. Moreover, an individual's substance use may directly or indirectly affect all sectors within a community. Inversely, policies, cultural expectations, and availability of substances play a substantial role in an individual's decision to use certain substances. As one of the most widely cited developmental models, the EST has been used to address socially important behaviors in myriad populations such as HIV (Berkley-Patton et al, 2010; Rhodes et al., 2011), substance use (Thomas, Donovan, Sigo, Austin, Alan Marlatt, & The Suquamish Tribe, 2009), and health care access (Christancho, Garces, Peters, & Mueller, 2008; Springgate et al., 2009).

In addition to using the EST, the assessment draws upon the principles of CBPR (Israel et al., 2010; Israel, Schulz, Parker, & Becker, 1998; Ward, Schulz, Israel, Rice, Martenies, & Markarian, 2018). The purpose of CBPR is to minimize the existing gaps between research and practice by actively engaging community partners and stakeholders as collaborators throughout the research process. This participatory approach has been shown to benefit both academic and community partners with respect to addressing mutually-defined problems and goals.

### *The Community-Academic Partnership*

The Arab Community Center for Economic and Social Services (ACCESS) is a community-based organization located in Dearborn, Michigan, dedicated to serving the needs of the

community since 1971. It is the largest Arab American community nonprofit organization in the United States, offering more than 120 programs in the metropolitan Detroit area. Among its many programs are substance abuse prevention, primary and specialty health care, youth development, adult literacy, and citizenship classes. ACCESS has a long history of working with academic partners. In the past, ACCESS and Michigan State University (MSU) have partnered successfully to address socially important issues in the community. Since 2010, ACCESS has worked extensively with coalitions and community organizations to address socially important problems. Figure 1 describes the types of services and programs provided by ACCESS to members of the broader community.



*Figure 1. Distribution of ACCESS Programs and Services (N = 179)*

The CBPR partnership began in July 2017 through the CBPR Partnership Academy. The partnership has held several meetings to identify priority projects and activities for partnership. Moreover, the academic partner (second author) leads a team of nine post-graduate, graduate, and undergraduate researchers whose research and advocacy are centered on promoting health equity in marginalized and disempowered communities and identifying processes that facilitate positive social and environmental changes in those communities.

#### *Implementation of the Community Assessment*

The currently ongoing community assessment draws from a mixed-method approach to understand the impact of heroin and opioid use on the community, as well as facilitating and inhibiting factors of opioid use within the community. Data for the community assessment include key informant interviews and focus groups, as well as archival data collection. The

archival data sources included the U. S. Census, the Michigan Profile for Healthy Youth (MiPHY) (Michigan Department of Education, 2017). Content analysis was used to analyze the qualitative data through Atlas.ti version 8.

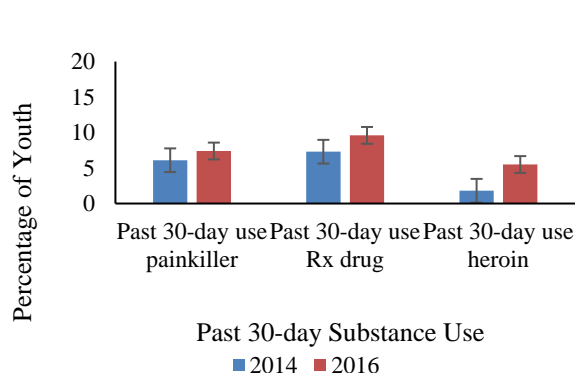
## Results

### *Community Socio-demographics*

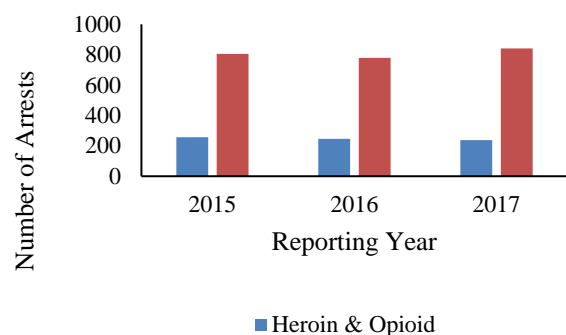
Recent estimates indicate that Dearborn, MI, has a population of 95,171 and Dearborn Heights, MI, has a population of 54,145, both representing approximately a 4% population decrease from 2010 (U.S. Census, 2018). Approximately 37.5% ( $n = 55,929$ ) of the Dearborn and Dearborn Heights area comprise self-identified Arab Americans, with 13.0% ( $n = 19,447$ ) of Arab Americans in the community living at or below the federal poverty line. The gender distribution is approximately equal (Male: 49%,  $n = 73,165$ ; Female: 51%,  $n = 76,151$ ). Across Dearborn and Dearborn Heights, 82.5% ( $n = 123,186$ ) of residents have at least a high school education, and 25.7% ( $n = 38,429$ ) have a bachelor's degree or higher.

### *Past 30-Day Youth Outcomes and Influencing Factors for Use*

Figure 2 shows 2014 and 2016 data for the percentage of youth using heroin and opioids in the past 30 days. Overall, there was a marked increase in opioid and heroin use over time, with the greatest increase occurring in past 30-day heroin use (1.8% versus 5.5% in 2014 and 2016, respectively). Moreover, more students reported misusing prescription drugs (16.9%), followed by painkillers (13.5%) and heroin (7.3%).



*Figure 2.* Past 30-day heroin and opioid use among youth, 2014 and 2016. Error bars show the 95% confidence interval.



*Figure 3.* Number of arrests for heroin, opioids, and other narcotics in Dearborn, MI, 2015-2017.

From 2015-2017, the trend for arrests in Dearborn, MI, for opioid and heroin use remained relatively stable, with a 7.3% decrease in arrests in 2017 compared to 2015 (Figure 3). Although the number of these arrests were substantially lower than those of all other narcotics, heroin and opioid related arrests accounted for 22.1% - 24.2% during the reporting period.

### *Influencing Factors of Opioid and Heroin Use in the Arab American Community*

Key informants have identified several barriers and areas of concern, including access to programs and treatment facilities, perceived cultural stereotypes, and stigma. Many key informants noted that obtaining services for opioid and heroin use was problematic, commenting

that there is no process to streamline access to treatment. One informant noted, *“It’s so much pressure to have to call an office and contact 10 people [to get a client into treatment]. Having a one-stop shop would be good.”* Not only have *“80% of the substance abuse and mental health treatment facilities closed”* in the community, but the existing services are widely perceived to be too expensive. Notably, one key informant remarked that she had a *“client whose family member told us, ‘If this is what I have to go through to get [the client] treatment, I’d rather [the client] stay on drugs.’”*

Perceived cultural stereotypes were cited as another barrier among key informants. More specifically, participants noted that *“battling outside assumptions,”* such as the stereotype that all Arab Americans adhere to the same religion and in the same manner. Moreover, participants perceived that non-Arab Americans are not cognizant of the fact that Arab Americans comprise multiple cultures (as opposed to one homogenous culture), because they represent each of the 22 Arab Nations. Key informants also perceived there were *“within-community assumptions”* that served as barriers to heroin and opioid treatment and prevention. For example, when discussing the confluence of religion and culture within the Arab American community, she said, *“There’s a difference between religion and culture. It’s about 10% religion and most of it is cultural.”* This statement exemplified the overall impression among participants that community members are conditioned from a young age that substance use is *haram*, and they desired for the community to become more informed and educated about the scientific evidence surrounding heroin and opioid use prevention and treatment.

Stigma was the most salient theme regarding barriers and challenges to treatment and prevention. Many key informants noted that maintaining a good reputation among community members was important. The fear of being stigmatized by other members in the community is exemplified by the fact that

*We’ve have people OD [overdose] and parents have put it out [in the newspaper] as passing away in their sleep. [They are] worried about not being good enough parents, [that] if they were more religious this wouldn’t have happened.*

A related concern is that family support to receive opioid and heroin use treatment can be increased. One of the challenges is that some parents fear the social repercussions of having a child receive treatment services. Furthermore, several key informants noted that often, community members *“don’t talk about these issues with [our] kids.”* It must be noted, however, that the perceived stigma of heroin and opioid use has far-reaching implications. For example, as one key informant noted,

*I think a barrier that is common, is – is this gonna follow us to our job, [or be] on our record, or if I go through therapy will I lose custody? There needs to be a real conversation about your rights and what will and will not happen to go through this process. [People] need to feel protected and be in a safe place.*

### *The Need for Culturally-Appropriate Programs*

Despite the challenges and barriers identified by key informants in the community, they also noted that culturally-appropriate efforts would be highly beneficial at the individual, family, and community levels. One of the most prominent areas was having counseling centers for individuals affected by substance use, particularly centers that are sensitive to the community culture. One opportunity posed by some key informants was the need for programs that are

gender-specific (e.g., women's Alcoholics Anonymous groups). This opportunity would not only aid in making community members more comfortable in obtaining needed services, but it would also maintain cultural sensitivity. Moreover, key informants noted that the community's efforts can borrow from other community sectors to address opioid and heroin use; as one key informant noted, *"There are so many youth groups and churches who have had this for such a long time. I think mosques should do the same thing."* Finally, participants noted opportunities to provide even greater services to community members, particularly in providing materials in English, Spanish, and Arabic. This opportunity is rooted in the community's readiness to bring about positive change and eradicate opioid and heroin use. As the key informants overwhelmingly noted, *"we don't accept what's happening, and we want to come to a solution. We have to find the right language, the right messages."*

## **Discussion**

This ongoing community assessment draws from EST and CBPR to understand the impact of opioid and heroin use in the Arab American context. The assessment relies heavily upon shared resources and expertise between the community and academic partners and uses both quantitative and qualitative methods to understand the level and scope of the issue. Although arrests for heroin and opioids are markedly lower relative to all other narcotics, youth have increasingly reported the use of opioids in the community of interest. Key informant interviews showed several barriers and opportunities for further community efforts, including destigmatizing opioid and heroin use, developing culturally-appropriate treatment centers and prevention programs, and mobilizing community sectors to address the issue at all ecological levels.

In addition, language barriers were perceived to influence community awareness and education regarding opioid and heroin use. Many of the existing resources and educational materials that address substance use are not available in Arabic, making it difficult for parents and other community members, who do not speak English, to access them and learn about the issue. In addition, cultural and religious stigmas serve as a barrier to accessing substance use disorder services among Arab Americans and may cause reluctance in participation and willingness to provide accurate personal information.

This work represents one of the first systematic assessments of heroin and opioid use among Arab Americans. As noted previously, one of the primary challenges in obtaining accurate epidemiological data is that Arab Americans have been considered White on federal and state surveys since the early 20<sup>th</sup> century (*Dow v. United States, 1915*). This ethnic aggregation has stymied much-needed efforts to understand not only the disparities that exist among Arab American populations, but also to highlight the unique strengths these populations possess. It must also be noted that our epidemiological data are limited in that it was impossible to obtain heroin and opioid use citation and arrest data specifically for Arab Americans. From an ethical and social justice perspective, the community sector representatives believed it would be better to have an imprecise estimate of heroin and opioid use among Arab Americans than to engage in racially/ethnically profiling community members based on their last names.

Future work in examining the impact of opioid and heroin use in the Arab American community will include using Photovoice, asset and resource mapping with geographic information system (GIS) mapping technology, and additional semi-structured interviews and



focus groups with community sector representatives. These results will be used to identify and culturally adapt strategies to address substance use and promote health equity in the Dearborn and Dearborn Heights, Michigan, community, with special attention to ecological dynamics such as stigma, discrimination, and acculturation experienced by community members. Moreover, we will implement the Community Readiness Survey to obtain quantitative measures for the community's readiness to support change. More broadly, the results from this and future studies can inform efforts in similar communities that provide services to, and benefit from the contributions of, Arab Americans.

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## **Exploring Cultural Factors Influencing Iraqi Immigrants' Views of Michigan Hazards Utilizing the PEN-3 Model**

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### **Abstract**

Communicating information during an emergency is a difficult task. In order to ensure the message is understood, the emergency response personnel need to understand the cultural makeup of their population. Each culture will have a different way they accept and digest information. Michigan has one of the largest populations of Arab immigrants outside the Middle East. Iraqi immigrants are the largest group. This study examines how Iraqi immigrants view five of the most common hazards in Michigan and what cultural factors influence these views. A qualitative survey instrument, based on the PEN-3 model, identified the cultural factors that influenced the views of common Michigan hazards. In-person interviews were conducted using this instrument with 84 immigrants from Iraq who lived in the United States 4 years or less. The results showed emergency information is not filtering to the Iraqi immigrant population. They find their emergency information from the Internet and would prefer to learn about emergency preparedness from in-person classes. They viewed snowstorms as the most exotic of the five most common Michigan hazards and language was the biggest barrier to learning about them. More information needs to reach Iraqi immigrants regarding unfamiliar hazards. Communicators should use Iraqi immigrants' experience with familiar hazards to identify effective ways of responding to this population. The results of this study may promote social change of more effective communication and saving lives in the future should an emergency occur in Michigan that affects Iraqi immigrants.

### **Introduction**

Cultural sensitivity is an important part of emergency preparedness and response (Federal Emergency Management Agency [FEMA], 2011). In the heat of an emergency, the messages need to go out quickly (Centers for Disease Control and Prevention [CDC], 2014). Cultural sensitivity means more than mere political correctness (FEMA, 2011). These messages need to be understood by all who hear them (CDC, 2011b). This means understanding the cultural makeup of the jurisdiction and tailoring the message to how it is best received with cultural sensitivity. Not doing so could cost lives and cause legal troubles for the jurisdiction (Sherry & Harkins, 2011).

Public health preparedness cooperative agreement funding has been around since 1999 (CDC, n.d.). In 2011 the Centers for Disease Control and Prevention switched to a capability-based structure (CDC, 2011a). There are 15 capabilities in total (CDC, 2011a). One capability,

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Emergency Public Information and Warning, focuses directly on communicating before, during, and after an emergency (CDC, 2011b). As part of this capability, one of the planning elements states, “Written plans should include a process and protocol to translate materials/resources for populations with limited language proficiency” (CDC, 2011b. p. 43). The document also specifies other specific populations that need to be reached as well (CDC, 2011b). While communicating with diverse populations is a requirement of public health preparedness funding, public health may not be reaching everyone that they can before, during and after an emergency.

Emergency response depends on the hazards that affect a local area. The definition from FEMA (1997) defines a hazard as “events or physical condition that has the potential to cause fatalities, injuries, property damage, infrastructure damage, agricultural loss, damage to the environment, interruption of business, or other types of harm or loss.” (p. xxv). Hazards are typically measured through items such as number of fatalities and the total cost of damages. It is important to determine which hazards are the most likely to occur in a particular location to determine where to focus emergency planning efforts.

### **Iraqi immigrants in Michigan.**

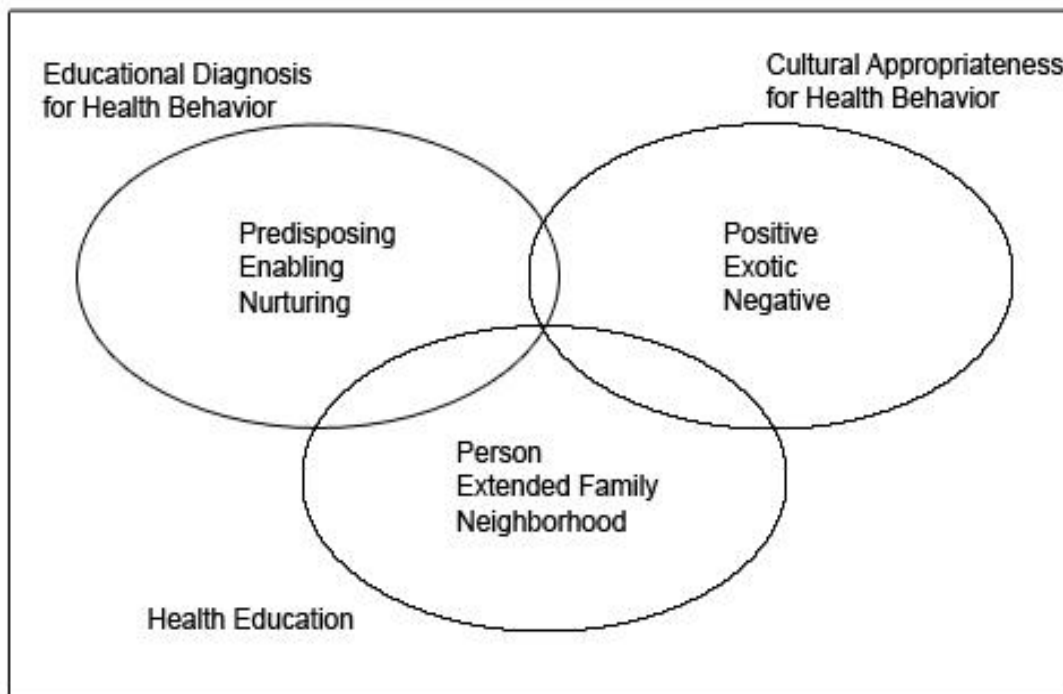
One of the major immigrant groups in Michigan is Arab Americans (Arab American Institute Foundation, 2015). The largest Arab immigrant group is from Iraq (Arab American Institute Foundation, 2015). What was missing from the literature on emergency preparedness in diverse communities was anything about Iraqi immigrants. In many parts of the United States, immigrants from the Middle East are a very small group. In states like Michigan the groups make up a sizable percentage of the overall population (Arab American Institute Foundation, 2015). The reason for not exploring this group in the literature is unclear; however, one reason may be social stigma due to the September 11, 2001 terrorist attacks (Rousseau, Hassan, Moreau, & Thombs, 2011; Schoeb, Weinstein, & Halpern, 2007). What is known about Iraqi immigrants is where they came from affected their experiences in the United States (Sirkecki, 2005). Conflict is not a new issue in the Middle East. For decades, cultural differences have given rise to conflict between cultures and nations (Sirkecki, 2005). Two waves of Iraqi immigrants in 1991 and 2003 were due to the 1991 Gulf War and the 2003 Iraq War (Sirkecki, 2005). Even though there are many immigrants who have made a home in the United States, there are distinctions that should be accounted for in immigrants from Iraq. One specific overarching distinction is no matter the education level, male or female, or how long an Iraqi immigrant has remained in the United States, traditional values are very important (Abdulahad, Delaney, & Brownlee, 2009). Religion is a place of comfort to Iraqi immigrants, thus is tied strongly to personal well-being (Schoeb, Weinstein, & Halpern, 2007).

There are also psychological factors that affect how an Iraqi immigrant’s views life in the United States. Psychological well-being is tied to whether or not the person is resilient (Arnetz, Rofa, Arnetz, Ventimiglia, & Jamil 2013). Resilience is greatly reduced if the person experienced violence in the home country prior to immigrating to the United States (Arnetz, Rofa, Arnetz, Ventimiglia, & Jamil 2013). Stress in Iraqi immigrant populations was also tied to how recently they immigrated to the United States (Jamil, Nasser-McMillan, & Lambert, 2007). While these are very important in the distinction of Iraqi immigrants, it does not address how this applies to hazards that they may face while living in the United States. Ignoring a specific group in the emergency preparedness planning process, whether intentionally or not, may produce legal

consequences that could cost the locality millions (Shelly & Harkins, 2011). As seen in previous disasters, not understanding the communication needs of a group could leave them vulnerable (Erwin et al., 2006).

### **PEN-3 Model.**

Many of the strategies for learning about a culture are based on a Western cultural mindset (Airhihenbuwa, 1990). Culturally-based health education for immigrants and refugees from countries that are non-Western, such as the Middle East or Africa requires a different strategy (Airhihenbuwa, 1990). Immigrating to a Western culture from a non-Western culture does not guarantee the person will adopt the new culture quickly (Airhihenbuwa, 1990). There are many models available for health education (Sørensen et al., 2012). Public health emergency preparedness is part of health education. Protecting one's health in an emergency is as important as learning about eating right and exercising. However, very few models take into account cultural factors that influence health education of diverse populations. Even fewer address non-Western health education. The only model that addresses health education of non-Western cultures is the PEN-3 model (Figure 1) (Airhihenbuwa, 1990).



**Figure 1.** PEN-3 model. From "A Conceptual Model for Culturally Appropriate Health Education Programs in Developing Countries," by C. O. Airhihenbuwa, 1990, *International Quarterly of Community Health Education*, 34, p. 55. Reprinted with permission.

The goal for the PEN-3 model is to ensure health education programs are culturally appropriate (Airhihenbuwa, 1990). The model has three domains and three factors per domain as seen in Figure 1. In the domain of Educational Diagnosis for Health Behavior there are three factors: Predisposing, Enabling, and Nurturing (Airhihenbuwa, 1990). Predisposing can be explained as perception (Airhihenbuwa, 1990). This is how people perceive the health behavior as it affects

them and their family. Enabling is equivalent to cultural peer pressure and actual or perceived resources (material or psychological) (Airhihenbuwa, 1990). These are the cultural influences that promote or discourage a health behavior. If being prepared for an emergency is part of the culture, for example living in a place that experiences frequent hurricanes, then that would be an enabler to personal preparedness. Nurturing is specific to family influences whether a spouse, children or extended family (Airhihenbuwa, 1990). The next domain is Health Education with the three factors being: Person, Extended Family and Neighborhood. Person is how the individual is influenced by a health behavior (Airhihenbuwa, 1990). Family is how the immediate family influences a health behavior (Airhihenbuwa, 1990). Neighborhood is how the community influences health behavior (Airhihenbuwa, 1990). The final domain is cultural appropriateness of health behavior with the three domains being: Positive Behavior, Exotic Behavior, and Negative Behavior. The positive behavior domain are the positive influences for health behavior (Airhihenbuwa, 1990). Exotic behavior are health behaviors that are viewed as unfamiliar (Sherry & Harkins, 2011). Finally, negative behavior are the negative acts that influence health (Airhihenbuwa, 1990).

Throughout the literature the PEN-3 model has been used to assess many types of health education issues (Airhihenbuwa, 1990). The PEN-3 model was originally developed to address creating HIV/AIDS education programs in Africa (Airhihenbuwa, 1990). Several studies in the literature use the PEN-3 model for this purpose (Airhihenbuwa et al., 2009; Brown et al., 2010; Okoror et al., 2007; Okoror et al., 2014). A few studies use the PEN-3 model for studying the African-American community in the United States (Cowdery et al., 2010; James, 2004; Purcell & Cutchen, 2013). Other uses of the PEN-3 model focus more on Latinos and Hispanics (Erwin et al., 2007; Erwin et al., 2010; Melancon et al., 2009; Saulsberry et al., 2013; Scarinci et al., 2012; White et al., 2012). While there are many studies that have used the PEN-3 model for all types of health education programs, none have been used for emergency preparedness. Emergency preparedness is not a traditional subject for health education. However, this does not make it less important to create programs to educate the public.

The importance of utilizing the PEN-3 model for health education regarding emergency preparedness in Michigan is great. Since the largest immigrant group in Michigan is a non-Western group, it is most important to use a model that is tailored to such a group. Understanding how culture influences the perception of emergency messaging is key to ensuring more lives are saved. In this study we used the PEN-3 model for health education, as applied to the topic of public health preparedness, to answer the research question: What cultural factors influence the views of Iraqi immigrants living in Sterling Heights and Dearborn, Michigan with regard to the top five hazards in Michigan? We chose Sterling Heights and Dearborn, Michigan because they are two areas with large concentrations of Iraqi immigrants (Arab American Institute Foundation, 2015).

The answer to this question will derive a community perspective that emergency management and preparedness professionals can use in emergency preparedness planning mainly for the purposes of emergency communication. However, it may also be used for other types of emergency planning. The objective was to discover themes that can help make overall emergency preparedness planning more culturally sensitive as it relates to the Iraqi community.

## Objectives

To discover themes that can help make overall emergency preparedness planning more culturally sensitive as it relates to the Iraqi community.

## Methods

The Michigan Hazard Analysis determined the top five hazards (Michigan State Police Emergency Management & Homeland Security Division, 2012). The top five hazards are: floods, tornadoes, power outages, pandemic influenza, and snowstorms (Michigan State Police Emergency Management & Homeland Security Division, 2012). This assessment ranks each hazard based on several factors. These factors include average annual events, deaths, injuries, and property damage; development trend effects, risk rating property, economic costs, infrastructure, and environment; and frequency as a top local hazard. Totaling all of these figures will give a hazard risk.

We collected the data from an in-person survey instrument. The survey instrument asked nine open-ended questions. The questions addressed each factor as part of the three domains in the PEN-3 model. This defined the cultural factors unique to Iraqi immigrants that influence their risk perception. The survey instrument measured each factor in the PEN-3 model in the following ways:

**Predisposing.** This factor was measured by asking participants how they thought their family members would handle an emergency if one happened today.

**Enablers.** This factor was measured by whether or not the participant took an emergency preparedness class.

**Nurturer.** This factor was measured by asking the participants if they thought their families had emergency preparedness information.

**Person.** The Person factor in this study sought how the individual finds emergency information.

**Extended Family.** Extended family factor was measured by asking the participants if they felt their family understood Michigan disasters.

**Neighborhood.** The question concerning neighborhood was worded to ask if the Iraqi community in Michigan was aware of Michigan disasters.

**Positive.** Positive factors for promoting understanding of disasters in Michigan were measured by asking what would help them learn more. More specifically we wanted to know what organizations they are familiar with that could provide help.

**Exotic.** To measure the exotic behaviors factor the interview question was framed in a way to ask about Michigan hazards that they felt were new to them. The goal was to find out what hazards they were unfamiliar with to inform emergency management and response personnel on where to focus outreach efforts. The hazards presented were: tornado, power outage, snowstorm, pandemic influenza, and flooding.

**Negative.** Negative influences to health behavior was translated to mean barriers to learning about hazards in Michigan.

We selected participants based on the following criteria: (a) living in the United States for four years or less, (b) an adult aged 18 or older, and (c) living in the Sterling Heights or Dearborn Michigan areas. The participants were selected at the Sterling Heights and Dearborn community health and research centers of the Arab Community Center for Economic and Social Services (ACCESS). They were recruited through classes, Women Infant and Children [WIC] clinics, and through case workers. All participants (n=84) were interviewed in person using a newly created survey instrument that measured cultural factors based on the PEN-3 model. The questions were open-ended to allow for detailed answers. Interviews were conducted in Arabic and English. All interviews were recorded and the English translation transcribed. The data were encoded via NVIVO version 10. Themes were based upon word frequency. This study was approved by the Walden University Institutional Review Board number 02-24-15-0071099.

## Results

### Demographics.

All interviews were conducted from March to November of 2015. Table 1 shows the study sample demographics. Most of the sample interviewed were 29-39 years old, female, and from Sterling Heights, Michigan. Of those interviewed, 58 were conducted in Arabic with the aid of an interpreter and 26 were in English. The average length of time living in the United States was 40.25 months, with the majority of the interviewees having lived in the United States from 36 to 48 months. Many interviewees had a high school diploma (37%) or a bachelor's degree (19%).

**Table 1**

| <b>Sample Demographics<sup>a</sup></b> |          |                  |          |
|--|----------|------------------|----------|
| <b>Age</b>                             |          | <b>Sex</b>       |          |
| 18-28                                  | 16 (19%) | Male             | 26 (31%) |
| 29-39                                  | 29 (35%) | Female           | 58 (69%) |
| 40-50                                  | 18 (28%) | <b>Location</b>  |          |
| 51-61                                  | 14 (17%) | Sterling Heights | 57 (68%) |
| 61+                                    | 7 (8%)   | Dearborn         | 27 (32%) |

*Note:* Data are based on surveys that were conducted March-November 2015. <sup>a</sup> **n = 84.**

Adapted from "A Concurrent Mixed Method Study Exploring Iraqi Immigrants' Views of Michigan Hazards," by K.L. Chamberlain, 2016. Adapted with permission.

The goal of the interviews was to learn how Iraqi culture influenced the interviewees' views of Michigan hazards. We use thematic analysis and deductive approach. Themes were organized by domain and further by factor.



## Emergent Themes

**Table 2**

### Emergent Themes per PEN-3 Model Domain and Factor

| Education Diagnosis for Health Behavior |                        |   |                        |   |                        |
|---|------------------------|---|------------------------|---|------------------------|
| Predisposing                            |                        | Enabling  |                        | Nurturing   |                        |
| Answer                                  | Number of interviewees | Answer  | Number of interviewees | Answer  | Number of Interviewees |
| Choose to stay home                     | 7                      | Did not take a class on emergency preparedness    | 68                     | Family does not have emergency preparedness information | 34                     |
| Protect themselves                      | 9                      | Yes, I have taken an emergency preparedness class | 15                     | Family has emergency preparedness information.          | 20                     |
| Evacuate                                | 7                      | Other   | 1                      | Not sure  | 3                      |
| Doesn't know                            | 13                     |   |                        | A little bit of information                             | 9                      |
| Other                                   | 48                     |   |                        | Only the children                                       | 6                      |
|   |                        |   |                        | Other   | 12                     |

*Note:* Data are based on surveys that were conducted March-November 2015.

<sup>a</sup>  $n = 84$ . Adapted from "A Concurrent Mixed Method Study Exploring Iraqi Immigrants' Views of Michigan Hazards," by K.L. Chamberlain, 2016. Adapted with permission.

Looking into the cultural factors that influence Iraqi immigrant's views of Michigan hazards, the first looking at the factors that are the most likely or unlikely to influence change. The most common themes regarding how to handle emergencies in general were: not knowing, evacuate, stay home, and protect themselves. The answers were a simple, "I don't know." or "I don't know how I would handle it." Some talked about evacuating. Most answers were not descriptive of how they would evacuate if an emergency occurred.

"They would go to a safe place."

"We would leave the house."

"We will go to the safest place to be."

There was one specific answer to this question that mentioned a power outage and what they would do.

“They would, it depends on what happened. Let’s see if electricity they would look at the place they could be away from any electrical outage and stuff like this. If it’s a water, they will try to run to a dry place. So they will try their best to use their thinking in order to prevent risk to themselves.”

Many talked about staying home, what is also known as sheltering in place. Most spoke as generally staying home.

“They will sit at home.”

“The best solution is to stay at home.”

“If you can keep inside, stay home, and prepare ourselves.”

One interviewee mentioned lighting candles.

“She will stay at home getting together, lighting some candles with her children. Preparing things like food and candles.”

In terms of protecting themselves, there were two types of answers. One talked about working with the authorities and the other said they would try to figure things out first. These answers were different than those that simply stated, “I don’t know” is that they would try to figure something out rather than give up. Protecting their family was the common thread throughout all of the answers. There was no talk of only protecting oneself, but protecting a family.

Societal structures may promote change or provide barriers. For emergencies, one way to categorize societal structures for change is classes or training about them. Emergency response agencies provide outreach by going to events or providing classes locally. The most common theme was not taking a class regarding emergency preparedness. Many simply answered “No.” to this question. There were a fair number of interviewees that said, “Yes”. Of those that did, some said they took a class overseas in Iraq or Jordan. Some took classes when they arrived in the United States. A few said they took classes in Michigan. One said they took a class in Georgia.

Families play an important part in influencing a family member’s views (Airhihenbuwa, 1990). Family members having emergency preparedness information, may influence their family to be more prepared. Most of the interviewees said their families did not have emergency preparedness information. Those who said they did not have emergency preparedness information did not elaborate on their answers. Some did say they did have this information, however, again did not elaborate. Others talked about knowing of disasters, but not how to deal with them.

“They know about such disasters, but they have a lot of information [sic] on what they should have on what they should have an emergency case.”

“They know disasters will occur but don’t have any information on how to deal with it.”  
There were a few interviewees that mentioned getting emergency preparedness information from schools. This may mean that the children bring back information they learn in school to their families.

**Table 3**

| <b>Health Education</b> |                        |   |                        |  |                        |
|-------------------------|------------------------|---|------------------------|--|------------------------|
| Person                  |                        | Extended Family   |                        | Neighborhood   |                        |
| Answer                  | Number of interviewees | Answer  | Number of interviewees | Answer   | Number of Interviewees |
| Internet                | 19                     | Family doesn't understand disasters in Michigan         | 30                     | The Iraqi community is not aware of disasters in Michigan              | 34                     |
| Television              | 26                     | Family understands a little about disasters in Michigan | 8                      | The Iraqi community is aware of disasters in Michigan                  | 24                     |
| Radio                   | 10                     | Family understands disasters in Michigan                | 34                     | I am not sure if the Iraqi community is aware of disasters in Michigan | 14                     |
| Word of Mouth           | 10                     | Other   | 12                     | Other  | 12                     |
| Other                   | 19                     |   |                        |  |                        |

*Note:* Data are based on surveys that were conducted March-November 2015.

<sup>a</sup> *n* = 84. Adapted from "A Concurrent Mixed Method Study Exploring Iraqi Immigrants' Views of Michigan Hazards," by K.L. Chamberlain, 2016. Adapted with permission.

Beyond the individual factor that influence the Iraqi immigrant's view of Michigan's hazards, there are specific factors that influence health education. While emergency preparedness may not frequently be seen through the lens of health education, there are similarities that make utilizing this model effective. Influencing the view of a hazard is how the individuals empower themselves, how their family empowers their learning of hazards and how their neighborhood influences their views. These factors can influence health-related behaviors as well as how a person views an emergency.

How the individual learns about hazards in Michigan fell in line with how your average person learns about emergencies that affect them (FEMA, 2016). Even though the Internet is a very popular way of gaining information, most of the interviewees said they learned about Michigan emergencies through television. A few mentioned specifically the Weather Channel. Most said, just television or the news. Where the interviews took place is in the metro Detroit

television market which is the largest in the state (Neilson, 2018). There is a wide variety of local television news stations available. Those who did mention the Internet as their source of information said their information was sourced from Google searches. Only a few mentioned social media sources, such as Facebook and YouTube. Radio and word of mouth were equal in influence. Those that mentioned word of mouth specifically mentioned hearing information from their family or neighborhood.

Extended family influence was more specific. The interviewees felt strongly either their family understood the hazards in Michigan or they did not. Those who said their family understood hazards in Michigan did not elaborate on their answers. Those who did elaborate said their family learned about Michigan hazards from their children's school, from the social services agency ACCESS, or from others in their neighborhood. Those who said their family did not understand Michigan hazards did not explain why they did not.

In the case of this study the neighborhood influence was not necessarily the neighborhood in which a person lives, but the Iraqi immigrant community as a whole. How much do individuals get their information on Michigan hazards from their cultural community? An equal number of interviewees said both the Iraqi immigrant community in Michigan understood and did not understand Michigan hazards. Many of those who did not feel the Iraqi immigrant community understood Michigan hazards was because they considered the hazards to be different than those in Iraq.

"No. We only have a good knowledge of sandstorms from the Middle East."

"No. Nature is completely different here."

"The newcomers, no."

"They don't know what to expect."

For those who said the Iraqi community understood Michigan hazards, they described how they distributed information. Some mentioned learning from the community that has lived in Michigan for some time. Others said the community learns from television, media or the news.

"Yes. It's not like before anymore. Always on the news looking for the weather and also on Internet. I do think they have this knowledge."

Those that weren't sure if the Iraqi community had knowledge of Michigan hazards mostly said there are some that are more knowledgeable than others. This points to there are some that seek out this knowledge and some that do not.

Finally, a deeper dive into more specific factors of cultural influences touches on positive and negative influences and things that are considered exotic. Positive factors were themes identified that help the new Iraqi immigrant learn about Michigan hazards. Negative factors were barriers identified by the interviewee. Exotic factors centered around the top five hazards in Michigan.

**Table 4**

| <b>Cultural Appropriateness for Health Behavior</b> |                        |                     |                        |                                   |                        |
|---|------------------------|---------------------|------------------------|-----------------------------------|------------------------|
| Positive  |                        | Exotic <sup>b</sup> |                        | Negative                          |                        |
| Answer  | Number of interviewees | Answer              | Number of interviewees | Answer                            | Number of Interviewees |
| Training  | 17                     | Snowstorm           | 41                     | Language                          | 21                     |
| Class   | 37                     | Tornado             | 29                     | Not sure                          | 12                     |
| Television  | 7                      | None                | 26                     | No barriers                       | 13                     |
| Printed Materials                                   | 7                      | Influenza           | 24                     | No classes                        | 5                      |
| Other   | 16                     | Flood               | 28                     | Disasters are different in the US | 6                      |
|   |                        | Power outage        | 3                      | Too busy                          | 5                      |
|   |                        |                     |                        | Lack of awareness                 | 9                      |
|   |                        |                     |                        | Other                             | 13                     |

*Note:* Data are based on surveys that were conducted March-November 2015.

<sup>a</sup>  $n = 84$ . Adapted from “A Concurrent Mixed Method Study Exploring Iraqi Immigrants’ Views of Michigan Hazards,” by K.L. Chamberlain, 2016. Adapted with permission.

<sup>b</sup> Participants could choose more than one hazard.

For positive factors most said that a training or class would help to learn about hazards in Michigan. Several mentioned that a class on emergency preparedness would be helpful during the intake process for new immigrants. Some said having the class available at social services organizations such as ACCESS would be helpful. Others specifically mentioned first aid as something they would find helpful to learn about. Lectures and presentations were the preferred methods identified as the most helpful mode for relaying information.

As for barriers identified, the main barrier noted was language. With the majority of the interviews taking place in Arabic as opposed to English, the language barrier was present. Most said it would be easier to learn if they understood the language better. One person specifically mentioned the issue of interpretation.

“Language. Translation or interpretation is not always great for getting the point across.” There were others that said there were no barriers to learning. The majority said there are enough ways to get information available that makes learning easier. One person mentioned having seen more disasters in her life than this.

“I don’t think there are any barriers. I’ve seen more disasters than this.” Many said that things are different in the United States than in Iraq.

“I don’t see the same things at home [Iraq]. They are not the same.”

“The snowstorms, floods. It’s very hard for us.”

“I didn’t know about these things when we came.”

In terms of what types of hazards are exotic to the Iraqi immigrant living in Michigan, they had a choice of the top five hazard. The interviewee could pick more than one from the list of flooding, tornado, power outage, pandemic influenza and snowstorm. Almost half of the participants listed a snowstorm as the most unfamiliar hazards. The next most unfamiliar was the tornado followed by flooding and influenza. Over a quarter of the interviewees said none of the five hazards was unfamiliar.

### **Analysis.**

The PEN-3 model was used to identify cultural factors that influence Iraqi immigrants’ view of hazards in Michigan. One of the main observations is the emergency information is not getting to the people who need it. The responses to questions in the Cultural Appropriateness for Health Behavior and Educational Diagnosis for Health Behavior domains showed that most individuals felt their families and communities did not have the necessary information to prepare. However, it was found that families were aware of disasters in Michigan. This may be because emergencies are broadcast through mass media such that there is a basic level of awareness about them, but what to do to protect individuals and their families is not clear to them.

It was not surprising to find the Internet being the main mode of gathering information about hazards in Michigan. When the interviews were conducted in 2015, the Internet had become a primary source of information (Mitchell & Holcomb, 2016). Even if individuals did not have Internet service in their residences, it was likely they had access through a smart phone (Mitchell & Holcomb, 2016). These data showed that posting information to the Internet is valuable because many people will get their information there. This does not exclude the use of traditional media sources to push information out to the public. Many of the participants also received information through traditional media sources which include radio and television. While gathering information from the television was not unusual, using radio as a source of information was. Traditional AM/FM radio reaches 91% of the population in the United States, however, more people are using the Internet as a radio source (Levac et al., 2012). Since language was found to be barrier to learning, it may be necessary to utilize the Arabic language radio stations in the Detroit area and programs designed for Arabic speakers on others as another source of emergency information.

Along with using Arabic language media to communicate emergency information, having different methods to convey the information in Arabic will be necessary. One of the ways that is currently used is posting translated fact sheets to a website. This assumes the translation is correct and the person reading the information is literate. Another way to mitigate the language barrier during emergencies is to plan ahead to use community members for assistance

Another format for helping Iraqi immigrants learn about hazards in Michigan is through classes. The majority of participants said they would prefer classes to learn. Since the participants in this study were recruited at ACCESS, the preference for classes may be influenced by location. One of the main services that ACCESS provides to new Arab immigrants and refugees is classes where they can learn about living in the United States. ACCESS regularly provides classes on English as a second language, citizenship, and health issues. This may have influenced the answers since many new Arab immigrants and refugees seek out ACCESS for assistance. Even with the possible bias due to location, it would be worthwhile to seek out the agencies that the

immigrant population turns to the most for a way to better communicate emergency information.

What makes something exotic is a matter of perception. What is normal to one person may be exotic to another. In the case of this group of Iraqi immigrants something that is very common in Michigan, a snowstorm, is an exotic event to them. When considering presenting information to an immigrant group, finding out what they are used to in their home environment will help direct what hazards to educate on. Many of the participants in this study felt snowstorms were exotic whereas power outages were not mentioned at all.

## **Discussion**

Cultural adaptation may be slower among Iraqi immigrants in Michigan to life in the United States. The bulk of the interviewees have been living in the United States for over three years. The answers to many of the questions suggest it takes much longer to adapt to Michigan hazards. Snowstorms are still considered exotic even for immigrants who have lived in the United States for over three years. It may be prudent to work with the community on learning about snowstorms to help them understand. To ensure the learning is taking place it might be good to measure before and after a training session to see if their outlook on snowstorms has changed.

One of the limitations to this study was in the survey tool used to interview the participants. All of the questions were written as open-ended. Some of the questions only yielded a very short answer. The question that only received a short answer will need to be amended to move away from a short answer. Regardless, performing this study as an interview rather than an online survey we were able to elicit more information beyond the questions asked. Several of the participants talked about their lives and gave insight into the culture.

Another limitation is generalizability. This study shows the cultural beliefs of one sample of Iraqi immigrants from Michigan. The data collected may not apply to Iraqi immigrant populations in other states. Iraqi immigrants from other states are living within different environments due to where they live. This study will need to be performed in other Iraqi immigrant populations around the country to test generalizability.

### **Public Health Implications.**

Preparing for emergencies is a tough sell to most people (Levac et al., 2012). It is an even tougher sell to immigrant populations who are more concerned with settling in their new environment than with possible emergencies. However, because new immigrants and refugees have so much to lose, it is important to ensure they are prepared as well. Cooperative agreement guidance from the Centers for Disease Control has many of its 15 capabilities with requirements to reach out to diverse populations beyond Emergency Public Information and Warning (CDC, n.d.). This study provides a way to reach out to immigrant and refugee groups in a jurisdiction.

We recommend that the communication pathway be more than one way. In the case of the power outage being the least exotic hazard to Iraqi immigrants, there may be a learning opportunity for public health. Allowing the immigrant population to teach public health workers about hazards they are more familiar with could be a means for building communication bridges. This may lead to building programs that are sustainable well into the future. Beyond this the overall goal of saving lives by ensuring emergency plans are more inclusive. While this study has implications for public health, it also has implications for emergency management.

Another recommendation is to include diverse populations in the planning process. A term first coined in 1998 says, "Nothing about us without us." (Charlton, 1998. pg. 3 para. 2). If

there are plans that need to address diverse populations, a representative needs to be part of the process. Collecting data on beliefs is good, but in order to address the needs of the population properly the population representative will be able to assist in the planning process.

The goal of this qualitative study was to measure the cultural factors that influence the perception of Iraqi immigrants of five top hazards in Michigan. These cultural factors are important to the emergency planning process. What is exotic to an Iraqi immigrant living in Michigan is different from the rest of the population. The country where the immigrant traveled from may have different emergency situations than Michigan. Even if the immigrant has been living in the United States for some time, it doesn't guarantee he received the emergency information that is meant for everyone. One hope is this study promotes other jurisdictions to dive deeper into the diverse populations in their area.

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## Task-Shifting Approaches to Refugee Mental Health in the Middle East: Literature Review

*Zaineb Alattar and Carlos F. Mendes de Leon*

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### Abstract

**Background:** Ongoing conflict in Syria has produced the largest refugee crisis in decades, the majority fleeing to neighboring low- and middle-income countries (LMICs) in the Middle East and North Africa (MENA). Exposure to war, displacement, loss of loved ones, and discrimination places refugees at heightened risk of developing mental disorders. However, the lack of mental health professionals in refugees' host countries poses a challenge to meeting the mental health needs of this population. To work around these capacity constraints, many LMICs around the world have adopted a task-shifting model of care delivery, relying increasingly on community health workers (CHWs), or non-specialist health care providers.

**Objectives:** The purpose of this literature review is to explore the value of a task-shifting model of mental health care delivery for use with refugees in the MENA region. We first provide an overview of key mental health issues faced by this population and follow with a discussion of different types of CHW-delivered mental health interventions that have been evaluated among survivors of systematic violence in the region.

**Methods:** A literature search was conducted in May – July 2017 to identify quantitative and qualitative studies that report mental health needs of refugees in the MENA region and that evaluate, or describe the adaptation of, mental health programs that use a task-shifting approach in these populations. For the latter, we expanded our search to include studies implemented with survivors of systematic violence more broadly, due to the limited availability of literature evaluating programs specific to refugees.

**Results:** Ten publications evaluating mental health needs of refugees and CHW-delivered mental health programs in the MENA region were inventoried over a three-month period. The most prevalent mental disorders were depression (27% on average, ranging from 8% to 44%) and post-traumatic stress disorder (PTSD) (25% on average, ranging from 2% to 38%). These findings came from Syrian, Kurdish, and Palestinian refugees in four countries: Lebanon, Iraq, Jordan, and Turkey. CHW-delivered mental health programs were found to be effective at reducing symptoms of depression, anxiety, dysfunction, and PTSD among adult survivors of torture and violence in Iraq. Interventions incorporated Cognitive Processing Therapy, Behavioral Activation Treatment for Depression, Common Elements Treatment Approach, and trauma-informed supportive counseling.

**Conclusions:** High rates of depression and PTSD have been found among refugee populations in the MENA region. CHW-delivered mental health programs have been effective at reducing

adverse mental health outcomes among survivors of systematic violence in Iraq, the only country where such programs have been evaluated to the best of our knowledge. These positive findings point to the potential value of expanding training of CHWs in mental health care delivery to other parts of the MENA region. Therefore, future studies should evaluate programs that use a task-shifting approach in other countries where there are large refugee populations with significant mental health needs.

## **Background**

In the past eight years, the Middle East and North Africa (MENA) have experienced ongoing armed conflict with civil wars occurring in Syria, Iraq, Yemen, and Libya. Millions have been caught in the cross-fire, displaced either internally or becoming refugees [1-4]. The situation in Syria represents the largest humanitarian and refugee crisis of our time [5], where in 2016, over half the population was displaced from their homes, including 6.3 million displaced internally and 5.5 million refugees [6]. As of 2017, Syrians represent the largest forcibly displaced population in the world, and account for nearly a third of refugees worldwide [7].

While many refugees and migrants have attempted to cross the Mediterranean Sea in hopes of finding refuge in the European Union, the majority have fled to neighboring low- and middle-income countries (LMICs) in the MENA region [7]. In the first half of 2016, over half of refugees were escaping violence in Syria [8]. As of 2017, the primary hosts of Syrian refugees are Turkey (3.4 million), Lebanon (992,127), Jordan (653,031), Iraq (247,057), and Egypt (126,688) [9]. Relative to population size, Lebanon hosts the most refugees in the world, where they represent 1 in 6 of the population, followed by Jordan (1 in 14) and Turkey (1 in 23) [7]. In addition to the more recent influx of Syrian refugees, there are also significant populations of Palestinian refugees in Lebanon and Jordan, dating back to those historically displaced during the 1948 Arab-Israeli conflict as well as more recent refugees, including those who have fled the current conflict in Syria [10].

Exposure to traumatic events associated with living through war may place refugees at heightened risk of developing adverse mental health outcomes such as depression and post-traumatic stress [11, 12]. These pre-migration stressors can include experiencing or witnessing violence, torture, persecution based on religion or other social category, displacement, and loss of loved ones. Moreover, after migrating to their host country, refugees may be met with additional challenges such as difficulty accessing secure housing, employment, and health care, or experiencing discrimination and social isolation, which further impact mental health [11-14].

The lack of qualified mental health professionals in primary host countries poses a serious challenge to meeting the mental health needs refugees may face [15-17]. For example, Lebanon has just under 1 psychiatrist and 1.65 psychologists per 100,000 residents [18]. The deficit is even greater in Jordan where there are 0.51 psychiatrists and 0.27 psychologists per 100,000 and in Iraq where there are 0.37 psychiatrists and 0.09 psychologists per 100,000 [18].

In response to the shortage of mental health professionals, several MENA countries, such as Iraq, Lebanon, Jordan, and Egypt, have begun efforts to integrate mental health services into primary health care and train health care staff to identify and manage mental health needs using the World Health Organization (WHO) Mental Health Gap Action Program (mhGAP) [15, 19-21]. Developed to help meet the global mental health burden, mhGAP provides a framework for

mental health care in non-specialized health care settings where there is high need and low capacity [22]. This can involve training community health workers (CHWs) or non-specialized health workers like nurses, social workers, or even trusted members of the community, to deliver psychosocial interventions while specialized professionals take on a more supervisory role [22]. Task-shifting models of care delivery have been implemented in many LMICs around the world such as Pakistan, Kenya, and Brazil to address a variety of health issues from maternal and child health to HIV and mental health [23]. By distributing responsibility across more abundant, less specialized health workers, this model of care increases health care coverage and makes more efficient use of human resources that are already available [24].

The purpose of this literature review is to explore the value of a task-shifting model to enhance capacity in mental health care delivery for refugees in the MENA region. First, we provide an overview of the peer-reviewed literature on refugee mental health needs in MENA, and then we discuss the literature on CHW-delivered mental health programs in these populations.

## **Methods**

### **Data sources and search strategy**

A literature search was conducted in May to July 2017 to identify quantitative and qualitative studies that (1) report mental health needs of refugees in the MENA region, or that (2) evaluate, or describe the adaptation of, specific mental health programs delivered by CHWs in these populations. CHWs could include any non-specialized health worker or lay worker trained to deliver a psychosocial health intervention. Six electronic databases and search engines were used, including PubMed, PsycInfo, Google Scholar, Web of Science, ProQuest, and JSTOR. To identify eligible studies, search terms included 'refugee,' 'mental health,' 'post-traumatic stress,' 'depression,' 'Arab,' 'task shifting,' 'community health worker,' 'community mental health worker,' 'lay health worker,' 'lay counselor,' 'Middle East,' 'North Africa,' as well as names of each MENA country. We also reached out to colleagues communicating with or affiliated with non-governmental organizations (NGOs) that serve refugees in the MENA region for direction to further potentially relevant studies (see acknowledgments).

### **Study selection**

Abstracts of the identified literature were screened for potential eligibility and full-texts of those deemed potentially relevant were reviewed. Relevant references cited in the identified studies were also reviewed. Studies were included in the literature review if they met the following eligibility criteria: the study was (1) conducted in the MENA region, (2) published from 2012 to July 2017, (3) written in English, and either (4) (a) assessed mental health needs of refugees, or (b) evaluated, or described the adaptation of, CHW-delivered refugee mental health programs. We chose to look at studies published in the past five years to gain an understanding of current mental health needs and programs, following the recent conflicts in Syria, Iraq, and Yemen. Due to the limited availability of literature evaluating mental health programs specific to refugees, the search was expanded to include programs implemented with survivors of systematic violence more broadly, still focused on the MENA region.

### **Data abstraction and synthesis**

Following study selection, the full-texts of included studies were reviewed again to compile any relevant data on mental health needs and program impact or adaptation. Specifically, among

studies reporting mental health needs, information regarding sample characteristics, study design, survey instruments, and point prevalence of mental health outcomes was extracted. Among studies examining mental health programs, data was extracted on intervention type, background and training of CHWs delivering the intervention, characteristics of study participants receiving the intervention, study design, survey instruments, and intervention impact on mental health outcomes. All retrieved data was tabulated to estimate the prevalence of mental health outcomes among refugees across MENA and to identify patterns in intervention characteristics and compare their effectiveness.

## **Results**

### **Overall search results**

Ten publications met the inclusion criteria and were included in the review. These consisted of six cross-sectional studies assessing mental health needs of refugees [25-30]. The remaining four publications included three randomized controlled trials (RCTs) evaluating the impact of CHW-delivered mental health programs in the MENA region [31-33], as well as one study describing the adaptation of one such program [34].

### **Part 1. Identification of mental health needs**

#### *Study setting and sample characteristics*

Among the six cross-sectional studies assessing the prevalence of mental health outcomes, three were conducted in Lebanon [25-27], while the remaining three were conducted in Jordan [28], Turkey [29], and the Kurdistan Region of Iraq [30]. All of the studies measured mental health needs among adult refugees, including five studies conducted with Syrian refugees [25, 26, 28-30] and one conducted with Palestinian refugees [27].

#### *Mental health outcomes*

The most prevalent mental disorders were depression (27% on average, ranging from 8% to 44%) and post-traumatic stress disorder (PTSD) (25% on average, ranging from 2% to 38%). More detailed descriptions of study findings are described below. Study characteristics and main findings are shown in Table 1.

Kazour et al. (2017) found a 27.2% point prevalence of PTSD in a sample of adult Syrian refugees living in camps in the Central Bekaa region of Lebanon ( $n = 452$ ). Lifetime prevalence of PTSD was 35.4% [25]. Mental health was evaluated using the Arabic validated Mini International Neuropsychiatric Interview (MINI).

Similarly, an earlier study by Alpak et al. (2015) also conducted among adult Syrian refugees, found a 33.5% prevalence of PTSD in a sample living in a tent city in Gaziantep, Turkey ( $n = 352$ ); 89% of cases were chronic, 9.3% were acute, 1.7% were late-onset, and 11.6% spontaneously remitted. PTSD was diagnosed through in-person interviews in Arabic with a fourth-year psychiatry resident using DSM-IV-TR criteria [29].

Another more recent study by Ibrahim & Hassan (2017) found a 38.46% point prevalence of PTSD in a sample of Syrian Kurdish refugees ( $n = 91$ ) in Arbat camp in the Sulaymaniyah Governorate of the Kurdistan region of Iraq. In this study, PTSD was diagnosed based on clinical cutoff scores for the Harvard Trauma Questionnaire, a self-report checklist that assesses PTSD symptoms, traumatic events, and torture. Like Alpak et al. (2014), the authors of this study found a

statistically significant positive correlation between experiencing traumatic events and PTSD symptoms [30].

The highest prevalence of depression among the studies in this review was 43.9% and came from Naja et al. (2016). The study was conducted with a sample of adult Syrian refugees registered with NGOs in Beirut and Mount Lebanon ( $n = 310$ ), using the MINI. Prevalence of current dysthymia was 4.5% [26].

**Table 1. Prevalence of Mental Health Outcomes of Refugees in the Middle East**

| Author (year)           | Country | Sample characteristics   |             |               | Mental health outcomes (Point prevalence) |                    |
|-------------------------|---------|--|-------------|---------------|---|--------------------|
|                         |         | Population   | Sample size | Mean age (SD) | % Depression                              | % PTSD             |
| Kazour et al. (2017)    | Lebanon | Adult Syrian refugees living in Central Bekaa camps                    | 452         | 35.08 (12.35) | NR  | 27.2 <sup>a</sup>  |
| Ibrahim & Hassan (2017) | Iraq    | Adult Syrian Kurdish refugees in Arbat Camp in Sulaymaniyah            | 91          | 29.91 (9.54)  | NR  | 38.46 <sup>b</sup> |
| Naja et al. (2016)      | Lebanon | Adult Syrian refugees registered with NGOs in Beirut and Mount Lebanon | 310         | NR            | 43.9 <sup>a</sup>                         | NR                 |
| Gammouh et al. (2015)   | Jordan  | Adult Syrian refugees attending Caritas centers in 6 Jordanian cities  | 765         | NR            | 29.5 <sup>c</sup>                         | NR                 |
| Alpak et al. (2015)     | Turkey  | Adult Syrian refugees in a Gaziantep camp                              | 352         | 37.58 (11.06) | NR  | 33.5 <sup>d</sup>  |
| Llosa et al. (2014)     | Lebanon | Adult Palestinian refugees in Burj el-Barajneh camp                    | 748         | 39 (15.8)     | 8.3 <sup>a</sup>                          | 2.2 <sup>a</sup>   |

Abbreviation: NR, Not reported.

<sup>a</sup> Measured using Mini International Neuropsychiatric Interview (MINI)

<sup>b</sup> Measured using Harvard Trauma Questionnaire (HTQ), Sections I, IV, V.

<sup>c</sup> Measured using Beck Depression Inventory (BDI-II).

<sup>d</sup> Measured using Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR)

According to findings from a study by Gammouh et al. (2015), depression was prevalent in 29.5% of a sample of adult Syrian refugees attending Caritas centers in six cities in Jordan ( $n = 765$ ). Depression was evaluated using the Arabic translation of the Beck Depression Inventory-II (BDI-II) in a self-administered questionnaire [28].

Relative to the other studies, Llosa et al. (2014) found a lower prevalence of current PTSD, which was detected in 2.2% of its sample ( $n = 748$ ), while depression was more prevalent at 8.3%. The study was conducted with adult Palestinian refugees living in the Burj el-Barajneh camp in Lebanon. Established in 1948 in a suburb of Beirut, the camp is home to a long-term refugee community. The authors hypothesized that the much longer duration of residence may account for the lower prevalence of PTSD and depression in this camp. Mental health outcomes were

diagnosed by a clinical psychologist using the MINI. While free mental health services are available to residents of the camp, the authors found a mental health treatment gap of 96%, which is remarkably higher than Lebanon's already high treatment gap of 51% [27].

## **Part 2. Identification of mental health programs**

### *Population served*

The second part of this review focuses on the results of mental health programs in refugee populations. The four studies that were identified were all conducted among adult Iraqi or Iraqi Kurdish survivors of systematic violence, defined as individuals who have experienced or witnessed torture or militant attacks. The programs were conducted in rural areas considered to be low-resource and generally high conflict. Three of the studies discussed programs administered in Duhok, Erbil, and Sulaymaniyah governorates of the northern Kurdistan Region of Iraq [31, 33, 34] and one evaluated a program administered in five cities across southern Iraq, including Basra, Nasiriyah, Hillah, Najaf, and Karbala [32].

### *Community health worker background*

CHWs were recruited from non-specialized health care staff at government primary care clinics. These included medics, nurses, physician assistants, pharmacy assistants, and pharmacists. All came from health care backgrounds; however, they had no specialized formal training, and little to no experience, in mental health or behavioral therapy. Prior to administering the mental health programs, a U.S. based NGO, Heartland Alliance International (HAI), provided general supportive counseling training to the CHWs as part of a larger initiative to incorporate mental health into Iraq's health care system. Developed at a paraprofessional level, the mental health curriculum covered the basics of the therapeutic relationship, confidentiality, active listening, empathy, assessment, treatment planning, psychoeducation, traumatic stress, suicide risk, and advocacy [31, 34]. This overarching project was carried out through 240 hours of in-person training and monthly field supervision by a psychiatrist over a two-year period [31].

### *Intervention-specific training*

The CHWs also received shorter, intervention-specific trainings as part of the studies identified in this review. The training programs ranged from one to two weeks in length and were led by U.S. based trainers with expertise in the intervention, in collaboration with local experts, HAI program staff, and physicians. In addition to CHW training, supervisors (consisting of local psychiatrists and psychologists) were also trained in the intervention and continued providing training and supervision to CHWs throughout the study periods. Several studies described using an apprenticeship model of training and supervision [32-34].

CHWs were trained to deliver interventions that incorporated a variety of psychotherapeutic approaches, with Cognitive Processing Therapy (CPT) being the most common across the four studies [32, 33]. This trauma-focused intervention centers on restructuring maladaptive beliefs and emotional processing of traumatic experiences. Another trauma-informed intervention identified in the review included a more general supportive counseling program [31]. Based on psychotherapies developed for trauma-affected populations, it provides survivors of trauma with a supportive environment to share their traumatic experiences while employing techniques like problem solving, stress management, relaxation, psychoeducation, and developing coping



strategies [31]. In contrast, Behavioral Activation Treatment for Depression (BATD) is not a trauma-focused intervention. CHWs in the Bolton et al. (2014) and Magidson et al. (2015) studies were trained to deliver a brief form of BATD, which aims to help the client plan and practice positive activities that reflect their values and goals [33, 34]. The final intervention identified in this review was Common Elements Treatment Approach (CETA), a transdiagnostic method that integrates techniques from other therapies, such as behavioral activation, psychoeducation, cognitive restructuring, and relaxation, in order to address a variety of mental health issues [32]. Most of the interventions lasted for twelve sessions [32-34], while one ranged from six to twelve sessions depending on the client's needs [31].

### *Intervention adaptation*

The study authors considered multiple factors in adapting the interventions for delivery by CHWs with survivors of systematic violence in low-resource areas of MENA. This included simplifying the intervention and training materials for the paraprofessional level in order to accommodate a task-shifting model of care delivery. Several of the studies also described adapting the intervention materials to accommodate lower literacy and education levels among the patient population [32-34]. For example, to facilitate behavior monitoring in BATD, Bolton et al. (2014) and Magidson et al. (2015) employed a sticker system in place of writing. Ensuring the interventions were culturally relevant was also a factor [33, 34]. Additionally, given the financial challenges facing the patient population, the BATD intervention also focused on helping patients identify low-cost activities [33, 34].

### *Study design*

Once adapted, the mental health interventions were evaluated in three RCTs [31-33]. Two of the studies evaluated multiple psychotherapeutic approaches to assess which CHW-administered methods were most effective at ameliorating mental health symptoms (Table 2). Bolton et al. (2014) conducted a three-arm trial, in which study participants were randomly assigned to either a BATD group, CPT group, or waitlist control (WLC) group; all three conditions were conducted at clinics in both Erbil and Sulaymaniyah in the northern Kurdistan region of Iraq [33]. In a two-arm study, conducted at two sites in parallel, Weiss et al. (2015) evaluated CETA and CPT relative to two separate WLC groups, with the CETA arm of the study carried out in the Karbala/Najaf area and the CPT arm further south in Basra/Nasiriyah [32]. The third RCT, by Bass et al. (2016), evaluated the impact of one intervention, the trauma-informed supportive counseling program, against WLCs in the northern city of Duhok [31]. Participants in the WLC condition in all three trials were contacted by their assigned CHW each month to assess their mental health symptoms and ensure their safety.

### *Study instruments*

Mental health assessments were administered before and after the interventions, to both the intervention and WLC groups. The primary outcomes in two of the RCTs were depression and dysfunction, with secondary outcomes of anxiety, post-traumatic stress (PTS), and traumatic grief [31, 33]. The third RCT assessed symptoms of trauma (primary outcome) and dysfunction (secondary outcome), as well as depression and anxiety [32].

All three trials used the same instruments to assess mental health. Depression and anxiety symptoms were measured using a locally validated version of the Hopkins Symptom Checklist for

Depression and Anxiety (HSCL-25) [31-33]. PTS or trauma symptoms were measured using a locally validated version of the Harvard Trauma Questionnaire (HTQ) [31-33]. Dysfunction was measured using locally developed scales that ask participants to rank their difficulty with carrying out regular activities [31-33]. Traumatic grief was assessed using the Inventory of Traumatic Grief [31, 33]. After administering the baseline and post-intervention assessments, the authors then calculated effect size estimates to compare changes in mental health symptoms between intervention and WLC groups.

### *Study findings*

Mental health effect size estimates from the RCTs are summarized in Table 2. We used the following frame of reference for effect size: 0.2 - 0.5: small; 0.5 - 0.8: medium; > 0.8: large [35]. The trauma-informed supportive counseling program had a statistically significant, moderate-sized effect on depression and dysfunction, and small effect on anxiety [31]. In the study by Bolton et al. (2014), BATD was found to have a statistically significant, large effect on depression, moderate-sized effect on PTS and traumatic grief, and small effect on anxiety [33]. The same study found CPT to have a statistically significant, moderate-sized effect on dysfunction, anxiety, PTS, and traumatic grief. In contrast, Weiss et al. (2015) found CPT to only have a statistically significant, small effect on trauma symptoms and depression [32]. However, the same study found CETA to have a statistically significant, large effect on all outcomes: trauma symptoms, dysfunction, depression, and anxiety.

**Table 2. Effectiveness of CHW-Delivered Mental Health Interventions in the Middle East**

| Author (year)        | Sample size | CHWs | Intervention type     | Mental health impact (Effect Estimate) <sup>a</sup> |                          |                      |                            |                              |
|----------------------|-------------|------|-----------------------|---|--------------------------|----------------------|----------------------------|------------------------------|
|                      |             |      |                       | Depression <sup>b</sup>                             | Dysfunction <sup>c</sup> | Anxiety <sup>b</sup> | PTS or Trauma <sup>d</sup> | Traumatic Grief <sup>e</sup> |
| Bass et al. (2016)   | 209         | 11   | Supportive counseling | 0.57*   | 0.53*                    | 0.41*                | 0.35                       | 0.26                         |
| Weiss et al. (2015)  | 342         | 29   | CETA                  | 1.82*   | 0.88*                    | 1.60*                | 2.40*                      | NR                           |
|                      |             |      | CPT                   | 0.40*   | 0.07                     | 0.27                 | 0.41*                      | NR                           |
| Bolton et al. (2014) | 281         | 20   | CPT                   | 0.44  | 0.63*                    | 0.59**               | 0.61**                     | 0.42*                        |
|                      |             |      | BATD                  | 0.84***   | 0.79***                  | 0.48*                | 0.56***                    | 0.69*                        |

Abbreviation: BATD, Behavioral Activation Treatment for Depression; CETA, Common Elements Treatment Approach; CHWs, Community Health Workers; CPT, Cognitive Processing Therapy; NR, Not reported; PTS, Post-traumatic stress; Trauma, Trauma symptoms.

<sup>a</sup> Measured using Cohen's d statistic and calculated with pooled baseline variances.

<sup>b</sup> Measured using Hopkins Symptom Checklist for Depression and Anxiety (HSCL-25).

<sup>c</sup> Measured using locally developed scale.

<sup>d</sup> Measured using Harvard Trauma Questionnaire (HTQ).

<sup>e</sup> Measured using Inventory of Traumatic Grief.

\*p<0.05, \*\*p<0.01, \*\*\*p<0.001

## Discussion

We conducted a review of the literature on refugee mental health outcomes in MENA and CHW-delivered task-shifting mental health programs that have been evaluated in the region. High rates of depression and PTSD have been found among refugee populations in the MENA region in the past five to ten years. Based on the studies identified in this review, prevalence of depression and PTSD among adults were recorded as high as 43.9% and 38.46%, respectively [26, 30], with an average of 27% and 25% [25-30]. Mental health needs were particularly prevalent among Syrian refugees who comprised most of the study samples in this review.

It was also apparent from the second half of our review that CHW-delivered task-shifting mental health programs have been effective at reducing adverse mental health outcomes among adult survivors of systematic violence in Iraq. All of the interventions had a statistically significant impact on at least half of measured mental health outcomes based on evidence from three RCTs [31-33]. CETA and BATD were found to be particularly effective interventions, associated with statistically significant, mostly large reductions in symptoms of depression, dysfunction, anxiety, PTS, trauma, and traumatic grief. While we found no such studies specifically targeting refugees, the findings are still valuable, particularly given that refugees tend themselves to be survivors of systematic violence.

An important pattern to note is that CHWs in these programs in the MENA region were already health care professionals prior to recruitment. This contrasts with many other task-shifting programs in LMICs outside the MENA region which often train members of the community with no health care experience as CHWs. For example, Lady Health Workers in India are members of the community with high school education, trained to provide preventive maternal and child health care [36]. Another example is the recruitment of volunteer CHWs with no prior formal health training in Kenya, trained in health promotion, prevention, identification of health problems, and some interventions such as referrals for medication [37].

There are a number of limitations to this review. First, this was an initial scoping review of the literature related to mental health issues in refugee populations. As a result, a more systematic review, including a search of the gray literature, might have identified additional studies relevant to the aims of this paper. Second, the mental health studies that were identified in this review were all conducted in Syrian and Palestinian refugees. Data is lacking on mental health needs of other refugee populations, such as refugees escaping civil war in Yemen, as well as refugees in North Africa. Additionally, all studies examining CHW-delivered mental health programs were conducted in Iraq. There is a need to evaluate these programs in other areas with large populations of refugees and survivors of systematic violence in the MENA region. Following the completion of this review, evaluations of such programs with other populations are being developed [38].

Despite the limited literature on task-shifting approaches to mental health in MENA, these positive findings point to the potential value of expanding training of CHWs in mental health care delivery to other parts of the region. At the time of this review, Iraq was the only country where such programs have been evaluated in the literature. Other nearby countries such as Lebanon are also moving towards integration of mental health into primary health care. However, there have yet to be studies evaluating the effectiveness of CHW-delivered programs in other parts of

the MENA region, to the best of our knowledge. Future studies should evaluate programs that use a task-shifting approach in other LMICs in MENA where there are large refugee and internally displaced populations with significant mental health needs.

## Conclusions

Research published in the past few years suggests that task-shifting, whereby CHWs are trained to deliver mental health interventions, may be an effective model to help meet mental health needs of refugees in the MENA region, amidst the shortage of mental health professionals. More systematic studies are needed to specify effectiveness of these programs across MENA and a broader array of mental health conditions. Thus far, this research has been concentrated on the Levante, however, studies evaluating task-shifting approaches to mental health care are urgently needed in other parts of the region such as Yemen and North Africa.

While the focus of this review is on health care, any efforts to address refugee mental health must also address more upstream social determinants of health and curb the conflicts that have contributed to the refugee crisis and produced decades of trauma in the MENA region.

Additionally, while refugees are more likely to be exposed to risk factors that make them more susceptible to adverse mental health outcomes, it is equally important to acknowledge their resilience and community assets that serve as protective factors [13]. Task-shifting approaches through CHWs may be an effective way to build capacity in refugee populations and pave the way for more sustainable solutions.

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## **LGBTQ Migrant Health Needs: a Case Study With Special Focus on Mental Health Services Provided at a Sexual Health Clinic in Stockholm**

***Calle Brunell***

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### **Abstract**

LGBTQ-migrants as a group has to a large extent been overlooked by academia, health services and civil society, and their experiences invalidated. The psychological treatments offered at a sexual health clinic in the outskirts of Stockholm includes both individual and group therapy interventions. At the centre of these interventions lies the challenge of exploring complex issues like sex, sexuality and identity within highly diversified cultural contexts. The strain put on queer migrants before, during and after migration are often multiple, complex and severe. Furthermore, the uncertainty of the asylum process as well as ongoing experiences of homo- and transphobia and racism in Sweden additionally complicates treatment of a potentially highly traumatized patient group. This is illustrated through the case of Niki.

### **Case introduction**

Stockholms Mansmottagning (Stockholms men's clinic) is a sexual health clinic situated in the outskirts of Stockholm offering both medical and psychological treatment primarily for men or transidentified peoples from migrant populations. The psychological treatments include both individual and group therapy interventions.

"Niki"<sup>1</sup> is a 40-year-old transgendered woman from Egypt, with an impeccable hairdo and a law degree from the American University in Cairo. As she walks into the clinic, she has been on Swedish soil for less than a month. She enters with a friend at either arm, heads high, as if they are going for a stroll around the lake. But as soon as she sits down, it is obvious she is in psychological trouble. Having left her job as a high-level manager at a Cairo-based shipping company, she now finds herself an asylum seeker, looking for refuge on the grounds of sexual orientation and trans identity.

Niki comes from stable middleclass background, her father a local businessman, her mother a teacher. She has two brothers, both older. Her family, she explains, means little to her now though, save her mom. Early on they were replaced with others, close friends she could rely on.

She presents with issues of post-traumatic stress reactions and depression. Assessment using clinical interview and The University of California at Los Angeles Posttraumatic Stress Disorder Reaction Index for DSM-5 (UCLA PTSD-RI) results in a PTSD-diagnosis, including some dissociative symptoms.

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A severe beating by her father when she was 15-years old put her into a two-week coma, since then she had suffered from crippling headaches. She had no history of alcohol or drug abuse. In this paper we will follow her treatment and see how her individual story reflects the general life circumstances of LGBTQ-migrants in Sweden.

### **Course of treatment**

#### *The world.*

Working with LGBTQ migrants forces one to look beyond the comfort of the clinic, and place ones patients in a wider political context. In all regions in the world LGBTQ peoples suffer discrimination, they are targets of abuse, physical and sexual violence and arbitrary detention (Carroll, 2016). Homophobia- and transphobia are global phenomenon, but they come in different strengths, some fierce some more moderate, depending on where you happen to be at. Migration is surrounded by many normative notions, and migrants are primarily portrayed as cis-gendered and heterosexual (Luibhéid, 2008). The journey is often described through established narratives: a catastrophe happens, a war, or a natural disaster, and the individual immediately flies to safety. But like many other LGBTQ-migrants, Niki's flight did not follow the expected routes (Jordan, 2009). Her journey to a new country entailed yearlong roamings across the borders of Europe and the Middle East.

#### *Home.*

And instead of a single catastrophe she reports a life characterized by violence. Abuse started at an early age: repeated verbal, physical, emotional and sexual assaults in her Cairo upbringing. Like with so many of my other patients, her family played a central part in the abuse. When harassment takes place at home, in school, in the religious community and at work the individual is left without professional support from healthcare- or juridical systems, nor can they find more informal emotional support amongst family and relatives (Alessi, Kahn, & Chatterji, 2016).

In therapy Niki explains that for her, the isolation and solitude has taken the worst toll, being alone with her pains and sufferings is far worse than the assaults themselves. Her body bear witness: scars from torture and abuse: "this is from when my father hit me with a hammer, this is from the police station in Istanbul, this from that time we will never ever talk about".

#### *Sweden.*

For those migrants that make it to Sweden many initially describe a sense of relief. The migration is finally over. But new difficulties arise, and old ones persistently remain. Navigating a new cultural context can be hazardous (APA, 2013). And asylum-seeking time is treacherous. During our therapy, Niki has to wait for more than a year for definitive decision concerning her asylum application. Meanwhile all dreams are suspended; the nightmares remain though. Life is put on hold, it centers around banalities, petty conflicts get extraordinary attention. "My life is far too precious", Niki complains, "to be left in the hands of strangers."

For transgendered migrants waiting for assessment and gender affirming care, this wait is even more excruciating.

Sweden is a country LGBTQ people tend to flee to, rather than from, but that does not mean it is a safe haven. In Sweden Niki, like so many other LGBTQ-migrants, has to face not only



trans- or homophobia, but also islamophobia and racism (Luibhéid, 2008; Cerezo, Quintero, Morales, & Rothman, 2014). Those with marginalized identities experience them simultaneously, the intersectional experience is always bigger than the sum of its parts (Munro et al., 2013).

Attacks come from many fronts. In Niki's asylum accommodation a man shows her a video of ISIS-fighters throwing a man off a tower, the man says it serves him right for being a homosexual. In the metro right wing activists threaten to push her off the platform.

"It connects the extremes it seems", Niki notes, "The solution to simply throw away that which is not allowed to exist".

### Treatment.

LGBTQ migrants' vulnerability before, during and after migration, the complexity of symptoms, the ongoing traumatization, and the exploration of such sensitive subjects as sexuality and gender identity calls for a widening of established therapeutical roles, and for flexible, integrative treatment models (Reading & Rubin, 2011).

At first Niki was suspicious of my psychological methods, for her mental illness was highly stigmatized (Socialstyrelsen, 2015). She fears she might go madder as a result of treatment, she doesn't. Other patients fear they might grow gayer, they might. Like many others Niki had endured harmful treatment from authorities, including health professionals, she had good reasons for her mistrust (Shidlo & Ahola, 2013). Creating a trustworthy alliance takes time.

Diagnostically many of the LGBTQ-patients in therapy at the sexual health clinic would meet the criteria of complex PTSD as defined in the upcoming ICD-11. The clinics treatments include both individual- and group interventions. Mostly, however, there is a focus on safety and stability. The asylum process is an ongoing trauma. The longer you stay in it, the worse you get (Schouler-Ocak, 2015; Cange, Brunell, Acarturk, Fouad, 2018). Niki has to be sheltered sufficiently from its effects. So, we create safe spaces, both in real life in collaboration with NGOs, health services and migration authorities, and symbolically in Niki's inner world.

### Exploring identity.

Niki had many traumatic experiences in the past, at times her reactions cripple her: nightmares, flashbacks, exaggerated blame, irritability, she had them all. But in therapy she wanted to focus on her trans identity. Her unexpressed feelings and unspeakable desires, what happened when she was finally able to verbalize them? Deep down her unlived life slowly began to stir.

In Egypt transgender as a concept had not existed, she told me. Niki had always felt different and suffered from fear of going mad as her gender dysphoria grew. She had no non-derogatory words in Arabic to describe her inner experiences and her identity. So, these remained hidden, and the friction took other pathways, into pathology (Qushua & Ostler, 2018). In therapy she could find new words and place her identity in a wider context. As a consequence, she transformed from a gay man into a trans woman within just a few months. It was like watching that sudden and delicate blossoming of cherry trees down by the opera house in May. After every session a scent of spring lingered in the corridors of the clinic throughout the afternoon. Patience was essential, Niki had to be given time to linger in ambiguity, to wander between identities before finally settling on one.

### Boundaries.

In treatment both patient and psychologist are steeped in powerful historical processes, and complex norm systems with century old roots. This can sometimes paralyze the therapy process, feelings of hopelessness and impotence are common (Blackwell, 2007). Collaborations with healthcare services and civil society helps me to regain hope. And reconnecting with caring others helps Niki to stop viewing the world as a predominantly hurtful, dangerous place.

### **Conclusion**

People like Niki, whose identity and sexuality defy established norms travel through a difficult physical, social and psychological terrain (Jordan, 2009). LGBTQ migrants are often overlooked, and their experiences annulled. Their particular vulnerability throughout migration and their, at times, great psychological suffering should lead to health care services, academia and migration authorities showing the group bigger concerns. Up until now, in Sweden at least, sadly this has yet to happen.

It is easy to get a dark picture of the life my patient lead. And it is true Niki face many hardships. But it is also true that I could have spent this entire paper focusing on the courage, the desire and determination, the hope that in many ways drive queer migration.

Niki had humble wishes, she just wanted to lead a safe life, she told me, to work and to love. That's all.

### **Notes**

<sup>1</sup> The identifying information has been changed to protect the identity of the case patient

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## Acceptability of a Multi-Media Healthcare Literacy Intervention among Arab American and Middle Eastern Communities

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### Abstract

**Introduction:** Uninsured rates have significantly declined in the U.S. However, historically marginalized racial/ethnic communities still comprise a large portion of those without insurance. As part of a community-based participatory research project in Southeast Michigan, we created a multi-media intervention (Insuring Good Health), comprised of a website with animated videos, aiming to improve health insurance navigation among diverse racial/ethnic communities.

**Objective:** Examine Arab American/Middle Eastern participants' perception of Insuring Good Health.

**Methods:** Participants (n=243) came from health centers in Southeast Michigan, including the Arab Community Center for Economic and Social Services (ACCESS) (n=60). Participants gave feedback on Insuring Good Health, including the format, language, most/least useful parts, and whether or not they intended to change a health or insurance behavior. Qualitative and quantitative data were analyzed and compared Arab American/Middle Eastern to non- Arab American/Middle Eastern participants.

**Results:** Among Arab American/Middle Eastern participants, the majority indicated the information they obtained from Insuring Good Health was useful to them. Compared to non-Arab American/Middle Eastern participants, fewer Arab American/Middle Eastern participants expressed an intention to change a health behavior. Most Arab American/Middle Eastern participants indicated that they liked Insuring Good Health and gave positive feedback on the Arabic language, organization, and content. They also expressed less favorability of the animation and characters embedded in the videos compared to non-Arab American/Middle Eastern participants.

**Discussion:** Insuring Good Health gave Arab American/Middle Eastern participants useful information about health insurance, but this did not always translate into an intention to change behaviors. More research is needed on the most effective ways to conduct insurance outreach to Arab American/Middle Eastern populations in order to create interventions that are more closely compatible with the population.

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## **Introduction**

The uninsured rate in the U.S. has dropped after the implementation of health insurance expansions under the Affordable Care Act (ACA); however, despite an overall increase in insurance coverage post-ACA, an estimated 28 million people still remain without insurance.<sup>1</sup> Although non-white racial/ethnic groups have experienced large gains in insurance coverage, disparities still persist and they continue to comprise the largest portion of the uninsured.<sup>1,2</sup> Health insurance coverage is closely tied to important health outcomes such as access to care, care utilization, chronic disease management, and mortality.<sup>3,4</sup> Increasing the number of people insured is an important part of a larger effort to increase health outcomes and reduce health disparities for diverse ethnic communities.

One way to increase insurance enrollment is through the use of enrollment assisters. The enrollment assister role (also known as patient navigator or certified application counselor) was created by the ACA to reach out to uninsured people and help them navigate expanded insurance options. Enrollment assisters provide a range of services to consumers from applying for health insurance to finding and utilizing a primary care provider. The complexity of ACA provisions can be confusing for consumers and limit their ability and desire to seek insurance<sup>5, 6</sup>. Use of enrollment assisters has been shown to be a successful strategy for helping consumers navigate the ACA.<sup>7</sup> Many federally qualified health centers and community health centers utilize multilingual enrollment assisters, but consumers are often unaware that they are available. In Southeast Michigan, the Arab Community Center for Economic and Social Services (ACCESS) in particular, has a large workforce of enrollment assisters.<sup>8</sup>

Arab American/Middle Eastern populations are not consistently identified in their own distinct racial/ethnic category, despite significant health disparities evident in these populations.<sup>9,10</sup> As a result of the lack of these justifiable data, few health education materials or interventions that are culturally and linguistically tailored to Arab American/Middle Eastern populations exist.<sup>11,12</sup>

We developed Insuring Good Health, a multi-media, multilingual (including Arabic) intervention designed to address health insurance literacy and navigation and connect consumers to enrollment assisters- especially in diverse racial/ethnic communities. The purpose of this study was to examine Arab American/Middle Eastern participants' perception of Insuring Good Health.

## **Objectives**

The objectives of this study were to: 1) assess the acceptability of Insuring Good Health for Arab American/Middle Eastern participants; 2) compare feedback from Arab American/Middle Eastern participants and non-Arab American/Middle Eastern participants, and 3) apply what we learned from this feedback to research and health education practice for Arab American/Middle Eastern populations.

## **Methods**

### **Study Design**

This study is a secondary, cross-sectional data analysis of baseline and acceptability data from a larger randomized controlled trial evaluating the effects of a multi-media health literacy intervention- Insuring Good Health- on health care navigation outcomes in racially and ethnically diverse adults in urban communities.<sup>13</sup> All study procedures were reviewed and approved by the University of Michigan Health Sciences and Behavioral Sciences Institutional Review Board.

### **Insuring Good Health**

Insuring Good Health is comprised of a website and a series of short videos that provides users with information on navigating health insurance and care ([www.insuringgoodhealth.org](http://www.insuringgoodhealth.org)). Using storytelling techniques and key messaging, the Insuring Good Health video series depicts superhero characters navigating health insurance/healthcare issues with the help of an enrollment assister. Insuring Good Health is available in English, Spanish, and Arabic. Description of the development of Insuring Good Health and the community-based participatory research partnership, Insure Detroit, is available elsewhere.<sup>14</sup>

### **Sample and Procedures**

The study sample was drawn from four local community health centers and federally qualified health centers. Participants were recruited and screened by phone and in-person, by research staff, for the following eligibility criteria: 1) between 18 and 64 years in age; 2) self-identified as non-white race; and 3) regular access to a telephone. By appointment at the location where they seek services, participants completed an informed consent and an interviewer-administered baseline questionnaire by trained research assistants. Participants also completed a survey of intervention acceptability following their engagement with Insuring Good Health. Interviews were conducted in either English, Spanish, or Arabic, based on the preference of the interviewee. Participants received modest monetary incentives for completing the interview.

Over the 6-month recruitment period (September 2016- February 2017), a total of 822 individuals were identified and assessed for eligibility. Individuals were excluded due to not meeting inclusion criteria (n=79), declining to participate (n=359) (common reasons: time, transportation, declined to state reason), and unreachable to complete consent (n=141). As a result, 243 individuals were successfully contacted, consented to participate, and provided baseline data. Of this group, 226 completed the acceptability survey.

### **Measures**

#### *Acceptability Survey*

The Intervention Evaluation Form and the Client Satisfaction Questionnaire (CSQ-8) were adapted to assess participants' perceptions of Insuring Good Health.<sup>15-16</sup> The survey included 13 open-ended items that inquired about participants' perceptions of the website, videos, and video language using questions such as: what did you find useful/not useful, what is the most important thing you learned, and what do you plan to change as a result of engaging with Insuring Good Health. The survey also included 16 items that assessed participants' feedback on the videos (6

items), video language (4 items), and website (6 items) using a 5-item Likert scale (1-strongly disagree to 5-strongly agree).

Demographic data were also obtained from participants, including age, sex, race, employment status, educational attainment, marital status, annual income, and health insurance status.

### **Data Analysis**

Data from the open-ended questions were translated and cross-checked for accuracy. NVivo10 software was used to sort and categorize the data into distinct themes. Quantitative data were analyzed in SAS 9.4. Chi-square tests were used to compare Arab American/Middle Eastern and non-Arab American/Middle Eastern responses. Alpha values less than 0.05 were considered significant.

## **Results**

### **Sample Characteristics**

Table 1 describes the study sample. Of the overall study sample, 24% identified as Arab American/Middle Eastern. The mean age of the Arab American/Middle Eastern participants was 39.7 (SD = 12.8) years, 68% were female, 77% reported being married, and 37% identified as being the head of their household. Sixty-six percent of Arab American/Middle Eastern participants were not in the work force, 52% reported an educational attainment of high school or less, and 59% reported an annual household income of less than \$20,000. Seventy-three percent had Medicaid insurance and 7% reported having no insurance. Seventy-percent reported being a non-citizen with residency status, and 58% reported a diagnosed chronic condition.

Significant differences in demographic characteristics were observed between Arab American/Middle Eastern and non-Arab American/Middle Eastern participants, with Arab American/Middle Eastern participants being younger ( $p < .01$ ), married ( $p < .001$ ), fewer being head of their household ( $p < .001$ ), having greater educational attainment ( $p < .001$ ), greater reports of non-citizen with residency status ( $p < .001$ ), and fewer reporting diagnosis of one or more chronic diseases ( $p < .01$ ) compared to non-Arab American/Middle Eastern/Middle Eastern participants.

### **Arab American/Middle Eastern Perceptions of Insuring Good Health**

Figure 1 shows differences in feedback on Insuring Good Health between Arab American/Middle Eastern and non-Arab American/Middle Eastern participants based on quantitative assessments. Compared to non-Arab American/Middle Eastern participants, more Arab American/Middle Eastern participants agreed that the website made them more interested in the topics ( $p < .01$ ). However, Arab American/Middle Eastern participants were less likely than non-Arab American/Middle Eastern participants to recommend the videos within Insuring Good Health to others ( $p < .01$ ).

Qualitative themes comparing Arab American/Middle Eastern and non-Arab American/Middle Eastern perceptions of Insuring Good Health are shown in Table 2. Four distinct themes emerged from Arab American/Middle Eastern participants' perceptions of Insuring Good Health: 1) Participants learned something they defined as useful or important; 2) Most

participants did not state an intention to change a health or insurance behavior; 3) Very few participants responded positively to the characters and animation; 4) Participants liked the language, format, and information presented.

*Theme 1: Participants learned something they defined as useful or important from Insuring Good Health*

When asked about the most important thing they learned from Insuring Good Health, Arab American/Middle Eastern participants mentioned information related to eligibility, coverage, and enrollment. One participant noted: “It shows you how to get health insurance and avoid high bills, and that immigrants are eligible for Medicaid.” They also mentioned learning about enrollment assisters and about the importance of health insurance for both their financial security and their health as reflected in this quote: “Health is important, and we need to have insurance.” Non-Arab American/Middle Eastern participants also identified learning useful information from Insuring Good Health.

*Theme 2: Most participants did not state an intention to change a health or insurance behavior after interacting with Insuring Good Health*

When asked if they would change anything after engaging with Insuring Good Health, the majority of Arab American/Middle Eastern participants said they had no intention to change a health or insurance behavior as reflected in this quote: “Do not plan on changing anything now.” Whereas, most non-Arab American/Middle Eastern participants *did* indicate an intention to change a health or insurance behavior after interacting with Insuring Good Health.

*Theme 3: Very few participants responded positively to the characters and animation*

When asked what the least useful part of the website and videos was, many Arab American/Middle Eastern participants commented on the characters and animation in Insuring Good Health. Most Arab American/Middle Eastern participants had a negative perception and believed the videos to be made for children rather than adults, as reflected in this quote: “I felt like it was for kids.” Several participants suggested using “real people” to make the videos more appropriate for them. Non-Arab American/Middle Eastern participants had mixed feelings regarding the characters and animation, providing both positive and negative feedback.

*Theme 4: Participants liked the language, format, and information presented in Insuring Good Health*

Most Arab American/Middle Eastern participants found the language, both spoken and written, to be clear and easily understood. They mentioned this for both English and Arabic languages. One participant stated: “It helped a lot that the videos were in my mother language.” Most Arab American/Middle Eastern participants expressed no issues with the layout and overall design of the website, finding it easy to navigate. They also liked how the information was straightforward, making complex health insurance information accessible to them as represented in this quote “The way the website was organized was very good. It was very simple.” Similarly, non-Arab American/Middle Eastern participants also liked the language, format, and information presented in Insuring Good Health.



## Discussion

We evaluated Arab American/Middle Eastern participants' perceptions of Insuring Good Health- a multi-media intervention focused on increasing awareness and confidence with health insurance navigation and care-seeking. We found that Arab American/Middle Eastern participants liked and learned something useful from Insuring Good Health, and also reflected that it made them more interested in learning about health insurance and care navigation. However, compared to non-Arab American/Middle Eastern participants, more Arab American/Middle Eastern community members did not state an intention to change a health or insurance behavior as a result of engaging with Insuring Good Health and they did not have favorable perceptions of the characters and animation.

Many of the Arab American/Middle Eastern participants in our study had residency status rather than U.S. citizenship. Several participants were refugees and/or recent immigrants to the U.S. Due to their limited time in the U.S., they may not yet be familiar with the U.S. healthcare system or feel comfortable using it. In addition to lack of familiarity, there is a documented lack of trust of the U.S. healthcare system and government institutions among Arab American/Middle Eastern populations due to heightened discrimination over the past 20 years.<sup>17-18</sup> Together this creates a complicated path to healthcare with a number of potential barriers faced by Arab American/Middle Eastern populations new to the U.S. These complications may prevent them from seeing the value of or seeking out insurance and healthcare services.

It is also possible that accessing healthcare was not a priority for Arab American/Middle Eastern participants in our study given that they reported better physical health compared to non- American/Middle Eastern participants. This may explain why they were less likely to report a behavior they would consider changing. Preventative health care use has been shown to be low among Arab American/Middle Eastern populations<sup>19</sup>, and more messaging may be needed to target beliefs around preventative care.

Although Insuring Good Health did not motivate self-reported behavior change in Arab American/Middle Eastern participants, they found it useful and liked it, especially when using the Arabic language option. The website and video components of Insuring Good Health were designed to be used by Arabic speakers. Quality of material translation and voiceover was prioritized in the design of the website and videos.<sup>14</sup> This makes Insuring Good Health unique as there is a documented lack of health insurance information available in the Arabic language in the U.S.<sup>17, 20</sup> In addition to positive feedback on the language, Arab American/Middle Eastern participants found the health and insurance information in Insuring Good Health to be valuable. Taken together, there is a desire for more Arabic-language healthcare education resources.

There are several limitations of this study that should be noted. Arab American/Middle Eastern participants in this study were all recruited from one social service agency in Wayne County and may not be representative of all Arab American/Middle Eastern populations in the United States. We also had a small sample size which limits generalizability. In order to reduce the burden on staff at our study sites, we relied on self-reported data. Data may be subject to social desirability bias. A more flexible qualitative component may have allowed us to glean more information from participants.

Despite these limitations, this work has implications for practice and research. Arab American/Middle Eastern participants found the content of the intervention useful and said the Arabic language option made it easier to understand, indicating a need for health insurance and health care information in the Arabic language. Insuring Good Health is, to our knowledge, the only health insurance literacy intervention available in Arabic and more could be developed. More research should be done to learn about the beliefs of Arab American/Middle Eastern populations about healthcare and insurance and the most effective ways to provide outreach information.

## **Acknowledgements**

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**Table 1. Demographic Characteristics of Study Population and Arab American/Middle Eastern Participants**

| <b>Factor</b>  | <b>Total Sample<br/>(n=243)<br/>% (N)</b> | <b>Non-Arab<br/>American/Middle<br/>Eastern<br/>(n=183), % (N)</b> | <b>Arab<br/>American/Middle<br/>Eastern<br/>(n= 60), % (N)</b> | <b>P-value</b> |
|--|---|--|--|----------------|
| <b>Age (mean (SD))</b>                               | 43.4(13.0)                                | 44.6(12.8)   | 39.7(12.8)   | 0.01           |
| <b>Sex (% female)</b>                                | 74.1(180)                                 | 76.0(139)  | 68.3(41)   | 0.24           |
| <b>Marital status (% married)</b>                    | 51.0(124)                                 | 42.6(78)   | 76.7(46)   | <0.0001        |
| <b>Head of household (% yes)</b>                     | 57.2(139)                                 | 63.9(117)  | 36.7(22)   | 0.0002         |
| <b>Educational Attainment</b>                        |   |  |  | <0.0001        |
| Less than High school/High school                    | 59.7(145)                                 | 62.3(114)  | 51.7(31)   |                |
| Vocational/some                                      | 27.2(66)                                  | 31.2(57)   | 15.0(9)  |                |
| College or above                                     | 13.2(32)                                  | 6.6(12)  | 33.3(20)   |                |
| <b>Employment status</b>                             |   |  |  | 0.34           |
| Full-time  | 23.4(56)                                  | 25.4(46)   | 17.2(10)   |                |
| Part-time  | 18.8(45)                                  | 19.3(35)   | 17.2(10)   |                |
| Not in the work force                                | 57.7(138)                                 | 55.3(100)  | 65.5(38)   |                |
| <b>Household Income</b>                              |   |  |  | 0.23           |
| <\$20,000  | 65.1(149)                                 | 67.3(115)  | 58.6(34)   |                |
| >\$20,001  | 34.9(80)                                  | 32.8(56)   | 41.4(24)   |                |
| <b>Insurance</b>                                     |   |  |  | 0.08           |
| Medicaid   | 68.3(166)                                 | 66.7(122)  | 73.3(44)   |                |
| Medicare   | 0.4(1)                                    | 0.6(1)   | 0(0)   |                |
| Private  | 3.7(9)                                    | 2.2(4)   | 8.3(5)   |                |
| Parent's private plan                                | 3.7(9)                                    | 3.8(7)   | 3.3(2)   |                |
| Employer plan  | 6.2(15)                                   | 5.5(10)  | 8.3(5)   |                |
| Other  | 0.4(1)                                    | 0.6(1)   | 0(0)   |                |
| No insurance   | 17.3 (42)                                 | 20.8(38)   | 6.7(4)   |                |
| <b>Residency status</b>                              |   |  |  | <0.0001        |
| Citizen  | 63.0(153)                                 | 73.8(135)  | 30.0(18)   |                |
| Non-citizen with residency status                    | 25.5(62)                                  | 10.9(20)   | 70.0(42)   |                |
| Other status/ not declared                           | 11.5(28)                                  | 15.3(28)   | 0(0)   |                |
| <b>Reports diagnosed chronic disease<br/>(% yes)</b> | 73.3(178)                                 | 78.1(143)  | 58.3(35)   | 0.0026         |

**Table 2. Acceptability Themes for Arab American/Middle Eastern and Non-Arab American/Middle Eastern Participants**

| <b>Arab American/Middle Eastern Participant Themes</b>  | <b>Arab American/Middle Eastern Participants' Illustrative Quotes</b>  | <b>Non-Arab American/Middle Eastern Participant Themes</b>   | <b>Non-Arab American/Middle Eastern Participants' Illustrative Quotes</b>   |
|---|--|--|---|
| Participants learned something they defined as useful or important from Insuring Good Health.   | <p>"That it is very important to have health insurance even if you feel that you don't need it."</p> <p>"It [Insuring Good Health] tells you what kind of documents you need to take with you when you visit a doctor for the first time."</p> | Participants learned something they defined as useful or important from Insuring Good Health.                                  | <p>"That there is help. There are advisors that will help you when you feel like you don't have the finances."</p> <p>"To understand what you're using with your insurance and the definitions. Knowing what is a deductible, copay, or co-insurance. To understand all of it."</p> |
| Majority of participants did not state an intention to change a health or insurance behavior after interacting with Insuring Good Health. | <p>"Nothing as of now."</p> <p>"There is nothing I plan to change."</p>  | Most participants indicated an intention to change a health or insurance behavior after interacting with Insuring Good Health. | <p>"I plan to look for other insurance opportunities."</p> <p>"I plan to ask more questions when I go to see my doctor."</p>  |
| Very few participants responded positively to the characters and animation.   | <p>"Too cartoonish"</p> <p>"Less animation"</p>  | Reactions to the characters and animation were varied, with participants providing both positive and negative feedback         | <p>"The cartoon characters were helpful because they explained it more to me than a human would."</p> <p>"Do not use cartoons. Use something else like people."</p>   |
| Participants liked the language, format, and information presented in Insuring Good Health.   | <p>"The information was simple and clear for all ages."</p> <p>"It helped me that they speak in the same language that I speak."</p>   | Participants liked the language, format, and information presented in Insuring Good Health.                                    | <p>"The navigation. How the topics were easily put together, easily found, and easily explained."</p> <p>"It was well written. Easy to follow dialogue. It was easy and simple. Right straight to the point."</p>   |

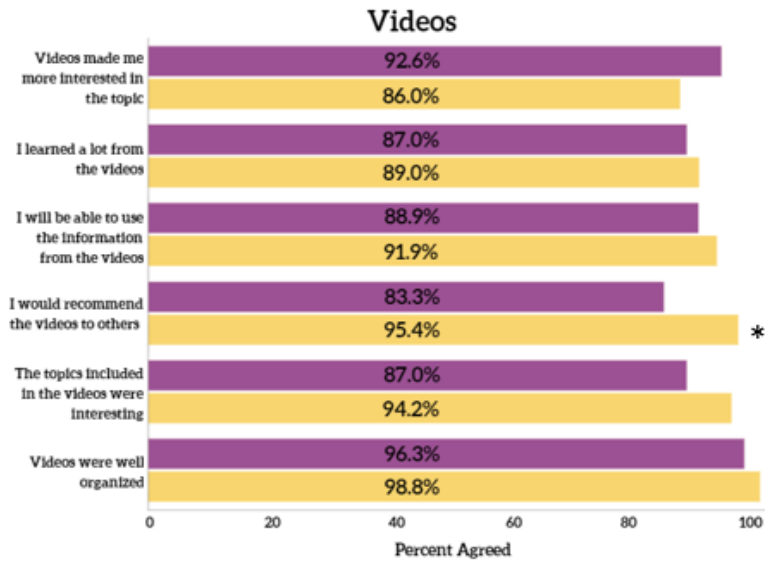
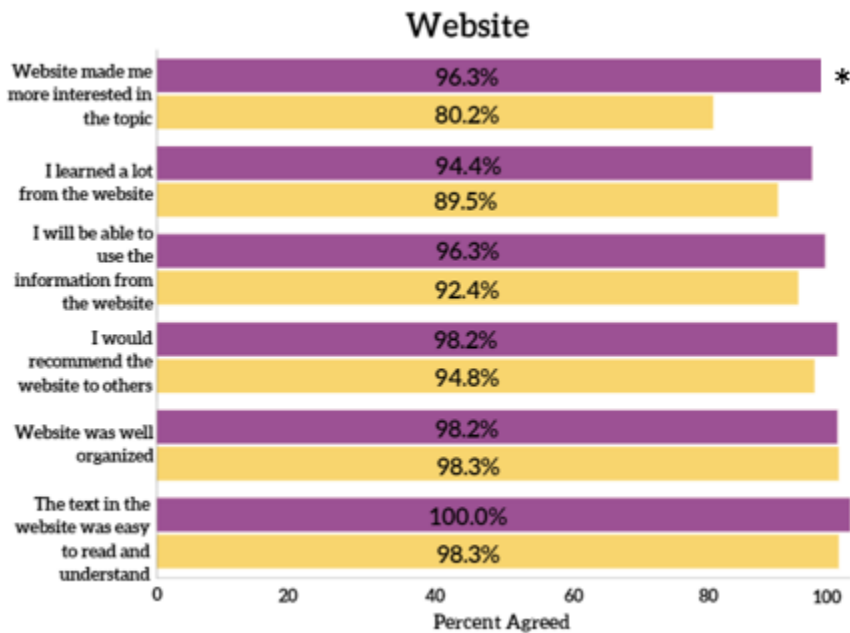
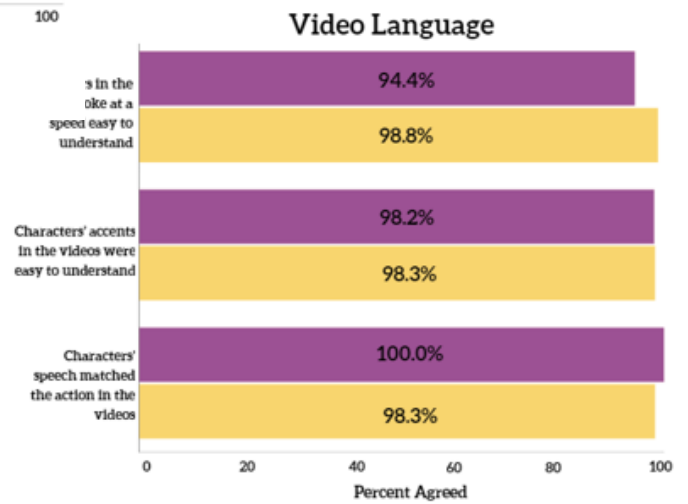
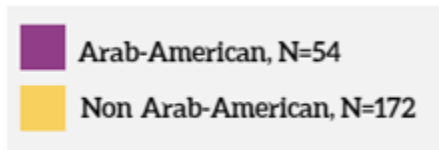


Figure 1. Acceptability of Insuring Good Health for Arab American/ Middle Eastern and non Arab American/Middle Eastern participants, N=226  
\*p-value <0.05



## Real Talk: Sexual Health Education for Muslim and Arab American Women in Southeast Michigan

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### Abstract

**Introduction:** Muslim and Arab American women are in need of culturally competent and accurate information regarding sexual health, a topic that is often considered taboo in faith-based communities. The study aimed (1) to measure sexual health knowledge of Muslim and Arab American women, (2) to evaluate a community-based approach to sexual health education, and (3) to contribute to the paucity of literature on this understudied population. By employing a theory-based framework, the study sought to destigmatize sexual health while facilitating more informed decision-making related to women's health.

**Methods:** A quasi-experimental study with pre-post measures of sexual health knowledge was employed. Study participants were women who attended sexual health and healthy relations workshops held by a local Arab American community nonprofit. Paired t-tests determined if there were significant changes in sexual health knowledge due to the health intervention. **Results:** Among a sample of 32 women, there was a mean increase in sexual health knowledge of over two points. This difference between pre-post workshop scores was statistically significant ( $p < 0.001$ ). Fourteen individuals reported difficulty in obtaining sexual health information. Greater sexual health self-efficacy was reported for issues related to contraception in comparison to STI/HIV testing. Following the workshop, low-scoring items tested knowledge of fertilization and reproductive anatomy, identifying potential improvements for workshop content and delivery.

**Conclusion:** The topic of sexual health is understudied in this population and study findings demonstrate the potential benefits of a community-based approach to sexual health education. Such findings may inform policy, funding, and support for preventative education in Muslim and Arab American women.

### Introduction

Arab Americans and Muslim Americans are two distinct populations as the former is identified by ethnic origins and the latter by religious affiliation. Nonetheless, there are many similarities between Arab American and Muslim American populations since culture is often a bigger influence than religion, especially with health-seeking behaviors (ACCESS Health Journal, 2015). The United States Census Bureau estimates that at least 1.9 million Americans are of Arab descent while the Arab American Institute Foundation estimates that 3.7 million Americans are of Arab descent (Arab American Institute Foundation [AAIF], n.d.). Since the Census Bureau

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classifies Arabs/Chaldeans as Non-Hispanic Whites, accurate figures on demographics are difficult to obtain. One report states that in the USA, 63% of Arab Americans are Christian and 24% percent are Muslim (Hamdy, n.d.). According to the Pew Research Center (2017), there are currently 3.45 million Muslims living in the United States, comprising about 1.1% of the U.S. population. Muslim Americans are racially diverse with approximately 41% of adults identifying as White (including people of Arab/Middle Eastern descent), 28% as Asian, and 20% as Black or African American (2017). This study focused on both Arab Americans and Muslim Americans because of the large population residing in Michigan. Approximately 2.75% of the population in Michigan is Muslim (Jackman, 2017) and in 2015, there were about 500,000 Arab Americans living in the state (AAIF, 2015).

Arabs in Michigan tend to be less healthy than the overall population in Michigan (Hekman et al., 2015). This disparity holds true for issues related to women's health, particularly regarding prevention. The 2013 Arab Behavioral Risk Survey reports that about 60% of Arab women had a Pap test within the past three years (compared to 79% of all women in Michigan) and about 40% of Arab women over 40 years old had a clinical breast exam and mammogram within the past year (compared to 50% of all women over 40 in Michigan). "In addition to barriers related to language and access," the survey states, "Arab women face additional barriers related to embarrassment, discomfort, modesty, and fear of detection." Education on sexual health education can directly address these behaviors.

The health of Muslims and Arab Americans residing in the USA has become an important focus of national discourse. This population is generally understudied, especially on the topic of sexual health. The World Health Organization (n.d.) defines sexual health as "a state of physical, mental and social well-being in relation to sexuality" and calls for sexual rights to include the right to "(1) the highest attainable standard of sexual health, including access to sexual and reproductive health care services, (2) seek, receive and impart information related to sexuality, and (3) sexuality education". Sexual health knowledge can have long-lasting impact on individuals, their health-seeking practices, and overall population health. Sexual knowledge has previously been shown to be related to safe sex practices, including healthy relationships. According to Weinstein, Walsh, and Ward (2008):

Research has found that communication between partners is critical in negotiating safe sex behaviors such as condom use (Catania et al., 1992), and that communication and trust in a relationship encourage safe-sex practices (McQuiston & Gordon, 2000). Therefore, sexual health knowledge may influence communication skills, leading to improved confidence and negotiation of safe-sex practices. (p. 214)

By targeting sexual health knowledge, theory-based interventions can improve safe sex practices and sexual health. The Muslim and Arab American community may benefit from such an intervention that connects sexual health knowledge and its related practices.

Traditionally, Muslim and Arab American women face barriers in accessing sexual health services that arise in part from cultural beliefs and practices (Yosef, 2008). One such belief is modesty and consequently, sexual health is deemed a taboo topic that is immodest to discuss. However, stigma and the absence of culturally competent sex education has had serious repercussions, including the "spread of misinformation and unhealthy attitudes toward gender



and sex” and the “lack of understanding of what constitutes a healthy relationship” (HEART Women & Girls, 2011). In order to promote empowered and informed decision-making, public health efforts have been focused on improving sexual health knowledge in this population.

As noted above, limited studies have been conducted on sexual health or sexual health knowledge among Muslim and Arabs and even less among women. A 2014 study on sexual and reproductive health knowledge in Saudi female university students found that unmarried women were at greater risk of sexually transmitted infections (STIs) and unintended pregnancy because they may not seek sexual health services (Farih et al., 2014). Avoiding public shame is an important value in Arab culture that ends up affecting help-seeking behaviors (Nassar- McMillan, Ajrouch, & Hakim-Larson, 2014).

For Muslim and Arab American women, sensitive health issues include STIs, sexual relationships, and counseling in cases of sexual dysfunction (Hammoud, White, & Feters, 2005). A 2016 study on Australian Muslim women indicated poor knowledge about STIs and contraception (Meldrum, Liamputtong, & Wollersheim, 2016). Another study on Muslim American women ages 18-45 revealed that 35% of them did not know how STIs were transmitted, 46% did not receive regular Pap tests, 49% were unaware of the most effective birth control form, and 53% could not identify when ovulation occurs (HEART Women & Girls, 2017). These knowledge deficits may result in under-utilization of health services, although constraints placed on this population’s health-related choices may also have an influence (Nassar-McMillan, Ajrouch, & Hakim-Larson, 2014).

Sexual knowledge acquisition has been identified as an integral component of sexual agency (Curtin et al., 2011). In their study, Curtin et al. explored how gender ideologies play a role in this acquisition and found that women who reported more traditional mindsets of being “passive sexual gatekeepers” were less likely to seek sexual health information (2011). Sexual self-efficacy, or confidence in the ability to perform positive sexual health behaviors, was also identified as an important component of sexual agency. Health interventions that consider this social context for Arab and Muslim women may therefore be better equipped to provide relevant and meaningful content. With this particular population, a community-based approach to sexual health education can produce multiple positive effects.

## **Objectives**

To our knowledge, no studies have evaluated the effects of interventions aimed at improving sexual health knowledge among Muslim and Arab American women. The purpose of this research study was to evaluate a community-based program that provided sexual health education to Muslim and Arab American women in Southeast Michigan. The study determined if the program was effective in improving sexual health knowledge and analyzed predictors of this change in knowledge. Knowledge was measured before and after a workshop on sexual health in order to determine if significant improvements occurred. It also explored the existing level of sexual health knowledge in this population, their information-seeking behaviors and sources of information, and predictors of change in knowledge pre- and post-intervention, such as race, marital status, religiosity, and generation status. These questions were evaluated through a quasi-experimental study.

## **Methods**

### **Population**

Participants were recruited from women-only workshops on sexual health and healthy relationships conducted as part of a collaboration between two community agencies. The Arab Community Center for Economic and Social Services (ACCESS) is located in Dearborn and it is the nation's largest community health center that serves the Arab population. HEART Women & Girls is a national organization headquartered in Chicago that specializes in sexual health education and sexual violence prevention in Muslim communities. In order to deliver these workshops in Michigan, a formal partnership was created between the two organizations. Preliminary discussions with the local community were also held to determine whether community members shared concerns regarding a lack of openness surrounding this topic, perceived such workshops as potentially beneficial, and what type of sexual health information would be helpful.

The workshop content focused on consent, communication skills, reproductive anatomy, contraception, and common health myths in the Muslim and Arab American communities. It was an interactive and discussion-based workshop that included activities, videos, and a condom demonstration. Titled "Real Talk", the two-hour workshop was delivered multiple times in different locations across Southeast Michigan, including Ann Arbor, Dearborn, and Rochester Hills. It was heavily advertised through organizational networks, local community leaders, printed flyers, and social media. It was advertised as women-only and for those over 18 years old, given the sensitive nature of the discussion. The workshops were conducted in private locations that were not open to the general public.

### **Procedure**

The research study itself was not separately advertised to the community. Rather, women who attended the workshop were informed about the study before the workshop began. They were eligible to participate if they met the following criteria: (1) identified as Muslim and/or Arab, (2) were over 18 years old, and (3) spoke English. The research study was conducted in the same area where the workshop took place, ensuring privacy when participants completed the measures. The informed consent process entailed describing the study according to the standard script from the Research Information Sheet. Each participant was given a copy of this sheet and the opportunity to ask any questions about the study. Then, the pre-workshop questionnaire was administered. Participants were asked to use a unique 6-character ID, which consisted of their initials, birth month, and birth year, to match post-workshop data. Both pre- and post-tests were administered on pencil and paper. There was no compensation for participation in the study (or workshop). Women were able to attend the workshop without participating in the research study. The research protocol was approved by the Institutional Review Board at Wayne State University.

Sexual health knowledge was measured at three different time points: before the workshop began (pre-intervention), immediately after it ended (post-intervention), and one month after it was completed (follow up). Sexual health self-efficacy was also measured because of its role as a key construct in health behavior change and theory (Glanz, Rimer, & Viswanath, 2015). It was tested at two different time points: pre-intervention and one-month follow up (via

Qualtrics). Currently available follow-up data is sparse due to ongoing data collection and attrition; therefore, the one-month follow up measures of sexual health knowledge and sexual health self-efficacy are excluded from this analysis.

## **Materials**

The questionnaire collected data on knowledge and self-efficacy related to sexual health, information-seeking behaviors, and demographics. Psychometrically-sound and culturally-sensitive instruments are lacking for this population (Nassar-McMillan, Ajrouch, & Hakim-Larson, 2014). Nonetheless, validated tools of measurement were used in attempt to showcase their effectiveness with this particular population.<sup>[1]</sup><sub>SEP</sub>

### Sexual Health Knowledge

For the knowledge component, an 11-item questionnaire was adapted from Sexual Health Knowledge Scale, which originally contains 37 items (Walsh & Ward, 2009). The subscales for Reproductive Health (5 items) and Contraception (6 items) were used to assess sexual health knowledge related reproductive systems and contraception. Permission to use this scale was provided by the authors. For each item, participants answered either true or false. A correct answer was coded as “1” and an incorrect answer was coded as “0”. The total points earned were summed for pre- and post-workshops tests.

Reliability testing indicated that the Sexual Health Knowledge scale had poor reliability (see Table 2). The Kuder Richardson-20 (KR-20) score was .18 for the pre-workshop measure and .38 for the post- workshop measure. Such findings are not uncommon for knowledge measures where items do not necessarily covary in a consistent fashion (i.e. knowledge in one area of sexual health may be unrelated to knowledge in another area).

### Sexual Health Self-Efficacy

For the self-efficacy component, the 4-item subscale for Sexual Health Care from the Sexual Health Practices Self-Efficacy Scale was used (Koch, Colaco, & Porter, 2013). The questions asked about practices related to self-breast exams, STI and HIV testing, and contraception using a five-point Likert scale anchored by “not at all confident” (1) and “extremely confident” (5). Permission to use this scale was provided by the authors. It was a reliable measure of sexual health self-efficacy in this population ( $\alpha = .86$ ).

### Sexual Health Beliefs and Information-Seeking Behaviors.

For beliefs and information-seeking behaviors, three items were adapted from the World Health Organization Core Instrument (Cleland, Roger, & Nicole, 2001) and a questionnaire developed for Saudi women (Farih et al., 2014). These items collected exploratory data on population needs and potential predictors of changes in sexual health knowledge. With dichotomous yes/no responses, two questions asked if it is easy to obtain sexual health information and if sexual health education would increase the incidence of sex practices. These responses elucidated beliefs on available resources regarding sexual health and the influence such education has on sex, a practice that is explicitly reserved for marital relationships in the religious/cultural context.

A third multi-select question asked where participants would seek help if there was a problem or question about sexual health. Response options included clinic/hospital, qualified doctor, spouse, parents, religious leader, friends, teachers, and other (with space to specify). A hypothesis was that this population may seek information from religious leaders, since they are knowledgeable of Islamic views on certain health issues like abortion.

### Demographics

Demographic information was collected from participants on the post-workshop questionnaire. The responses for race/ethnicity were specific, with subcategories under Asian and Middle Eastern/North African categories. Other items included generation status, education level, marital status, religion, religiosity, and current zip code.<sup>[1]</sup>

### Statistical Analysis Plan/Strategy.

The statistical analysis plan (SAP) included providing descriptive statistics of sample demographics, beliefs and information-seeking behavior, and specific questions measuring sexual health knowledge. A paired t-test determined if there was a significant difference in sexual health knowledge pre/post the health intervention. Linear regression modeling identified any potential variables that predict the outcome of knowledge difference. Variables of interest include (1) demographics: specific race, age, generation status, education level, marital status, religiosity, (2) beliefs: ease in obtaining sexual health information, sexual education increases incidence of sex practices, and (3) baseline data: sexual health knowledge and sexual health self-efficacy. With respect to this regression analysis, the SAP covered the variable selection process, model assumptions, and fitting diagnosis.

### **Results**

During the course of this project, 51 women attended the workshops – 42 (82%) of them agreed to participate in the research study and 32 (62%) fully completed the pre-post measures on sexual health knowledge. Missing data resulted from participants omitting the unique ID question, which matched pre-post responses in data analysis. Participants also entered the workshop after it had started or left before it ended, missing the opportunity to learn about the research study and complete the pre-post workshop surveys.

The following demographic information was collected from 37 of the 42 women who agreed to participate: 20 (53%) were Middle Eastern/North African, with majority of this category identifying as Lebanese; the age range was 18-44 year olds; 32 (87%) were single, never married; 27 (73%) were second generation American, born in the U.S. and at least one parent immigrant; 19 (53%) possessed a bachelor's degree or higher, and 23 (62%) identified as "religious" or "highly religious". These results are summarized in Table 1.

Among 35 participants who completed questions regarding beliefs and information-seeking behavior, 14 (40%) reported that sexual health information is difficult to obtain and 8 (23%) reported that sexual health education would increase incidence of sex practices. Among 36 participants who completed questions regarding behaviors, only 3 (8.3%) reported that they would seek help from a religious leader if they had a problem or question about sexual health. This was contrary to the hypothesized potential influence of religious leaders in this population. Seeking information from a qualified doctor was the most common selection (67%).

Among individual items of the Sexual Health Practices Self-Efficacy Scale, the highest mean score was reported for sexual health care practices related to contraception ( $3.25 \pm 1.44$ ) over STI testing ( $2.75 \pm 1.54$ ), HIV testing ( $2.69 \pm 1.49$ ), and self-breast exams ( $2.64 \pm 1.18$ ).

Baseline data indicated poor existing sexual health knowledge, with a mean pre-workshop score of 68% (7.44/11). The lowest-scoring questions covered how long an egg is viable for fertilization (26% of the sample answered correctly), where fertilization occurs in the body (50% answered correctly), the birth control pill's effect on the lining of the uterus (54% answered correctly), and how antibiotics affect the pill (58% answered correctly). These results reflected existing gaps in knowledge related to fertilization, reproductive anatomy, and contraception.

Following the workshop, the mean post-workshop score increased to 86% (9.50/11). The lowest-scoring question remained how long an egg is viable for fertilization (53% answered correctly). The other ten knowledge questions were answered correctly by a range of 70-100% of the sample. This result identified a potential area for improvement (fertilization and reproductive anatomy) in workshop content and delivery. The pre-post results for each item of the Sexual Health Knowledge Scale are summarized in Table 3.

The paired t-test measured the null hypothesis that the true difference in means was equal to zero. A graphical representation of this difference showed a normal distribution (see Figure 1). The mean difference in pre/post scores was 2.13, with a 95% confidence interval of 1.48 to 2.77. Since the p-value was  $< 0.001$  at the  $\alpha = 0.05$  level for a two-sided paired t-test ( $t=6.71$ ,  $df=31$ ), it rejected the null hypothesis; there was a significant difference in sexual health knowledge from pre- to post-workshop.

In order to predict which individuals will have the most change in sexual health knowledge, linear regression modeling was employed via stepwise selection for variables of interest. After checking model assumptions and fitting, one observation was removed since it was identified as an influential point, leverage point, and outlier. Out of the variables of interest, only pre-workshop score was a significant predictor of the outcome ( $t = -6.105$ ,  $df = 30$ , p-value  $< .001$ ). The beta coefficient for this simple linear regression was -0.89; for every one (1) unit increase in pre-workshop score, the difference in pre/post knowledge scores decreased by 0.89. Essentially, a higher pre-workshop score predicts a lower difference in pre/post workshop scores. This reflects the fact that individuals who score high at baseline have little room for improvement on the post-workshop measure. The following predictors had p-values that were approaching statistical significance: generation status, education, religiosity. These predictors could be studied further in order to determine who will respond best to this intervention. However, a multiple linear regression was limited by the study's small sample size given the importance of preserving degrees of freedom.

## Discussion

A community-based approach to sexual health education in Muslim and Arab American women resulted in significant improvements in sexual health knowledge. The objectives-oriented evaluation considered pre-post measures of sexual health knowledge, which included reproductive health and contraception. Workshop content can be improved by providing more information on the process of fertilization, which remained a low-scoring item after the workshop. The study determined the effectiveness of an intervention targeting a population with

specific needs, barriers, and gaps in knowledge. Not only is it first of its kind, contributing to the paucity of literature on this population, but it fosters one of the goals of Healthy People 2020: “to create social and physical environments that promote good health for all” (Center for Disease Control and Prevention, 2011). The workshop discussed a taboo topic in an informative and open setting that promoted learning about sexual health.

Results from the study provide important information on the topic of sexual health in Muslim and Arab American women. Sixty percent of the sample found it difficult to obtain information on sexual and reproductive health. There are specific religious and cultural expectations and beliefs that may hinder access to and retrieval of sexual health information; therefore, culturally competent information may also increase the likelihood that such women access accurate sexual health information.

Romantic relationships and sexual experiences that occur before marriage are typically frowned upon within the cultural and religious context. In addition, one commonly held community concern regarding the provision of sexual education is that it increases engagement in pre-marital sex. However, studies on the effects of sexual education programs in White adolescents have not supported this belief. The effects of comprehensive sexual education are summarized by Weinstein, Walsh, and Ward (2008):

For example, a review of comprehensive sex education programs concluded that all the programs studied had increased students’ knowledge and some had reduced sexual risk-taking behaviors: four of 13 programs delayed students’ onset of sexual intercourse, five of 11 programs reduced their frequency of sexual intercourse, four of seven reduced their number of sexual partners, and four of eight programs increased their condom use (Santelli et al., 2006). Additionally, none of the reviewed programs hastened the onset or increased the frequency of sexual intercourse, alleviating fears that comprehensive curriculums actually encourage sexual activities. (p. 214)

These findings may need to be better communicated to Muslim and Arab American communities, in order to increase support for programs such as the one evaluated in the present study.

Cultural and religious expectations may explain the lower self-efficacy reported for sexual health practices related to STI and HIV testing versus contraception. The latter is viewed more positively (contraception is permissible in Islam according to most schools of thought) while the former may elicit unfamiliar terminology and concepts that connote risky sexual behavior. Greater understanding of such clinical testing, from the cost and process to the confidentiality of testing, may improve sexual health self-efficacy in performing these positive health behaviors. This may be an area to explore for future workshops with extended content.

Study limitations include low internal consistency of the Sexual Health Knowledge scale. Some researchers posit that knowledge scales do not need high reliability since different items intend to measure different components of knowledge. However, the low internal consistency may also indicate that the scale is not appropriate for this specific population. There may be a disconnect between the scale and the workshop content, as both were developed separately. In addition, the full scale was not used, as only eleven items measuring knowledge on reproductive

health and contraception were included. Nonetheless, the reliability issues with this scale highlight the need for psychometrically-sound measures for minority populations.

The initial survey design posed challenges for the regression analysis. For example, collecting race-specific information was important to the study's objectives so multiple options were provided on the survey. The levels of this categorical predictor had to be collapsed in order to ensure that the regression analyses could be conducted with acceptable degrees of freedom. Given the small sample size, there were also limitations placed on the number of covariates that could be included in the final regression model.

The sample also included predominantly college-aged women (84% of the sample were in the 18-24-year-old category). To enhance attendance, the workshops were offered at organizations that were more willing to discuss this topic like Muslim Student Associations on college campuses. These organizations serve younger audiences compared to the broader age demographic visiting mosques, for example; however, mosques in Southeast Michigan were less inclined to offer such programming. Due to this factor, more college-aged women were included in the sample. By extension, the majority of the sample was single; it would be interesting to explore marital status further as there may be a direct link to sexual health knowledge given the cultural and religious expectations surrounding marriage. Because of these limitations and small sample size, our results may lack generalizability to other Muslim and Arab American women, especially those who are older and differ in marital status. The topic of sexual health is still relatively new for the Muslim and Arab American community and may take more time to garner vested interest from the broader population. Providing the workshop and survey instruments in Arabic may also help with this effort.

The data collected from this study can be used to inform public health programs serving Muslim and Arab American women. It showcases the effects of a community-based intervention for sexual health education while contributing to the lack of literature on this underserved population. Educational health programs can help prevent stigma about sensitive topics in Muslim and Arab American communities; at the very least, these initiatives can neutralize public opinions that may be stigmatizing (Nassar-McMillan, Ajrouch, & Hakim-Larson, 2014). Sexual health researchers should know this population seeks such programming and are willing to participate in research studies despite existing stigma. Any efforts towards reaching populations who may lack access to health information can assist in advancing overall health and wellbeing.

**Table 1. Internal Consistency of Sexual Health Practices Self-Efficacy and Sexual Health Knowledge Scales**

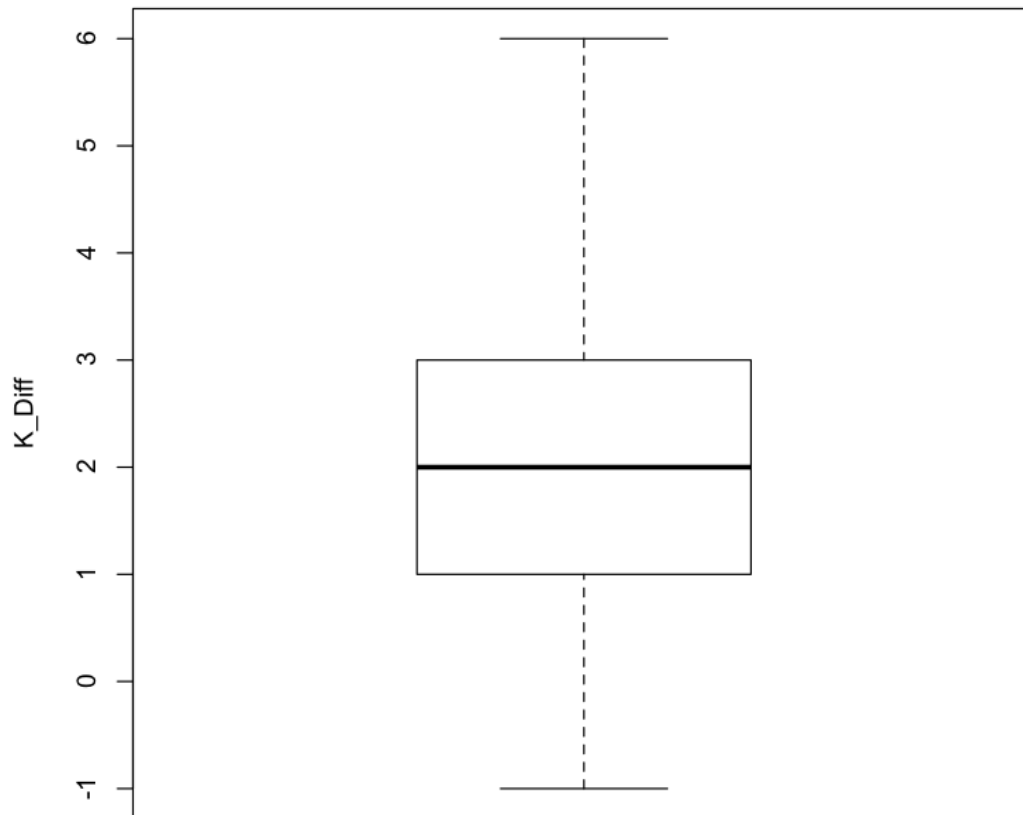
| Scale                                 | $\alpha$ /KR-20 | Mean $\pm$ SD    | Range                 |
|---------------------------------------|-----------------|------------------|-----------------------|
| Sexual Health Practices Self-Efficacy | 0.857           | 11.33 $\pm$ 4.75 | 11.34<br>11.35 4 - 20 |
| Sexual Health Knowledge               |                 |                  | 9.51                  |
| Pre-workshop                          | 0.178           | 7.44 $\pm$ 1.50  | 0 - 11                |
| Post-workshop                         | 0.375*          | 9.50 $\pm$ 1.23  | 0 - 11                |

\*Item 3 (regarding alcohol consumption) had zero variance and was removed from the reliability analysis

**Table 2. Proportion of Sample Scoring Correctly on Each Item of Sexual Health Knowledge Scale at Pre- and Post-Workshop Measurements**

| Sexual Health Knowledge Items   | Pre-workshop<br>mean $\pm$ SD<br>(N=34) | Post-<br>workshop<br>mean $\pm$ SD<br>(N=32) |
|---|---|--|
| Q1: Fertilization of the egg by the sperm (conception) occurs in the woman's uterus.  | .50 $\pm$ 0.51                          | .94 $\pm$ 0.25                               |
| Q2: Sexual dysfunction is often a symptom of underlying problems like diabetes or hypertension in men.  | .74 $\pm$ 0.45                          | .97 $\pm$ 0.18                               |
| Q3: Consumption of significant amounts of alcohol can have serious negative effects on men's sexual functioning.  | .91 $\pm$ 0.29                          | 1.00 $\pm$ 0.00                              |
| Q4: A female ovum (egg) is viable for fertilization for approximately one week after it is released.  | .26 $\pm$ 0.45                          | .50 $\pm$ 0.51                               |
| Q5: A small amount of sperm can be released before ejaculation.   | .85 $\pm$ 0.36                          | .97 $\pm$ 0.18                               |
| Q6: If a woman has taken the pill for two years and then stops, she will have a much more difficult time getting pregnant, compared to a woman who has never used the pill. | .79 $\pm$ 0.41                          | .94 $\pm$ 0.25                               |
| Q7: In terms of preventing pregnancy, antibiotics do not reduce the effectiveness of birth control pills.   | .59 $\pm$ 0.50                          | .75 $\pm$ 0.44                               |
| Q8: After unprotected sex > 98% of women will not get pregnant if the emergency contraceptive pill is taken in the first 72 hours.  | .62 $\pm$ 0.49                          | .91 $\pm$ 0.30                               |
| Q9: Oral contraceptives work immediately, therefore backup methods (additional methods of contraception) are not necessary when a woman is on her first cycle of the pill.  | .88 $\pm$ 0.33                          | .91 $\pm$ 0.25                               |
| Q10: The pill changes the lining of the uterus to make implantation unlikely.   | .56 $\pm$ 0.50                          | .84 $\pm$ 0.37                               |
| Q11: Blood clotting is a possible serious side effect of the pill.  | .74 $\pm$ 0.45                          | .97 $\pm$ 0.18                               |





**Figure 1. Boxplot of Difference in Sexual Health Knowledge: Pre- and Post-Workshop Scores**

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## Seventy Years on: Palestine Refugees and UNRWA

***Akihiro Seita and Wafa Zeidan***

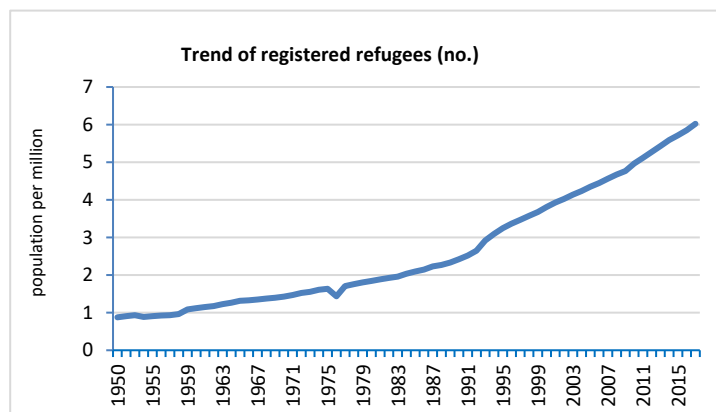
The United Nations Relief and Works Agency was established following the 1948 Arab-Israeli conflict, in accordance with United Nations General Assembly (UNGA) resolution 302 IV of 8 December 1949. Its mandate is to promote the human development of the Palestine refugees. The Agency began operations on 1 May 1950. In the absence of solution to the Palestine refugee problem, the General Assembly renews the Agency's mandate periodically, most recently in resolution 71/91, in which the mandate was extended until 30 June 2020 (1).

The Agency's services encompass healthcare, education, relief and social services, camp infrastructure and improvement, microfinance and emergency assistance, including in times of armed conflict. UNRWA is funded almost entirely by voluntary contributions from UN Member States. UNRWA also receives some funding from the Regular Budget of the United Nations, which is used mostly for international staffing costs.

### Who are Palestine refugees?

Palestine refugees are defined as "persons whose normal place of residence was Palestine during the period 1 June 1946 to 15 May 1948, and who lost both home and means of livelihood as a result of the 1948 conflict.

UNRWA is unique in terms of its long-standing commitment to one group of refugees. It has contributed to the welfare and human development of four generations of Palestine refugees. The descendants of Palestine refugee males, including legally adopted children, are also eligible for registration (2).



UNRWA services are available to all registered refugees present in its area of operations who meet this definition who are registered with the Agency and who need assistance whether they live in camps or not. When the Agency began operations in 1950, it was responding to the needs of about 750,000 Palestine refugees. Today, over 5.0 million Palestine refugees are eligible for UNRWA services (1).

UNRWA is the largest humanitarian operation in the region for over 68 years and has been the main comprehensive Primary Health Care provider for Palestine refugees. UNRWA's mandate on health is to protect and promote the health of Palestine refugees registered in the Agency's five

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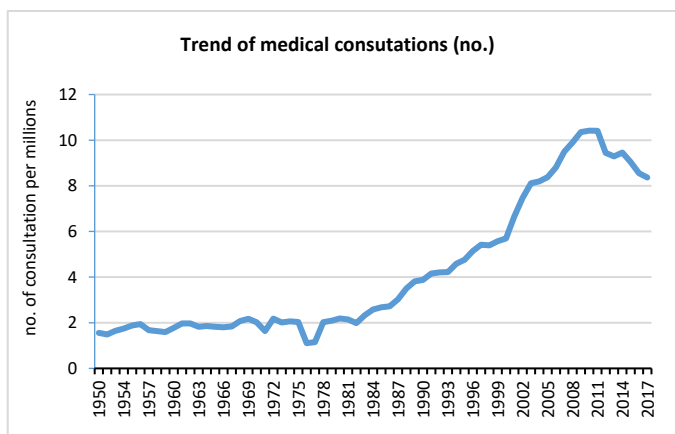
Fields of operation (Jordan, Lebanon, Syria, Gaza and the West Bank). It aims for them to achieve the highest attainable level of health. Nowadays UNRWA is committed to foster the human development of Palestine refugees by helping them to acquire knowledge and skills, lead long and healthy lives, achieve decent standards of living and enjoy human rights to the fullest possible extent.

After 70 years, one-third of the registered refugees still live in refugee camps. Because of the population growth and the limited plot of the camps, most of the other two-thirds live in cities, towns and villages throughout UNRWA's area of operations, and some have moved outside the area and are living in other countries. A Palestine refugee camp is defined as a plot of land placed at the disposal of UNRWA by the host government to accommodate Palestine refugees and set up facilities to cater to their needs. Socioeconomic conditions in the camps are generally poor, with high population density, cramped living conditions and inadequate basic infrastructure such as roads and sewers.



### UNRWA Health Services

Health is a fundamental human right, universally recognized and agreed upon. Everyone has the right to a standard of living adequate for the health and well-being of himself and of his family, including food, clothing, housing and medical care and necessary social services, and the right to security in the event of unemployment, sickness, disability, widowhood, old age or other lack of livelihood in circumstances beyond his control (3). Since 1950, UNRWA



remains committed, together with WHO and other concerned UN agencies and authorities, to its mission to help Palestine refugees achieve their full human development potential and well-being. Under the terms of an agreement with UNRWA, the World Health Organization has provided technical supervision of the Agency's health care programme through the sustained support of the Eastern Mediterranean Regional Office.

In its almost 70 years of history, UNRWA has expanded its health care services in the five areas of operation: Jordan, Lebanon, Syria, West Bank and Gaza. In 1955, there were 90 health canters in operation. As of 2017, there are 143 health canters operating across the fields. Medical consultations have increased from 1.5 million to 8.5 million.

## Health Status of Palestine Refugees

Since the 1950s, there were mainly three epidemiological transitions of operational objectives for the population with varying disease burden.

- Phase I (1950 -1970):  
Meeting basic needs of survival.
- Phase II (1970 -1990):  
Protection and promotion of health and well-being of the population with a particular focus on maternal and child health services and communicable diseases
- Phase III (1990 - 2017):  
Responding to the demographic transition and shifting health needs of the population to the disease prevention and control of chronic non-communicable diseases (NCDs) and mental health.

**Phase I: (1950-1970):** Meeting basic needs of survival.

UNRWA's critical work on humanitarian assistance for Palestine refugees started in 1950. Initially, 69 per cent of the budget spent towards financing relief operations. Mass ration distributions also began in 1950, and included basic items such as flour, rice, cheese and soap. As contributions allow, clothing, shoes, bedding and domestic items are added. Access to



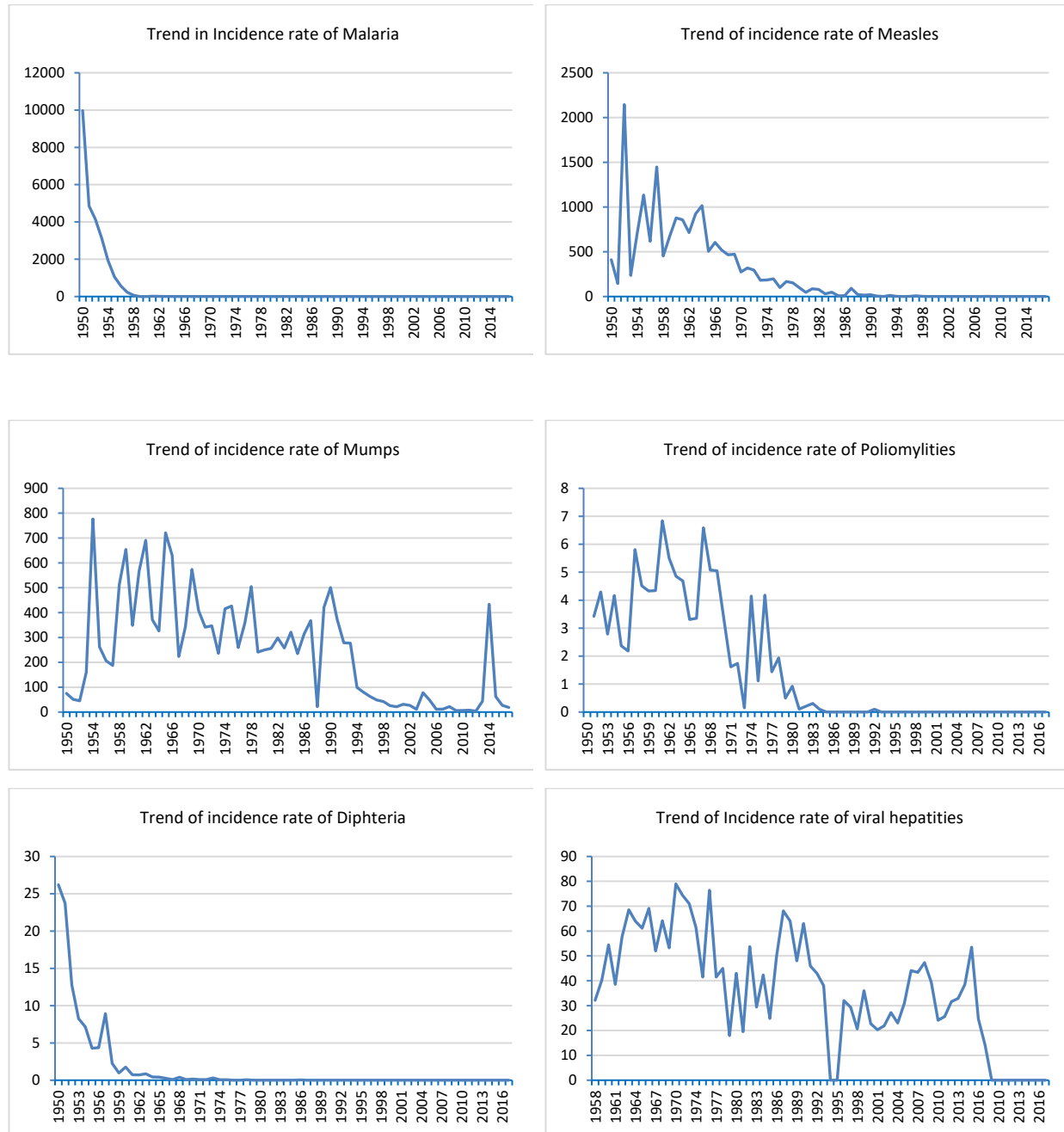
shelters (tented camps), household supplies, basic education, food, and health interventions were provided as a comprehensive package to then 750,000 Palestine refugees.

After 1967 war between Israel and Egypt, Jordan and Syria; over 300,000 people are rendered homeless or left their homes, including some 120,000 Palestine refugees (1). UNRWA responded by providing emergency aid and relief and establishing ten camps to accommodate the wave of displaced persons, including persons not registered as Palestine refugees. Main health concerns during the period of 1950s and 60s were heavily associated with Infectious and communicable diseases, malnutrition, personal hygiene and environmental sanitation related conditions due to high-density neighbourhoods with limited access to resources in emergency settings.

Prevention and control of communicable diseases were carried out by vector and rodent control and surveillance of certain communicable diseases; weekly incidence reports from the UNRWA health canterers were reviewed by epidemiologists.

In early 60s, vaccines provided to children included those against diphtheria, pertussis (whooping cough), and tetanus (DPT), typhoid and paratyphoid A and B (TAB), and small-pox. Today, vaccinations against tuberculosis, IPV, poliomyelitis, triple DPT, hepatitis B, Haemophilus influenza type B (Hib), measles, mumps, and rubella are provided to children with more than 99%

of coverage. Today, UNRWA's Department of Health continues to provide WHO and health authorities of host countries with information on the incidence and prevalence of communicable diseases.



In the early years of UNRWA operation, vulnerable individuals of the population heavily relied on nutritional support provided by UNRWA. Nutritional support was provided:

- Milk-distribution to children 0-36 months old, to non-breast-fed babies under six months, as well as to pregnant women, nursing mothers and tuberculosis patients;

- Daily midday meals to children up to six years of age and, upon medical recommendation, those over that age;
- Special extra rations to tuberculosis patients and to pregnant women from the fifth month of pregnancy and for one year after delivery

Maintaining clean environment of the camps was essential in preserving sanitation of Palestine refugees and prevent diseases. In 61 camps and locations, UNRWA provided portable water sources, sanitary disposal of solid and liquid wastes, drainage of storm water and control of disease-carrying insects and rodents. Today, cooperation of host governments, local councils and municipalities are steadily growing in the delivery of the service through the establishment of camp improvement committees, construction of community water supply and sewerage schemes in some camp.



#### **Phase II: (1970-1990)**

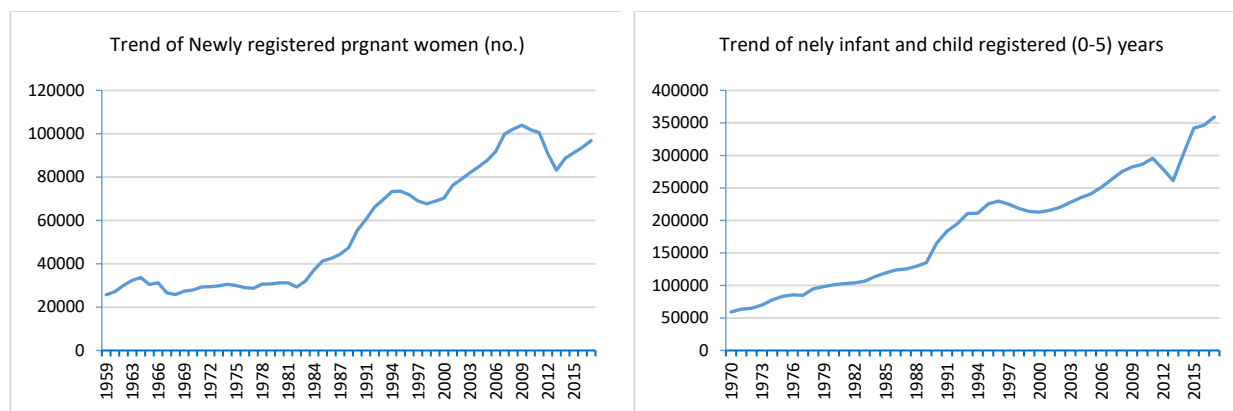
Towards protection and promotion of health in mothers and children.

In the 1970s, maternal and child health (MCH) services were further strengthened. MCH services then were comprised of antenatal care, postnatal care, and growth monitoring of children. UNRWA is known to be one of the first to introduce growth charts for children in the region. Fifty-nine thousand child births were newly registered in 1970 that increased to 165,146 in 1990. The total population of Palestine refugees surpasses 2.4 million in 1990.

In 1986, school health services covered 349,224 children in 635 UNRWA schools. Medical examination at school entry, including vision screening, reinforcing immunizations against diphtheria, tetanus and tuberculosis (BCG), were carried out by either a school health team or at health centres. Regular visits were paid to the schools for health monitoring of the pupils and inspection of school premises. School children with suspected visual or hearing defects, usually identified by either regular screening or by their teachers, were referred to specialists for examination through the health centres. With assistance from UNRWA, spectacles and hearing aids were provided to all schoolchildren who need them.

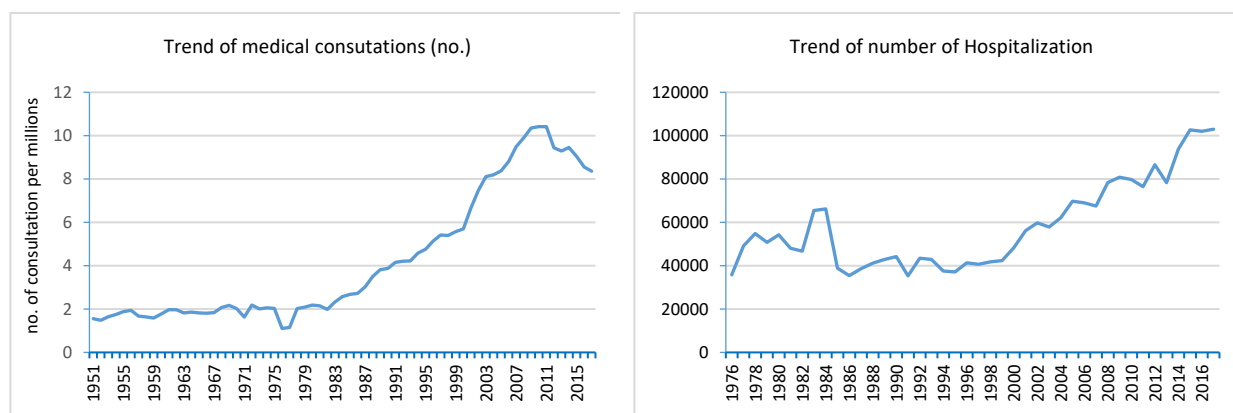






Outpatient medical care, dental, Pharmacy, Laboratory and rehabilitation services continued to be provided by UNRWA during the period to registered Palestine refugees, locally-recruited staff members and their authorized dependants who are not participating in Agency-sponsored insurance schemes. These services were made available at various health centres and health points, polyclinics, hospitals, laboratories, X-ray departments, and rehabilitation centres fully operated or partially subsidized by the Agency.

UNRWA maintained its standing policy of providing in-patient care by securing facilities in government, local authority, university, voluntary agency and privately-owned hospitals and medical institutions. UNRWA also administers a hospital in the West Bank (36 beds), nine maternity centres (totalling 71 beds) mostly in the Gaza Strip, and 21 daytime rehydration and nutrition centres (229 cots) located throughout its area of operation. In all the Fields, the cost of in-patient care continued to rise and the Agency had to increase substantially its subsidy to hospitals where beds are reserved for refugee patients. However, the refugees also had access to government, private and voluntary hospitals, locally available, either free of charge or for fee.

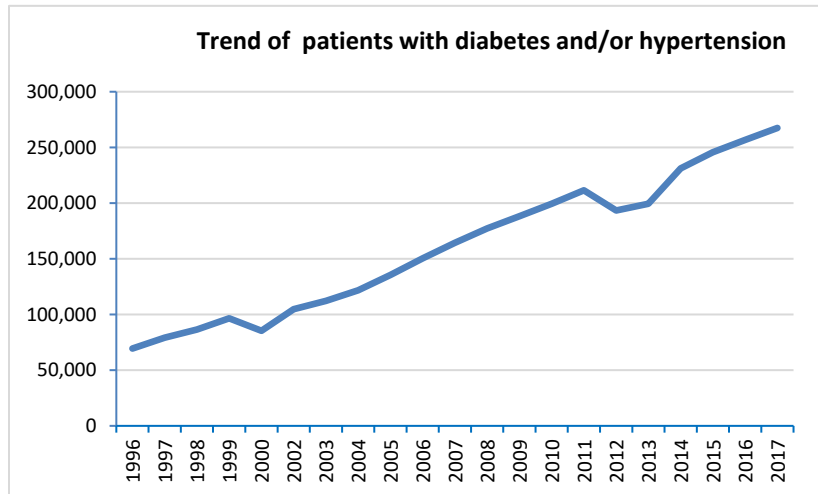


**Phase III: (1990 -2017)** New innovative measures to challenge the burden of chronic diseases. The health status of Palestine refugees has shown sizable improvement. Deaths of mothers and children have been considerably decreased. Progress in the Millennium Development Goals 4 and 5, namely to reduce child and mother deaths, respectively, is on track. Immunization coverage has always been close to 100%, much higher than the WHO Target of 95%.



The demographic transition dramatically shifted the health care needs of the Palestine refugee population. People are living longer and the population started to age. Epidemiological transition was significant during this period as main causes of mortality and morbidity were no longer communicable diseases.

In the 90s, non-communicable diseases (NCDs) such as diabetes mellitus (DM), hypertension, and cardiovascular, chronic respiratory diseases and cancer were becoming increasingly more prevalent among the Palestine refugee population. These are life-style illnesses, life-long, difficult to prevent and hard to control health conditions. Refugees were particularly vulnerable to NCDs



as many families flee violence with limited resources, endure conditions of prolonged displacement and deepening poverty, and thus struggle to pursue healthy lifestyles and access adequate care. Today, NCDs are primary cause of death across all five areas of UNRWA operation. UNRWA continues to introduce new tests, medicines and public awareness campaigns to promote NCD prevention and condition management.

After the second Intifada, began in September 2000, the Palestinian lived very difficult situations. This affected the mental wellbeing of children, and adults. Trauma from war and violence has led to psychological disorders in individuals living in the Gaza strip and West Bank. Different studies documented the burden of psychological disorders. In one of the studies that was conducted in Gaza and the West Bank among 1254 patients, 23.2% reported post-traumatic stress disorder [PTSD], 17.3% anxiety disorder (other than PTSD or acute stress disorder), and 15.3% depression.



PTSD was more frequently identified in children  $\leq 15$  years old, while depression was the main symptom observed in adults. Among children  $\leq 15$  years old, factors significantly associated with PTSD included being witness to murder or physical abuse, receiving threats, and property destruction or loss ( $p < 0.03$ ) (4).

In response, to additional health burden, UNRWA Health Department and Ministry of Health of the Palestinian Authority with the support of donors initiated a mental health programme to prevent and promote mental health through the early identification and provision of psychological support and referral when needed. In 2002, the Community Mental Health

Programme (CMHP) was established in Gaza and West Bank to empower vulnerable refugees, especially children. CMHP later developed into a comprehensive mental health and psychosocial support (MHPSS) services. In addition to the focus on NCDs, improvement of maternal and child health services continue with the integration of Family Planning services in 1993, introduction of the maternal mortality audit/confidential inquiry 1994, gynaecology services at PHC level, introduction of the ultrasound and improvements of the quality of medications provided to pregnant women.

In 1998, a comprehensive maternal health record was introduced in order to strengthen the integration of MCH services and to support the integration of family planning and breastfeeding services. The introduction of the outcome registry and the establishment of the Health Information System at PHC in 2001, support and programme management, monitoring and evaluation at all levels of the Agency and at all areas of operation. Updating the technical instructions and the clinical guidelines in accordance with WHO guidance and best available evidence, ensured the provision of high quality services and standardization of services in all UNRWA's areas of operation. In 1991, a special programme for monitoring of underweight children was initiated and in 2008, the WHO New Growth Monitoring Standards up to 5 years and Maternal and Child Handbook were introduced. Family protection and domestic violence screening was introduced with Preconception Care in 2009, achieving the lifecycle approach to health care. The Epidemiological surveillance was strengthened with the implementation of an Early Warning System for timely communicable disease detection and response.

Furthermore, operational research was integrated within all programmes to support evidence-based decision making and identifying priority actions with an average 4-5 studies every year conducted by UNRWA staff in accordance to the best research methodology.

Many of the studies conducted, were publish in reputable international journals such as The Lancet, The WHO Eastern Mediterranean Health Journals, the Plos One and other. The culture of data and operational research was part of the day-to-day of UNRWA health staff.

In 1995, quality of care and services provided was another dimension that URWA health programme concentrated on. Different studies to improve the quality of services were conducted such as patient flow analysis, waiting time and irrational use of antibiotics. Accordingly, the appointment system was introduced, and close monitoring of prescribing practices were put in place. In addition, several tools were developed to further improve the services including, checklists, flowcharts, and handy technical instruction ensure the technical quality and exit interviews for perceived quality/patient satisfaction. Competency-based training and supportive supervision were the main keys to the high-quality services that UNRWA Health Department is providing evidenced by the different internal and external evaluations conducted.

During this period, the prevailing social and economic difficulties and political instability also negatively affect health outcomes. Unemployment is extremely high among productive age groups. Poverty level still remains high. The latest survey in Lebanon, for example, indicated that 67% of the refugees are poor. Such economic and social stress sometimes results in gender-based violence and mental health distress.

Continued blockade by Israel has affected health service delivery in the Gaza Strip. Similarly, limitations in access to health care cause a significant health burden in the West Bank and wars in Lebanon, Gaza and Syria. The health programmes of UNRWA are fully aware of such challenges and difficulties and are committed to address them through a health reform based on the progress made to date.

In 2009, comprehensive health systems reform was launched in the five fields supported by the life cycle approach model to health care. In this reform, addressing the life style illnesses is a key message. This will entail improvement of quality of care in crowded health centers, and outreaching to communities to bring changes in life style. Addressing health needs will also entail increasingly costly hospital payments. In order to make this feasible, fundamental improvements in the health information system through e-health and, most importantly, support to health workforces through continued education and training. All Fields have made encouraging innovations along with the reform, partnerships with host countries, donors and all others will remain critical.

The ongoing protracted and acute conflicts, occupation, and the lack of a just and durable solution for Palestine refugees, continue to affect the population's physical, social and mental health. Mental health and psychosocial-related disorders are major issues to address when working to ensure that refugees enjoy the highest attainable level of health.

The crisis in Syria has entered its eighth year, with no lasting, peaceful solution in the horizon. Over 280,000 Palestine refugees from Syria (PRS) have been internally displaced, and more than 80,000 have fled to neighboring countries, including Jordan and Lebanon, where Palestine Refugees from Lebanon (PRS) have been accessing UNRWA services for years. This has placed additional pressures on camps, schools and health centers with scarce resources. The blockade and recurrent emergencies in Gaza, and the occupation in the West Bank, remain major obstacles to socioeconomic development of Palestine refugee communities, and on the health-care provision.

Family Health Team approach, confronted by the challenges of the changing environment, the UNRWA Health Department began implementation a major health service reform initiative in 2011. UNRWA introduced a new, modern PHC service delivery model the Family Health Team (FHT) approach. FHT use a family and person-centred approach to provide holistic primary care at UNRWA health primary centres. Families are registered with and assigned to a multidisciplinary health teams. This team is responsible for all the health care needs of the families registered to them over the life cycle. The strong patient-provider relationships coupled with longevity of care will ensure effective, efficient and timely delivery of care, an aspect especially critical in the management of NCDs. The notions of "my doctor" and "my patient", previously unknown in UNRWA facilities capture the essence of the new FHT approach.



The e-health information system to reach the target of “paperless clinic” was introduced in 2009. With the FHT model, a fully computerized electronic medical record and appointment system named e-Health was developed and implemented by UNRWA staff. E-Health helped health staff to access patient information quickly and easily, allowing for longer consultation times. As family health teams got to know better their families and each patient’s full history, it has become easier for them to provide the best advice and care.

In 2015 UNRWA launched the Family Medicine Diploma Programme (FMDP). The main goal of the FMDP is to offer doctors in the Field a model of in-service training that will build on their existing knowledge, skills and experience and to improve their mastery of the clinical management of the patient and raise the standards of clinical care. The programme started in Gaza with 15 doctors in 2015-2016 and expanded to Gaza, West Bank, Jordan and Lebanon targeting 69 doctors in the four fields.

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## Conducting Reproductive Health Research with Syrian Women who are Refugees: Methodological Considerations

*Meagan Chuey, Justine Wu, Iman Ali, Lisa Kane Low*

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### Abstract

Currently there are more refugees from Syria than any other country in the world, with the United States resettling approximately 20,000 Syrian refugees since 2011. Despite half of Syrian refugees being women, limited research has examined reproductive decision-making in this population. Prior research conducted in other countries has found refugees to be vulnerable to unwanted pregnancy due to challenges accessing family planning services. The reproductive needs and desires of refugee women in the United States are poorly understood, with no literature examining the experiences of Syrian women specifically. Additionally, there is little guidance regarding best methods for conducting reproductive health research with refugees in a manner that upholds ethical conduct of research.

Based upon our experience conducting a mixed methods study of this population, we provide lessons learned and recommendations for rigorously collecting data in a manner that is sensitive to the cultural expectations and traumatic experiences of refugee participants and maximizes safety for participant and study staff. This pilot study examined whether a mixed-methods approach is feasible and acceptable for collecting data regarding reproductive decision-making throughout the resettlement process. The London Measure of Unplanned Pregnancy, a quantitative survey measuring pregnancy planning, was completed for each pregnancy since leaving Syria. In-person qualitative interviews structured around an Event History Calendar were conducted to facilitate recall with participants.

Recommendations were developed to guide methodology in conducting reproductive health research with women who are refugees from Syria, including study team composition, considerations for recruitment, and navigating assumptions regarding participant agency. These methodological lessons can be used to improve future research examining reproductive decision-making in refugees not only from Syria, but also more broadly globally.

### Introduction

Following unrest in Syria beginning in March 2011, approximately 4.9 million Syrians have registered as refugees, more than any other country in the world.<sup>1</sup> Roughly half of refugees from Syria are women, with approximately 50% being of reproductive age.<sup>1</sup> Among the approximately 20,000 Syrian refugees who have resettled in the US since 2011, 1 out of 10 now live in Michigan.<sup>2</sup>

One in five reproductive age female refugees are pregnant at any time.<sup>6,7</sup> Access to reproductive health care for refugees pre- and post-resettlement is variable with a high unmet need for contraception and high rates of unintended pregnancies.<sup>8</sup> It is critical to consider the

reproductive health and healthcare needs of Syrians who are refugees within the context of reproductive services available and utilized prior to displacement. Prior to unrest in 2011, the contraceptive prevalence rate in Syria was 54%, with an average total fertility rate of 2.9.<sup>34</sup> Many Syrian women elect not to use contraception until after having a child or reaching the intended number of children, due to concerns that certain birth control methods may cause infertility.<sup>5</sup> Spacing pregnancies over time may be of lower priority than preventing pregnancy indefinitely after the personal ideal number of children has been reached.<sup>5</sup>

Prior literature has established changing fertility desires in light of refugee status. Syrian refugee women in Lebanon, who reported pre-conflict fertility ideals of four to five children, state that the ideal number of children while a refugee is one or two due to the social and political climate experienced as refugees.<sup>5</sup> However, women also report concerns with impaired fertility while experiencing displacement, with high rates of menstrual irregularity, hypothesized to be associated with stressors related to the refugee experience, resulting in concern about future fertility.<sup>5</sup>

There is an urgent need to improve reproductive healthcare access,<sup>6,7</sup> yet limited research explores the impact of refugee resettlement on reproductive health and decision-making.<sup>9</sup> However, research regarding reproductive health in Syrian refugees that is culturally aware and acceptable to the participants is impeded by a lack of methodological recommendations or guidelines for conducting sensitive research in this population. While clinical guidelines for providing sexual and reproductive healthcare to Arab American women have been presented, they are frequently criticized for generalizing the role, or assuming a centrality, of religion in healthcare decision-making.<sup>10–14</sup> Because of this, a nuanced and flexible understanding of the needs and desires of Syrian refugee women is integral to conducting research in this population.

### **Description of Study**

The overall goal of this research is to explore the lived experiences of Syrian women who are refugees resettled in the United States, and how these experiences influence reproductive decision-making throughout the resettlement process. To meet the research goal, the presented conceptualization of the project and implementation of methodological processes were piloted to assess the feasibility and acceptability of conducting qualitative interviews using an event history calendar combined with a quantitative survey focused on pregnancy planning.

This research project received approval from the University of Michigan's Institutional Review Board – Health Sciences and Behavioral Sciences. Recruitment occurred in collaboration with local refugee resettlement agencies. We recruited women who met the following criteria: aged 18-45, self-identified as refugees, could read and write in Arabic, left Syria as a refugee since 2011, were married, and had experienced at least one pregnancy since leaving Syria regardless of pregnancy outcome. Marriage has been used as a proxy for women who are sexually active in other reproductive health research conducted in Syrian refugee populations.<sup>36</sup>

Verbal consent was obtained prior to the interview. Written consent was not obtained to minimize the risk of data being linked with participant. Additionally, a verbal consent process ensured that even in women with limited literacy a comprehension of the informed consent could be achieved. Informed consent included making participants aware of the potential for

emotional discomfort or distress secondary to recounting stories.<sup>15</sup> Additionally, contact information for linguistically and culturally appropriate mental health services were provided for all participants should emotional discomfort or distress resume or intensify following the interview. Survey data were collected, and interviews were conducted, in-person by an Arabic-speaking interviewer, in a location of the participant's choosing. All participants elected to have the interview conducted in their home.

Participants completed one London Measure of Unplanned Pregnancy survey, a measure of pregnancy planning, for every pregnancy conceived since leaving Syria.<sup>16,17</sup> Following completion of the survey(s) participants participated in a qualitative interview structured around an Event History Calendar.<sup>18</sup> A total of 10 women were recruited for the pilot study. Eight of the women were able to complete the surveys themselves, and two asked that the survey questions be read to them. In the process of contextualizing study design, thoughts on construction of a research team, recruitment, and navigating potential biases are discussed below.

## **Methodological Decisions and Lessons Learned**

### ***Research Team and Positionality***

Positionality is the way in which one's identities and position in the world influence the ways an individual understands the world.<sup>20</sup> Feminist researchers have encouraged an awareness of positionality, rather than an assumed personal detachment from the research process, as a means of reflexively being aware of how their personal lens may influence the research process.<sup>21</sup> The Primary Investigator (MC) is a Certified Nurse Midwife who is white, United States-born, non-speaker of Arabic. Mindful that her attitudes regarding sexuality and reproductive health reflect a Western, progressive, and health-oriented perspective, she sought a research assistant who could provide cultural insight regarding the participants' lived experiences. The project's primary research assistant is a native speaker of Arabic, and is herself a refugee from the Middle East who grew up in Syria. The research assistant conducted and transcribed all interviews, and assisted in the coding of interviews.

Using racially-concordant staff has been recommended to improve recruitment in minority populations.<sup>27</sup> Additionally, while cross-language and cross-cultural research has established the importance and impact of conducting interviews with researchers who look like the participants,<sup>23-27</sup> research amongst refugee populations does not frequently additionally ensure that those conducting the interviews share the social position of refugee. Prioritizing the hiring of research assistants who are themselves refugees allows for a unique view of the research. Using such a peer interviewer has been demonstrated to be beneficial in recruitment and building trust with socially excluded or hard to reach populations.<sup>24,25,28</sup>

An intentional decision was made to have a trained research assistant conduct the interviews as opposed to the primary investigator conducting the interviews through a translator. The use of a translator in a healthcare setting has been found to result in patients having more questions about their care and being less likely to bring up mental health concerns.<sup>29</sup> Bearing this in mind, the primary research assistant was trained in qualitative interviewing techniques to conduct the interviews herself.

However, having research assistants who may share a history of trauma with participants, particularly trauma that may arise over the course of interviews, itself proposes a number of methodological concerns. In addition to wanting to protect the mental and emotional well-being of participants over the course of the interview process, it was also important to protect the well-being of research assistants. All research assistants were encouraged to tell the primary investigator if they were feeling overwhelmed by the quantity or content of the project, and discussions were had regarding taking deliberate breaks from the project as needed to maintain mental health. The primary research assistant, discussing her feelings about conducting more than two interviews in a day, reported, “My friends know that even after I only do two interviews I can’t talk for a few hours, because it’s so draining”.

### *Recruitment Strategies*

Appropriate recruitment strategies and proxies for variables of interest were discussed with Syrian community leaders during the project development process. After discussions with members of the community, marriage was the most culturally appropriate proxy for this research to assess if a woman was sexually active. Therefore only women who were currently married, or had been married at some point since leaving Syria as a refugee, were recruited as a means of capturing participants who were likely to be sexually active and at potential risk for unmet need for family planning.

Recruitment flyers presented potential participants with options regarding ways to contact researchers, including by text and calling via a cell number or WhatsApp. The option to contact project organizers via WhatsApp provided an opportunity for communication that may be more accessible or acceptable to Syrian women than the phone. WhatsApp is a free mobile phone application hosting no-fee texting and calling, used by 77% of people in the Middle East.<sup>37</sup> WhatsApp has been used in academic research both for recruitment and as a tool for data collection.<sup>38</sup> Multiple refugee resettlement agencies in southeast Michigan report using WhatsApp to communicate with their network of refugees. Additionally, WhatsApp has been used specifically for research with Middle Eastern refugees in refugee camps.<sup>39</sup> Women in refugee camps report WhatsApp as being a particularly popular form of communication amongst Syrian refugee women due to its sustained popularity in the Middle East, the lower cost affiliated with mobile-based apps as compared to cellular communication, and that internet-based communication is possible even where there is no cellular reception.<sup>40</sup>

|                            | Text | Call | Text & Call |
|----------------------------|------|------|-------------|
| <b>Cell Phone</b>          | 0    | 3    | 0           |
| <b>WhatsApp</b>            | 1    | 4    | 0           |
| <b>Cell &amp; WhatsApp</b> | 0    | 1    | 1           |



### Assumptions about Participant Agency

In seeking Institutional Review Board approval for this project, researchers navigated social and academic assumptions and biases held regarding the agency of the population being studied. Specifically, during the Board review process the researchers were asked if the Syrian women being interviewed had control over family planning, and how women's opinions and responses to family planning fit into the culture. Discussions surrounding agency of participants appeared to be rooted in false assumptions regarding Syrian women, a wife's overall agency within the family unit, and reproductive health agency in particular. Researchers were asked to provide participants with an informational sheet that did not indicate the content of the research, rather than a copy of the informed consent, in concern that a participant's husband would become angry if he knew she was speaking with researchers about reproductive decisions. Because of a desire to have a nuanced understanding of the cultural and social implications of reproductive health research within this population, multiple Syrian community organizations and members were consulted to ensure cultural appropriateness of methodology. Research participants were given the ability to voice where they felt the most comfortable to conduct the interview, as a means of respecting their agency in decision-making. Women participating in the study appeared eager to share their experiences and how these life experiences influenced their reproductive decisions, including decisions regarding fertility concerns, contraceptive use, and terminations of pregnancy. Multiple participants voiced thanks to the researchers for giving them the opportunity to share their stories.

In conducting research with vulnerable populations, it's important to recognize how stigma or bias may be influencing methodological decision-making. The public health implications of stigma include being at substantial social disadvantage with respect to resources including knowledge, money, social connections, and power.<sup>41</sup> A content analysis of references to Islam or Muslims in health and healthcare research found that latent themes included Muslims being negatively affected by tradition, being an observant Muslim poses health risks, and "Islam" being a problem for healthcare delivery.<sup>42</sup> Negative assumptions are perhaps heightened for Syrian women in the United States who frequently physically present in public spaces wearing the hijab, an act that is often interpreted as subordination or lacking in agency.<sup>43</sup> Muslims are not homogeneous in how they think their religion relates to their lives, social interactions, and identity.<sup>44</sup> Researchers in this project attempted to make informed, culturally-aware, and community-approved decisions regarding methods pursued. Additionally, it should be noted that women who identify as Muslim, as women who identify with other religions, may not personally adhere to restrictions or recommendations made by religious authorities.

In regards to better understanding reproductive decision-making in women from Syria, generalizations cannot be made regarding Islam's stance on contraception and its influence on decision-making.<sup>45</sup> Large families in Muslim communities are related to pronatalist attitudes rather than lower amounts of agency in Muslim women as compared to non-Muslim women.<sup>46</sup> Current cultural beliefs surrounding family planning in women who are Muslim vary from absolutely permitted to absolutely not permitted.<sup>47</sup> Additionally, diversity in opinion is also seen in religious clerical interpretation of Islam texts, and what these texts have to say about reproductive healthcare and decision-making.<sup>48</sup>

## Recommendations

The piloted methodology presented here was found to be an acceptable and feasible means to evaluate reproductive decision-making in Syrian women who are refugees. Overall, our approach was successful in accomplishing recruitment of the intended population, engaging in meaningful interviews focused on reproductive decision-making, and included a recognition of underlying assumptions that may be influencing methodological choices. Conducting this pilot project has resulted in a number of recommendations for future research with similar populations:

- **Team Composition:** Need for a comprehensive, culturally integrated research; composition of team needs to consider gender, age, and marital status as important to participants
- **Recruitment:** Innovative uses of technology and making the interview available to participants in a location they choose increases availability of research to the population of interest
- **Navigating Assumptions Regarding Participant Agency:** Concerns regarding participant agency and comfort with research need to be considered thoughtfully, with a nuanced understanding of the interplay of culture and religion

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## Research in MENA Region and Protection of Vulnerable Populations

**Michel Daher**

### Summary

Medical progress and improved patient care depend on innovative and vigorous research. The basic principle of research is honesty, which must be assured by institutional protocols. Honesty and integrity must govern all stages of research, from the initial grant application to publication of results.

**“Research is to see what  
everybody else has seen, and to  
think what nobody else has  
thought”  
-Albert Szent-Gyorgyi**

A traditional approach to vulnerability in research has been to label entire classes of individuals as vulnerable. Different characteristics may also co-exist, making some individuals more vulnerable than others. This is highly dependent on the context.

A special attention to research on vulnerable populations is reported in 3 international documents reviewed in this article. Local control through National Ethics Committees and regional control through the RERC of the EMRO are currently active in the MENA countries.

In this article, we will review the importance of Research in MENA countries, and how the local National Ethics Committees, and the EMR RERC can control the ethical issues of research on vulnerable groups or populations in this area.

**Key Words:** Research on Human Subjects, Vulnerable Populations, MENA Region

### Introduction

Medical progress and improved patient care depend on innovative and vigorous research. Research is the systematic collection, analysis and interpretation of data to answer a certain question or solve a problem. The basic principle of research is honesty, which must be assured by institutional protocols. Honesty and integrity must govern all stages of research, from the initial grant application to publication of results. What everyone needs to know about health research is if it is right: validity of measurements, quality and reliability of data, logic used to draw conclusions with a good correlation v/s causation, and reproducibility. It is a process starting with a Protocol and ending with Publication (Fig.1).

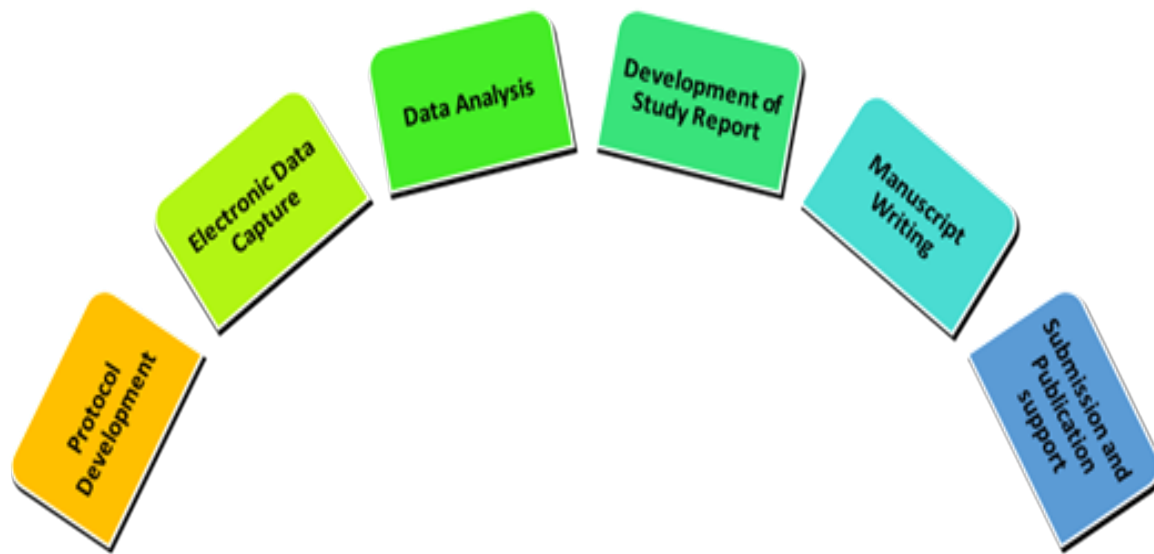
The medical profession must assume responsibility for assuring that research is potentially of significant value and ethically conducted. Benefits and risks of research must be distributed fairly, and particular care must be taken to avoid exploitation of vulnerable populations.

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Research participants must be instructed about the nature of the research; consent from the research participant or an authorized representative must be truly informed and given freely; research must be planned thoughtfully, so that it has a high probability of yielding useful results; risks to patients must be minimized; and the benefit-to-risk ratio must be high enough to justify the research effort.

In this article, we will review the importance of Research in MENA countries, and how the local National Ethics Committees and the EMR RERC can control the ethical issues during research on vulnerable groups or populations in this area.



**Figure 1: Research Process: From Protocol to Publication**

### **The Major Principles of Ethics in Research Involving Human Subjects**

Research, professional education, and clinical practice are combined activities that will provide important improvement in care for people with acute and chronic diseases. Any research in human subjects should comply with the ethical principles reported in the Belmont Report (1978) (Ref.1), including the respect for persons ( treat individuals as autonomous agents, protect those with limited autonomy, informed consent by research subjects), beneficence and non-maleficence (make every effort to secure the well-being of people, evaluation of risks and benefits for research subjects), and justice (selection of research subjects, fair sharing of the burdens and the benefits of research). The overall goal is to place the welfare and rights of the patient above all else.

Respecting the Ethics of Research has all its importance because there is an interaction between the Human Rights and Humanity, and the scientific and technical competence of the investigator, and the ethical design and conduct of the research.

The recovery of the major principles of ethics on human subjects started after World War II which was a transforming event in the conduct of human subjects research: Research agenda was dictated by military need, with use of vulnerable patients (mental patients, prisoners...); the well-known examples are the types of experiments by the Nazi Doctors and the Third Reich's program for 'racial hygiene', purifying the German people by extermination and sterilization of groups.

The Code of Nuremberg was declared in 1947 (Ref.2), following the Nuremberg War Crime Trials (1946). This Code, which is a statement for permissible medical experimentation on human participants, stipulates that voluntary informed consent of the human subject is absolutely essential: capacity to consent, freedom from coercion, comprehension of risks and benefits involved, with a favorable risk/benefit ratio, qualified researchers using appropriate research designs; participant must be free to stop at any time.

Later on, several International regulations of research, including Declarations, Codes and Guidelines were elaborated and approved by the international community of nations (Fig2).

|  |                              |
|--|------------------------------|
| Nuremberg Code                                       | USA (1947)                   |
| Helsinki Declaration                                 | WMA (1964, 1975, 2000, 2013) |
| Belmont Report                                       | 1978                         |
| CIOMS Guidelines                                     | WHO (1982, 1993, 2002, 2016) |
| International Conference on Harmonisation            | Europe (1996)                |
| Council of Europe                                    | Europe (1997)                |
| Nuffield Council                                     | UK (1999, 2002)              |
| UNAIDS   | WHO (2000)                   |
| NBAC Recommendations                                 | USA (2001)                   |
| Universal Declaration on Bioethics and Human Rights- | UNESCO 2005                  |

**Figure 2: International regulation of research, International Codes and Guidelines**

In 1978, the Belmont Report recognized the 3 Ethical Principles in Human Subjects Research (Ref. 1):

**Respect for persons** – treat individuals as autonomous agents, protect those with limited autonomy, respect privacy and confidentiality, and obtain informed consent by research subjects.

**Beneficence** (including Non-Maleficence) which is the essence of Hippocratic tradition– “first do no harm”: Make every effort to secure the well-being of people, maximize benefits and minimize harm or risk, research conducted by competent investigators, and a good research design.

**Justice**– selection of research subjects, fair sharing of the burdens and the benefits of research, are the inclusion/exclusion criteria fair? Is this done on a rational and justifiable basis? (e.g. excluding women from drug studies because they may get pregnant, older people, children).



## Research and Vulnerable Populations

Who are considered Vulnerable Persons and Groups? A traditional approach to vulnerability in research has been to label entire classes of individuals as vulnerable. Different characteristics may also co-exist, making some individuals more vulnerable than others. This is highly dependent on the context. For example, persons who are illiterate, marginalized by virtue of their social status or behaviour, or living in an authoritarian environment, may have multiple factors that make them vulnerable.

- Adults incapable of giving Informed Consent.
- Individuals in hierarchical relationships.
  - Institutionalized persons.
  - Women, Pregnant women
- People receiving welfare benefits or social assistance
  - Some ethnic and racial minorities
- Homeless persons, nomads, refugees or displaced persons
- People living with disabilities, with incurable or stigmatized conditions or diseases
- Furthermore, in some contexts vulnerability might be related to gender, and age (Children and Adolescents, Elderly...)

**Figure 3: Who are considered Vulnerable Persons and Groups?**

According to the Declaration of Helsinki, vulnerable groups and individuals “may have an increased likelihood of being wronged or of incurring additional harm.” This implies that vulnerability involves judgments about the probability and degree of physical, psychological, or social harm, as well as a greater susceptibility to deception or having confidentiality breached. It is important to recognize that vulnerability involves not only the ability to provide initial consent to participate in research, but also aspects of the ongoing participation in research studies. In some cases, persons are vulnerable because they are relatively (or absolutely) incapable of protecting their own interests. This may occur when persons have relative or absolute impairments in decisional capacity, education, resources, strength, or other attributes needed to protect their own interests. In other cases, persons can also be vulnerable because some feature of the circumstances (temporary or permanent) in which they live makes it less likely that others will be vigilant about, or sensitive to their interests. This may happen when people are marginalized, stigmatized, or face social exclusion or prejudice that increases the likelihood that others place their interests at risk, whether intentionally or unintentionally. Although research ethics committees can require special protections only for potential participants collectively for a particular project, researchers and others involved in research must take into account factors that render individual participants vulnerable and take appropriate steps to mitigate those factors. (Fig:3). A special attention to research on vulnerable populations is reported in 3 international documents.

WMA - Declaration of Helsinki: the article 19 specifies that “some groups and individuals are particularly vulnerable and may have an increased likelihood of being wronged or of incurring additional harm. All vulnerable groups and individuals should receive specifically considered protection.” (Ref.3)

In the Universal Declaration of Bioethics and Human Rights (UDBHR) of the UNESCO- 2005, the article 8 postulates “Respect for human vulnerability and personal integrity: in applying and advancing scientific knowledge, medical practice and associated technologies, human vulnerability should be taken into account. Individuals and groups of special vulnerability should be protected and the personal integrity of such individuals respected.”(Ref.4)

More elaborated recommendations about research with vulnerable populations or individuals are reported in the “International Ethical Guidelines for Health-related Research Involving Humans” (2016) of the Council for International Organizations of Medical Sciences (CIOMS) in partnership with the WHO and UNESCO.

There are 6 guidelines referring to research involving vulnerable groups and individuals: (Ref.5)

#### **Guideline 15: research involving vulnerable persons and groups**

“When vulnerable individuals and groups are considered for recruitment in research, researchers and research ethics committees must ensure that specific protections are in place to safeguard the rights and welfare of these individuals and groups in the conduct of the research”.

#### **Guideline 16: research involving adults incapable of giving informed consent**

“Adults who are not capable of giving informed consent must be included in health-related research unless a good scientific reason justifies their exclusion.

As adults who are not capable of giving informed consent have distinctive physiologies and health needs, they merit special consideration by researchers and research ethics committees. Specific protections to safeguard the rights and welfare of these persons in research are therefore necessary.”

Before undertaking research with adults who are not capable of giving informed consent, the researcher and the research ethics committee must ensure that:

- “- a legally authorized representative of the person who is incapable of giving informed consent has given permission and this permission takes account of the participant’s previously formed preferences and values (if any); and
- the assent of the subject has been obtained to the extent of that person’s capacity, after having been provided with adequate information about the research at the level of the subject’s capacity for understanding this information.”

#### **Guideline 17: research involving children and adolescents**

“Children and adolescents must be included in health-related research unless a good scientific reason justifies their exclusion. As children and adolescents have distinctive physiologies and health needs, they merit special consideration by researchers and research ethics committees.

However, their distinctive physiologies and emotional development may also place children and adolescents at increased risk of being harmed in the conduct of research. Moreover, without appropriate support, they may not be able to protect their own interests due to their evolving capacity to give informed consent. Specific protections to safeguard children's rights and welfare in the research are therefore necessary.

Before undertaking research involving children and adolescents, the researcher and the research ethics committee must ensure that:

- a parent or a legally authorized representative of the child or adolescent has given permission; and
- the agreement (assent) of the child or adolescent has been obtained in keeping with the child's or adolescent's capacity, after having been provided with adequate information about the research tailored to the child's or adolescent's level of maturity."

#### **Guideline 18 and 19: women as research participants**

"Women must be included in health-related research unless a good scientific reason justifies their exclusion. Women have been excluded from much health-related research because of their child-bearing potential. As women have distinctive physiologies and health needs, they merit special consideration by researchers and research ethics committees. Only the informed consent of the woman herself should be required for her research participation.

Since some societies lack respect for women's autonomy, in no case must the permission of another person replace the requirement of individual informed consent by the woman.

Women of child-bearing potential must be informed in advance of the possibility of risks to the fetus should they become pregnant during their research participation.

When participation in research might be hazardous to a fetus or a woman if she becomes pregnant, sponsors and researchers must guarantee access to pregnancy tests, effective contraceptive methods before and during the research and to safe, legal abortion."

Women still experience lack of respect and unequal treatment in some countries, demonstrated with evidence from local research (Lack of respect, low status of women, violence against women, poor quality of maternal care, poor communication skills, Informed consent, ethical dilemmas, etc.). The role of ethics committees but also role of society, national commissions, is here necessary.

#### **Guideline 20: research in disasters and disease outbreaks**

"Disasters arising from events such as earthquakes, tsunamis or military conflicts, and disease outbreaks, can have a sudden and devastating impact on the health of large affected populations. In order to identify effective ways of mitigating the health impact of disasters and disease outbreaks, health-related research should form an integral part of disaster response. However, the conduct of research must not unduly impact the response to the victims of a disaster.

In the conduct of research in disasters and disease outbreaks, it is essential to uphold the ethical principles embodied in these Guidelines. Conducting research in these situations raises important challenges such as the need to generate knowledge quickly, maintain public trust, and overcome practical obstacles to implementing research. These challenges need to be carefully balanced with the need to ensure the scientific validity of the research and uphold ethical principles in its conduct.”

Research in disasters and disease outbreaks should ideally be planned ahead. Health officials and research ethics committees should develop procedures to ensure appropriate, expedient and flexible mechanisms and procedures for ethical review and oversight. For example, research ethics committees could pre-screen study protocols in order to facilitate and expedite ethical review in a situation of crisis. Similarly, researchers and sponsors could make pre-arrangements on data- and sample-sharing that research ethics committees review in advance.

Sponsors and research ethics committees should evaluate and seek to minimize the risks to researchers and health professionals conducting research in a disaster context. Sponsors should include in the protocol a plan for mitigating adverse events. Furthermore, appropriate resources for mitigation measures should be included in the protocol budget.”

### **Research in the Eastern Mediterranean Region (EMR)**

There are 2 levels for controlling the ethics of research involving vulnerable populations or individuals. The first level is national through the National Ethics Committees; an example is with the Lebanese National Consultative Committee on Ethics (CCNLE, LNCCE)-



This committee was created by the Ministry Council in 2001, Decree No: 63/2001 (15/5/2001), recognized of Public Utility and as an Advisory Board for Bioethics Issues including Legislation, Recommendations, Promotion, and Education

A good collaboration between the Ministry of Public Health and the CCNLE/LNCCE had led to a Ministerial Decree (2014) defining the creation and role of Institutional Review Boards (IRBs) or Research Ethics Committees (REC) in the Universities and Hospitals conducting research in Human Subjects.

The role of the IRBs/ RECs) as an independent actor protecting human research participants is well described in key international guidelines (Declaration of Helsinki, CIOMS Regulations) and in this decree.

This role requires that the REC be properly constituted, with competent members, having adequate resources, working with a regulatory framework (Ref.6)

The other level of control is through the World Health Organization (WHO) and its Research Ethics Review Committee (RERC). This Committee is facing several challenges in the MENA countries: lack of national regulations, inadequate member diversity and membership competence, and inability to monitor approved protocols.

The members of the Research Ethics Review Committee (RERC) are appointed by WHO Regional Director to review the protocols of all health research projects involving human subjects submitted to WHO for funding in the Region.

For many years, WHO supported a great number of regional events in different MENA countries with the aim of education, and training of investigators and reviewers of research proposals.

### **Recommendations and Conclusion**

Research on human subjects is necessary for the advancement of knowledge, science and treatments of disease. Because, by “placing some people at risk of harm for the good of others, clinical research has the potential for exploitation”, we recommend enhanced educational efforts regarding general research concepts to enhance the validity of informed consent.

A way ahead should be initiated by developing capacity in health research & ethics, answer to resource requirements to conduct and sustain ethical review, and creation of novel training and learning opportunities.

The involvement of courageous people in such research has made possible major advances in science and medical treatment. Such people deserve the highest standards which can be ensured by using good clinical practices and ethical treatment when conducting research.

\*The Author declare No Conflict of Interest

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## Assessing Cultural Competence of Physicians in Diabetes Management during Ramadan

Prachi Shah<sup>1</sup>, and Asha Shajahan<sup>2</sup>

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### Abstract

**Introduction.** Islam is the fastest growing religion in the world and diabetes is one of the fastest growing chronic disease in the world. There is a growing number of Muslim patients being seen by primary care. Fasting during Ramadan is an obligatory part of religion for many Muslims. Patients with diabetes are generally considered exempt from fasting due to their chronic health condition. However, many diabetic followers choose to fast during Ramadan and, therefore, are at an increased risk of developing complications like hypoglycemia, dehydration, and diabetic ketoacidosis. Current guidelines recommend that diabetic patients must receive counseling and education before fasting during Ramadan. To meet these recommendations, it is essential that physicians are aware of the cultural practices of fasting during Ramadan and its sequelae in diabetes management.

### Objectives

1. Assess physicians' knowledge of the cultural practices of fasting during Ramadan and the complications faced by diabetic patients who fast during Ramadan.
2. Assess physicians' confidence and attitudes in counseling diabetic patients who fast during Ramadan.
3. Develop and evaluate an educational tool aimed at improving cultural competence in physicians caring for diabetic patients who fast during Ramadan.

**Methods.** This exploratory pilot study utilized a pre – and post – intervention survey design. Study participants included Family and Internal Medicine attending physicians from a large hospital system in Southeast Michigan. Physicians were provided with a pre-survey to assess their current knowledge about Ramadan and their attitudes about treating diabetic patients, who fast. One week later, an educational intervention was presented to the participants. This included an interactive PowerPoint presentation discussing Ramadan, fasting-related complications, and recommendations for diabetes management. Their knowledge and attitudes were evaluated with post-surveys administered immediately and 3 months after the intervention. Data was examined using descriptive statistics and multiple comparisons between the three time points were integrated to determine the change in knowledge and attitudes.

**Results.** The knowledge scores increased between the pre-intervention group (M= 11.50, SD= 2.96) and post-intervention group (M= 18.00, SD= 2.68) assessed immediately after the intervention. However, the knowledge scores decreased (M= 12.00, SD= 1.77) when participants were assessed three months after the intervention. Similarly, participants' confidence level in

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counseling diabetic patients who fast during Ramadan initially improved from before (50.0%) to immediately after the intervention (83.3%), and subsequently decreased three months later (37.5%). All participants (100%) found the educational intervention helpful.

**Conclusions.** Study findings suggest that there are deficits in physicians' knowledge about Ramadan and the fasting practices observed during this time. Our study also identified that the educational intervention increased physicians' knowledge and comfort level in managing diabetic patients during Ramadan.

## Introduction

As one of the five pillars of Islam, fasting during Ramadan is obligatory for all healthy Muslims. The fast lasts for a period of 29-30 days during which followers must abstain from eating or drinking. Although the fast starts at sunrise and ends at sunset each day, the duration of the fast depends on the season, with longer fasts during summer and shorter ones during winter.<sup>1</sup> During fasting, followers usually eat two meals: *Iftar* (after sunset) and *Suhur* (before sunrise).<sup>2</sup> Pregnant women, children and followers who suffer from health conditions are exempt from fasting. Missed fasts should be completed, once the follower has recovered to normal health. However, most of these followers embody a strong desire to participate in Ramadan and fast with their communities despite their exemption.<sup>3</sup>

Diabetic patients who fast during Ramadan are at an increased risk of developing complications like hypoglycemia (reduced blood glucose levels) and hyperglycemia (elevated blood glucose levels). Prior studies indicate that changes in eating patterns during Ramadan resulted in a 4.7-fold and 7.5 –fold increase in the occurrence of severe hypoglycemic and hyperglycemic events respectively.<sup>1</sup> These elevated risks encountered by diabetic followers can be attributed to the consumption of traditional, carbohydrate-rich meals consisting of fried foods and sweets during non-fasting hours.<sup>4</sup> Also, changes in blood glucose levels can be caused by variation in exercise and physical activities, and the frequency of taking oral anti-diabetic medications, which are prohibited during fasting hours.<sup>5,6</sup> Moreover, diabetic Muslims, who fast during Ramadan, can suffer from diabetic ketoacidosis. The risk for developing diabetic ketoacidosis increases, in response to declines in food intake and subsequent insulin dosages during Ramadan. Also, decreased fluid intake during fasting has the potential of causing other metabolic complications like dehydration, hypotension and thrombosis.<sup>7</sup>

The Epidemiology of Diabetes and Ramadan (EPIDIAR) study, a population-based, retrospective study, was conducted in 13 countries with large Muslim populations. This study served as the first large-scale attempt to understand the potential effect of fasting on the health of diabetic patients during Ramadan and the care they received. The EPIDIAR study concluded that a high number of diabetic patients continued fasting during Ramadan, despite being exempt from this duty by religious authorities. The study also identified the urgent need for patient education about the risks of fasting and the required changes to their diabetes management plans to accommodate fasting.<sup>8</sup> Following the EPIDIAR study, research has been conducted to better understand the pathophysiology of Ramadan fasting on diabetes and its metabolic effects. Several studies have identified risks such as hyperglycemia, and hypoglycemia as well as the effect of fasting on the efficacy of oral anti-diabetic medications and insulin treatments.<sup>9,10</sup>

Recently, few studies have assessed patients' knowledge and management of diabetes during Ramadan to highlight the benefits of an educational intervention program for patients. Upon the

implementation of a Ramadan focused-structured education program, a UK based study demonstrated the positive outcome of decreased adverse metabolic effects in diabetic Muslims and improved self-management skills during Ramadan.<sup>4</sup> However, there is a lack of similar studies assessing physicians' knowledge about the effects of Ramadan fasting on diabetes and the appropriate management and treatment guidelines.<sup>11</sup> Many providers may not be aware of cultural fasting practices followed by Muslims and the complications that diabetic patients may encounter during Ramadan. Uncertainties regarding the physicians' cultural awareness of Ramadan and their level of preparedness to mitigate fasting-related complications remain unaddressed. Additionally, there has been no definitive research about assessing physicians' cultural competence in discussing effects of fasting with diabetic Muslim patients or evaluating an education program geared towards physicians. Thus, this pilot study aims to address this issue by assessing doctors' cultural and specific knowledge about Ramadan fasting in diabetic patients; and providing an educational tool to increase their cultural competence.

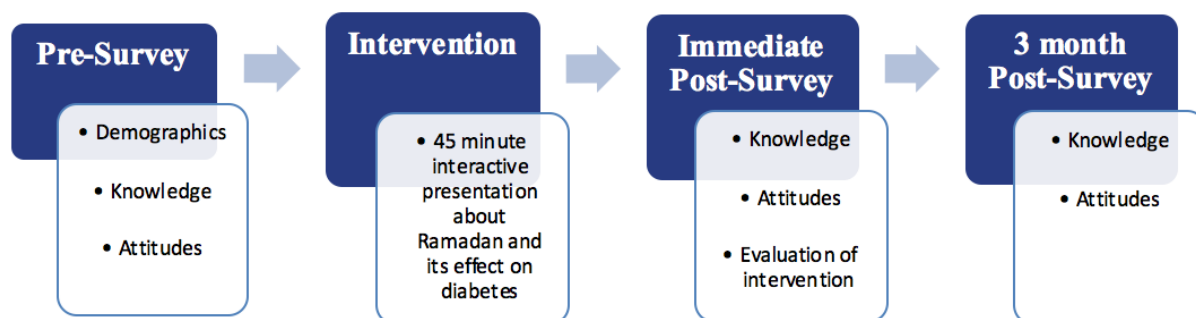
## Objectives

The objectives of this study were to assess physicians' knowledge and confidence in counseling diabetic patients, who fast during Ramadan; and to assess their attitudes and comfort in counseling such patients. The educational intervention was aimed to improve cultural competence in physicians, who care for diabetic patients fasting during Ramadan.

## Methods

### Study design

This project was a pilot observational study utilizing a pre- and post- intervention survey design. Study participants included attending physicians practicing Family medicine or Internal medicine at a large hospital system in Michigan, USA. Physicians were presented with a pre- intervention survey to assess their knowledge, confidence and attitudes about diabetic patients who fast during Ramadan. Using the results of the pre- intervention survey, an educational intervention was developed and provided to physicians. The subjects were evaluated using two post-intervention surveys, administered immediately and 3 months after the educational intervention, respectively (Figure 1).



**Figure 1.** Study Timeline. The pre-survey was followed by the educational intervention. Subsequently, participants were followed using post-surveys immediately and 3 months later.



### Surveys

Both the pre-intervention and post-intervention surveys were structured into two domains: knowledge and attitudes.

- Knowledge: These questions assessed the subjects' understanding of Ramadan, cultural practices observed by followers and complications arising in patients with diabetes due to Ramadan fasting. Questions were either multiple-choice or dichotomous (true/false).
- Attitudes: These questions assessed subjects' attitudes towards diabetic patients fasting during Ramadan, and their confidence level in counseling such patients and providing recommendations for changes in diet, physical activity and diabetes management plans. These attitudes were rated by subjects on a 5-point Likert scale (strongly disagree, disagree, neither agree or disagree, agree and strongly agree).

### Educational Intervention

The results of the pre-intervention survey informed the design of the educational intervention. The educational intervention included a PowerPoint presentation, outlining background information about Ramadan and cultural practices observed by followers during fasting. The intervention also briefly discussed potential fasting-related complications observed in diabetics and provided recommendations for diet and physical activity. The presentation was based on the guidelines released by the International Diabetes Federation and Diabetes and Ramadan International Alliance (IDF-DAR) in 2016, and those released by the American Diabetes Association (ADA) in 2010.

### Outcome Measures

The study aims to evaluate the effectiveness of the educational tool by comparing physicians' knowledge before and after the intervention is administered. The outcomes of interest from the pre – and post – intervention survey surveys include distribution of demographics and attitude responses as well as the frequency of correct responses for knowledge questions. This will allow us to evaluate the effectiveness of the educational intervention and ultimately the subjects' knowledge about Ramadan and their confidence in counseling and caring for diabetic patients who fast.

## **Results**

### Demographics Characteristics

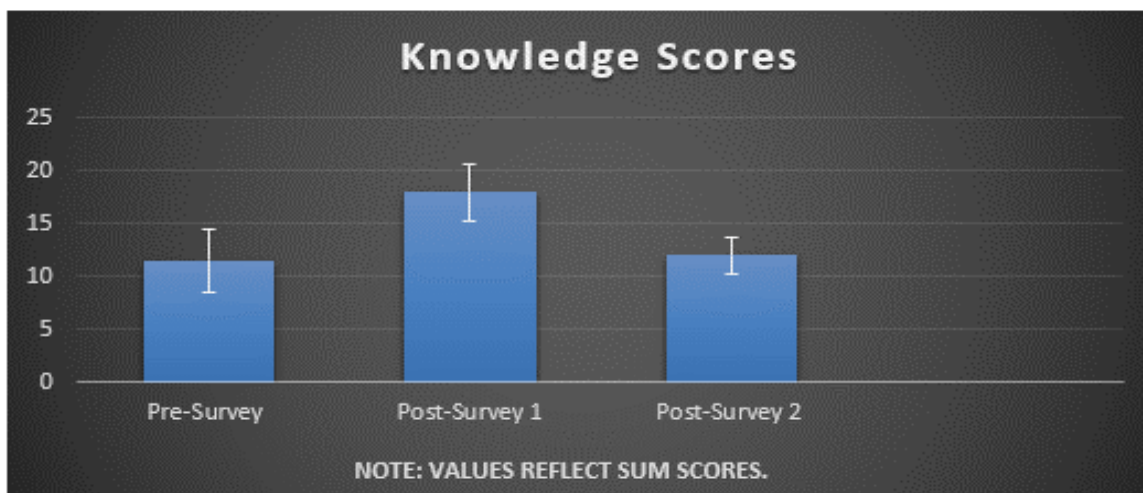
Of the 18 participants who completed the pre-intervention survey, 13 practiced Family medicine and 5 practiced Internal medicine. 88.9% of the participants knew someone who participates in fasting during Ramadan, while only 11.1% had participated in Ramadan themselves (Table 1).

### Knowledge Domain

The pre-intervention knowledge scores (M=11.50, SD=2.96, n=18) were lower than the post – intervention survey 1 knowledge scores (M=18.00, SD=2.68, n=6). However, our data suggests that these mean knowledge scores decreased again during the post – intervention survey 2 (M=12.00, SD=1.77, n=8), administered 3 months later (Fig

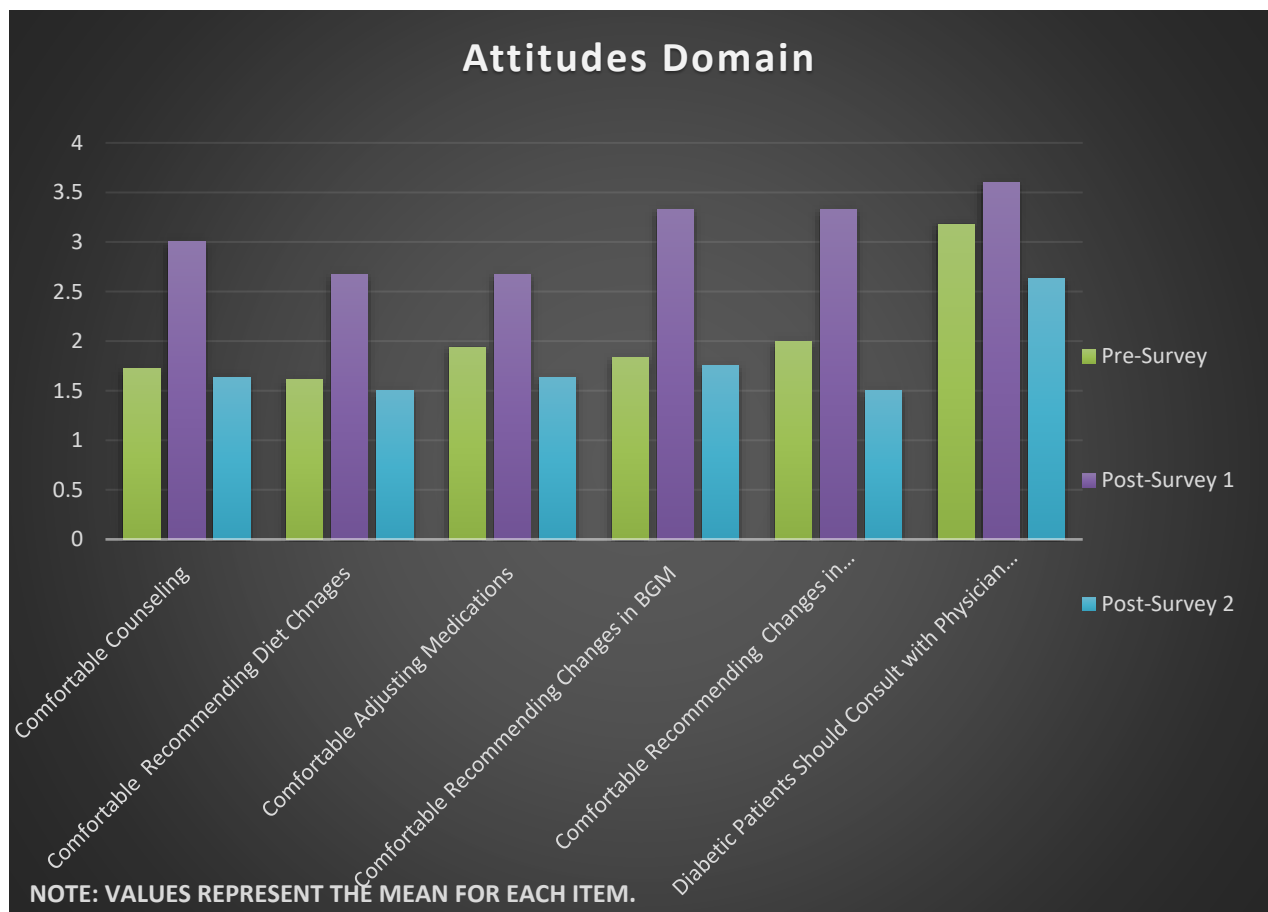
**Table 1.** Demographic Characteristics of the Study Participants

| Demographic Characteristics                                     |                                  | % of Total |
|---|----------------------------------|------------|
| Gender  | Male                             | 55.6%      |
|   | Female                           | 44.4%      |
| Race  | White                            | 66.7%      |
|   | Black or African American        | 5.6%       |
|   | Asian                            | 22.2%      |
|   | Other                            | 5.6%       |
| Ethnicity   | Hispanic/Latino                  | 0          |
|   | Not Hispanic/Latino              | 72.2%      |
|   | Arabic or Middle Eastern Descent | 5.6%       |
|   | Other                            | 22.2%      |
| Location of Medical School                                      | United States                    | 83.3%      |
|   | International                    | 16.7%      |
| Has participated in Ramadan                                     | Yes                              | 11.1%      |
|   | No                               | 88.9%      |
| Know someone who participates in Ramadan                        | Yes                              | 88.9%      |
|   | No                               | 11.1%      |
| Has asked diabetic patient whether he/she celebrates Ramadan    | Yes                              | 33.3%      |
|   | No                               | 66.7%      |
| Have diabetic patients asked for recommendations during Ramadan | Yes                              | 33.3%      |
|   | No                               | 66.7%      |

**Figure 2.** Knowledge Scores. The scores for the knowledge domain initially improved from the pre-survey to post-survey 1, administered immediately after the intervention. The knowledge scores subsequently decreased in post – survey 2, administered 3 months after the intervention.

### Attitudes Domain

In the pre-intervention survey, 50% of the participants reported decreased comfort in counseling diabetic patients who fast during Ramada, while 44.4% reported decreased confidence in recommending changes in both blood glucose monitoring (BGM) and medication regimen to these patients. Moreover, 77.8% responded positively to the need for diabetic patients to consult with their physicians prior to Ramadan. In post-survey 1 administered immediately after the intervention, 83.3% reported confidence in counseling diabetic patients who fast; and 66.7% and 100% reported comfort in recommending changes in BGM and medication regimens respectively. However, only 25% reported confidence in counseling diabetic patients (Figure 3).



**Figure 3.** Attitude Domain. The mean scores for the attitudes domain initially improved from the pre-survey to post-survey 1, administered immediately after the intervention. The knowledge scores subsequently decreased in post – survey 2, administered 3 months after the intervention.

## Discussion

Our study identified that participants were not familiar with cultural practices of fasting during Ramadan prior to the educational intervention as the mean knowledge scores were  $11.50 \pm 2.96$  and only 44.4% of the participants scored at or below 50%. These results can be attributed to the demographics of the study population with most participants identifying as being White (Non-Hispanic or Latino), and only a few participants identifying as being of Arabic or Middle Eastern descent. In addition, most subjects had never participated in Ramadan themselves, as only 11.1% having fasted before. Interestingly, 88.9% knew someone who has fasted during Ramadan; however, this was not reflected in the pre-intervention knowledge scores. Previous studies indicated a similar finding with providers having limited knowledge specific to Ramadan, and the practice of fasting.<sup>12</sup>

The pre-intervention results also identified an important gap in knowledge: only 11.9% of the study population knew that blood glucose monitoring is not considered as breaking the fast. Similarly, Zainudin et al. found a deficit in knowledge about blood glucose monitoring during their study.<sup>13</sup> This misconception can result in physicians improperly counseling diabetic patients who fast during Ramadan. It may also result in patients monitoring their blood sugar levels less frequently, and subsequently experience complications like hypoglycemia.

The mean knowledge score improved after the education intervention to  $18.00 \pm 2.68$ . This result supports the effectiveness of the educational intervention developed using the guidelines provided by the IDF-DAR and ADA. The intervention was focused on educating physicians about the common practices of Ramadan, the potential complications faced by diabetics and recommendations for changes in diet and physical activity. However, the mean knowledge score declined to  $12.00 \pm 1.77$  three months after the education. This suggests the study population did not retain the information from the educational intervention. This finding can be justified by when the study was conducted. The post-intervention survey was administered a few months prior to Ramadan, so physicians may not have encountered diabetic patients who practice who fast yet.

This study also identified that many physicians were initially not comfortable managing diabetic patients during Ramadan. However, after the education intervention, most physicians reported an increased confidence in counseling diabetic patients and recommending changes in diet, physical activity and blood glucose monitoring. This establishes the effectiveness of the educational intervention in informing physicians about the principles of Ramadan and fasting practices observed by followers. It is essential that physicians are able to counsel such patients despite differences in language, culture and religious practices. There is an immediate need of providing culturally appropriate education to help ethnic minority patients manage chronic diseases like diabetes.<sup>14</sup> Thus, to effectively care for diabetic patients who fast during Ramadan, physicians need to be aware of cultural and religious practices of fasting. This will allow physicians to address complications that arise from fasting and recommend changes in medications, diet and management plans.<sup>9</sup>

Moreover, increasing physicians' knowledge about fasting practices during Ramadan and its effect on the health of diabetic followers is necessary to improve self-management skills of patients. Diabetics patients who participated in pre-Ramadan medical assessments and

structured education programs were better equipped to manage their diabetes. These patients presented with fewer adverse complications because their culturally aware physicians were able to recommend individualized changes in medications and correctly educate their patients.<sup>7</sup> Therefore, the need to first educate physicians to provide optimal advice to patients is evident.<sup>3</sup> Additionally, improving physicians' knowledge will foster a stronger patient-physician relationship. Limited knowledge about fasting practices during Ramadan may result in physicians in prohibiting diabetic patients from fasting, despite the presence of interventions for accommodating this practice.<sup>15</sup> Instead, demonstrating cultural sensitivity to religious beliefs and practices, effectively communicating with patients about fasting associated risks and tailoring recommendations to match socio-cultural circumstances will increase patients' trust.<sup>3</sup> This will improve patients' adherence to recommendations, helping them have safe and healthy fasts.

### **Limitations**

The limitations of the study include the small sample size. Since this study is a pilot study, we believe the smaller sample size would still suffice in identifying gaps in knowledge about the impact of Ramadan fasting on diabetic patients and the effectiveness of the educational intervention. Additionally, due to limited research on this subject, no validated surveys or educational interventions were located. However, the surveys and intervention utilized in this study were adapted from published scientific articles and reputed organizations. Also, some subjects were lost to follow up due to the variable attendance of physicians at staff meetings, where the surveys and intervention were administered.

### **Conclusion**

Our study showed that most physicians were not familiar with the fasting practices followed during Ramadan and felt uncomfortable counseling diabetic patients who fast. Our findings indicated the need of informing physicians about the principles of Ramadan to improve their cultural awareness as well as the care they provide to diabetic patients.

### **Acknowledgements**

We wish to acknowledge the following programs and individuals: the OUWB Capstone Program for funding this project; Sophia Khalil for helping with developing the surveys and educational intervention; and Dan Gildner for assisting with data analysis.

### **Conflict of Interest**

No conflict of interest declared.

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## Older Adults Nutrition and Oral Health Assessments Documented by Interprofessional Team Visits with Older Adults

*Rania Krayem, Abraham Hussein, Leticia Haff, Stephanie Gilkey, and Jennifer Mendez*

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### Abstract

Patient-centered healthcare based on interprofessional care is an essential factor to improve health quality in patients. In the older adults' population, comorbidities and the lack of active preventive measures are factors that can impact their health. The focus of this study is to find an association between oral health and nutrition. Multidisciplinary interprofessional teams of students from the School of Medicine, Physician Assistant Studies Program, and other programs at Wayne State University conducted on-site quantitative Mini-Nutrition Assessment (MNA) and the General Oral Health Assessment Index (GOHAI) (mainly at older adults' residences) during Fall 2016. The study used quantitative assessments for nutrition (NMS) and for oral health (GOHAI). Attributes for the data collected correspond to "normal nutrition status" and "at risk for malnutrition" for NMS, and "no need for dental treatment" and "need dental treatment" for GOHAI. Oral health and nutrition are essential elements that healthcare providers need to address for "the preservation of general health." <sup>1</sup> Similarly, healthcare providers for older adults should focus on using multi-factorial general health maintenance attributes to achieve effective health outcomes.

Introduction: Oral health and nutrition are essential elements that healthcare providers need to address for the improvement of general health. The objective of this interprofessional team visit (IPTV) study is to relay the importance of health assessments and patient education as well as training healthcare providers to compile the assessments and advocate for preventive healthcare measures. The goals of health care providers, institutions, and medical systems are to provide services to patients and achieve optimal medical outcomes. By applying different preventive screening tools to the health care services, the healthcare quality improves and patients' satisfaction.

### Objectives

- Demonstrate the benefits of interdisciplinary collaboration among health members and its outcomes on the older patients' population.
- Gain an understanding about factors affecting older adults' general health issues, especially oral health and nutrition.
- Integrate different general assessment tools in patient-centered medical care.
- Be able to correlate findings from different assessments of data collected.

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## Methods

Tools used: Mini-Nutrition Assessment (MNA) and Oral Health Assessment Index (OHAI)

- The study used quantitative assessments for nutrition (NMS) and oral health (OHAI)
- Attributes for the data collected correspond to “normal nutrition status” and “at risk for malnutrition” for NMS, and “no need for dental treatment” and “need dental treatment” for OHAI
- 50 Multidisciplinary interprofessional teams of students from the School of Medicine, Physician Assistant Program, and other programs at Wayne State University conducted on-site quantitative Mini-Nutrition Assessment (MNA) and Oral Health Assessment Index (OHAI) during Fall 2016

## Results

50 older adults were interviewed; 34 females, 12 males, and 4 unidentified

- 31 out of 50 (62%) showed +1 correlation between nutrition and oral health
- 20 of the 31 had “normal nutrition status” and “no need for dental treatment,” and 11 were “at risk of malnutrition” and “need for dental treatment”
- 15 out of 34 (44%) females were “at risk of malnutrition” and 11 (32%) “need dental treatment”
- 1 out of 12 (8%) males were “at risk of malnutrition” and 7 (58%) “need dental treatment”
- 25 out of 34 (73%) females showed +1 correlation between nutrition and oral health
- 6 out of 12 (50%) males showed +1 correlation between nutrition and oral health

## Discussion

The focus of this study is to find association between oral health and nutrition in older adults. This study reflects on the continued medical demands from the growing older adults’ population; it shows some association between oral health and nutrition status. The study also addresses the need to integrate different medical health assessments to provide better care for the geriatric population. For the older adults’ population, co-morbidities as well as lack of active preventive measures can impact their health; therefore, healthcare providers for older adults should focus on using multi-factorial general health maintenance attributes to achieve effective health outcomes. The limitations to this study are the number of surveyed adults and other factors and co-morbidities affecting their health.

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# PRESENTATION SUMMARIES



## **Advancing Equity and Justice: A Leadership Mandate**

***Vence Bonham, Paul Elam, May Yassine Darwish, Renée Branch Canady, Bengt Arnetz***

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Courageous leadership is a vital ingredient in advancing a health equity agenda. In this session, accomplished leaders shared their experience and insight in how to create a culture where health equity can be addressed authentically. Examples of how to overcome barriers in this process and why it is more important than ever to do so now were discussed by the following panelists:

- **Vence Bonham, JD**, Senior Advisor to the Director on Genomics and Health Disparities and Associate Investigator, National Human Genome Research Institute
- **Paul Elam, PhD**, Chief Strategy Officer, MI Public Health Institute (MPHI)
- **May Darwish Yassine, PhD**, Chief Program Officer, MPH

Context for the panel was provided as a keynote by **Renée Branch Canady, PhD, MPA**, Chief Executive Officer, MPH; and the panel reactor was **Bengt Arnetz, MD, PhD, MPH**, Professor and Chair Department of Family Medicine, MI State University College of Human Medicine. Some would submit that we are faced with a crisis of leadership in the population health space. How do the experiences of public health and health care professionals and their unique experiences confirm or contradict that supposition?

Consistent with the conference theme, “A Call to Action for Global Health Equity and Social Justice,” the mandate for leadership is inextricably tied to attaining health equity. Dr. Canady emphasized that health equity cannot be advanced without leadership, a point reiterated by Dr. Arnetz in his closing remarks. In particular, the need is for transformative leadership and transformed leaders who are courageous risk takers. Just as the solutions to health inequities are “upstream,” so must current day leaders move upstream for an era of change to manifest.

Leadership takes many forms and styles as the panelist remarks revealed. But the need for strong leadership received unilateral agreement. The mandate for leadership that is responsive to issues of equity and justice requires focusing on both the beginning and the end of the leadership trajectory. Dr. Paul Elam spoke to the importance of succession planning and raised two key points:

- 1) Leaders should actively engage in leadership development, and
- 2) Leaders should prioritize talent pipeline development efforts.

Related to being engaged in leadership development, the Kresge Foundation Emerging Leaders in Public Health Initiative was raised as a model to demonstrate successful work in this

space. Similarly, pipeline development is another successful strategy, with many lessons learned, from the commendable efforts of the Annie E. Casey Foundation Leaders in Equitable Evaluation Initiative. Leaders should prioritize and use their expertise, knowledge, reputation and resources to support emerging leaders and prepare them for leadership roles. Leaders should also invest time in systematic efforts to identify diverse talent and engage these scholars and professionals in education, mentoring, networking, and training opportunities to help establish and sustain competent and diverse leaders in the field. Elam contended that the development of strong leaders in general and exemplary health equity leaders requires a generational mindset. Current leaders must maintain a commitment to the next generation of leaders and see themselves as responsible for leading both the future and the present.

In addition to advocating for the next generation of leaders, current leaders must effectively support emerging and mid-career leaders, as Dr. May Darwish Yassine explained. She identified key values that have led her successful support of emerging and mid-career leaders. Yassine set the fundamental reminder that leadership is not in a title or a position; rather leadership is about responsibility and more about influence and relationship. There are qualities that bring one to a leadership role including one's vision, confidence, and charisma, or perhaps one's experience, unique skills, or expertise. We need to remind ourselves that other leaders share some or all these qualities with us. The leaders we are called upon to lead are typically highly educated and field experts. The potential contributions of these leaders are vital to any organization, so relationships must be managed carefully. They are people with significant resources and strong opinions. How do you leverage the assets of the talented and powerful? How do you motivate and retain these essential talents? The name of the game for Dr. Darwish Yassine is "Servant Leadership" which is luckily a foundational core value for her organization. The principle of "First among equals" allows leaders to serve as thought partners for other leaders and as facilitator of their success. Finally, Yassine identified three essentials that are key to leading for health equity including:

- 1) Look to earn and keep leaders' trust, trust is a vital ingredient that I depend on;
- 2) Remain genuine and authentic; and
- 3) Cater to needs and not to equality, as this is the foundation of health equity.

Having thoughts about the nature of leadership stirred in the minds of attendees, Dr. Bonham applied these features to current emergent issues in the field. Precision Medicine as an innovation for disease treatment and prevention, and the integration of Genomic and Precision Medicine into health care today are cutting edge areas where skillful leadership is required. Another vital area where the application of leadership is required includes our ability to harness "Big Data" which offers health care providers the ability to integrate genomic and precision medicine into health care. Consider whether Precision and Genomic Medicine will be able to Improve the Health of All? Bonham argued that will depend on our ability to provide access to the diverse population of the United States and globally.



In summary, panelists closed with their favorite leadership quotes, shared here:

- “We cannot walk alone. And as we walk we must make the pledge that we shall always march ahead. We cannot turn back.” **Martin Luther King Jr.**
- “A leader must produce other leaders. Influence those who follow to birth their kind and develop others to lead.” - **Archibald Marwizi**
- “True leaders don’t create followers...they create more leaders!” - **Ralph Nader**
- “Great leaders check their ego at the door and empower others to excel.” - **Deborah Gillis**
- “You give but little when you give of your possessions. It is when you give of yourself that you truly give.” - **Kahlil Gibran**

This diverse and experienced panel summarily argued that leadership for health equity and social justice requires “staying the course.” Do not get lost in the noise of the day; value diverse voices; and be guided by values. We mentor others every day: be careful what they (others) take away from you; and always keep your focus on health equity.



## **Stress, Risk and Resilience in Syrian Refugees in the US: A Project of Prevalence, Neurobiology, Culture, Environment, and Interventions**

***Arash Javanbakht, Lana Grasser, Cynthia Arfken***

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Years of conflict in Syria have exposed millions to multiple layers of chronic stress. These include war related trauma, scarcity of resources, uncertainty about the future, loss of loved ones and belongings, relocation, and adjustment to the new environment with its cultural and political challenges. When resettlement happens after years of struggling to survive, new stressors, of becoming a minority, lack of relevant language, social, and cultural skills, poverty, and potential discrimination will add to the previously experienced stressors. Previous work from refugee camps and neighboring countries to Syria show high level of PTSD (27.2-83.4%) and depression (37.4-43.9%) among Syrian refugees. It is especially important in the light of the debilitating effects of these conditions on the person's functioning and the ability to cope with the new environment, and the long-term impact on physical and mental health both among adults and children. Only a few studies have researched the impact of trauma among Syrian refugee children, showing high level of trauma and anxiety.

Despite reports on high level of trauma among refugees in the Middle Eastern countries, much less is known about the consequences of exposure to chronic trauma and stress in Syrian refugees resettled in the Western countries. Over the past few years, Stress, Trauma, and Anxiety Research Clinic (STARC) at Wayne State University has taken the mission of determining the impact of such chronic exposure to trauma among Syrian refugees resettling in the US, and addressing the trauma with creative intervention methods. We have also taken on the important task of educating the public and the scientific community about the difficulties this population has faced, especially in the current political atmosphere. This project has been featured on the CNN, Aljazeera, NPR, American Psychiatric Association, Anxiety and Depression Association of America, and American Academy of Child and Adolescent Psychiatry.

We have screened 157 adults and 131 children Syrian refugees resettling in the southeast Michigan within the first month of their arrival in the US. This happened at the Arab American Chaldean Council primary care clinics where the mandatory health screening took place. For adults we used PTSD Checklist DSM-IV version (PCL; PTSD), and Hopkins Symptoms Checklist (HSCL) for anxiety and depression. For children we used UCLA PTSD Reaction Index for PTSD, and Screen for Child Anxiety Related Disorders (SCARED) to screen for anxiety and its subtypes. Findings suggest very high impact among both adults and children. 32.2% of adults screened positive for PTSD, which is comparable to lifetime prevalence among Vietnam war veterans. 40.3% of the adults screened positive for high anxiety, and 47.7% for depression. Comorbidity is also very high. More than 70% of adults with PTSD, also show high anxiety, or depression. This is very important as PTSD and depression both are among the most debilitating medical conditions. Perception of health, and adversity among adults highly correlated with their PTSD symptoms

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severity. Around 82% of those who perceived their health as poor or fair, and adversity as high, screened positive for PTSD. This suggests that perceived health and adversity may help identify those with higher level of trauma in primary care clinics. Although our data suggest the parents may have sheltered children against development of full-blown PTSD, the rates of anxiety are very high (53.5%) among children. Separation anxiety, which limits the child's ability of going to school and exploring the new environment needed for successful assimilation, affects 76.7% of the children. All measures of maternal PTSD, anxiety, and depression, correlate with anxiety in their children.

Given scarcity of experts in clinical care for traumatized individuals, and cultural and language barriers to providing such treatments (e.g. prolonged exposure therapy), our team used creative arts and movement therapies for addressing trauma and stress among children and their mothers. We conducted an initial pilot of a community-based program, which provided 9 weeks of art therapy and dance/movement therapy (DMT) to 14 children as well as mindful yoga to 7 mothers. Implementing programming simultaneously allowed multiple family members to benefit—critical as our work has shown symptoms to be shared between mothers and children—and improved adherence to the program, especially in light of high separation anxiety.

After establishing the feasibility and knowing that these methods were well-accepted by the population, we brought the program to a community recreation center and recruited families from a local resettlement agency, Samaritas, Survivors of Torture program. In total, 31 individuals from 9 families enrolled. This time, the programming lasted 12 weeks with data collected at weeks 1, 6, and 12. Data included psychological questionnaires, hair cortisol, and blood (adults) and saliva (children) inflammatory markers. DMT sessions included body-mind centering and musculoskeletal warmups, movement games, breath work and mindfulness exercises, and opening and closing discussions. Art therapy sessions were comprised of kinesthetic engagement through experientials such as drawing breaths, building mindfulness strategies by making items such as meditation jars, and sharing personal experiences in a safe way through collage building and puppetry. Yoga sessions were trauma-informed and mindfulness based, providing meditative mantras, restorative postures, and cultivation of a deep breathing practice for stress relief. Dance and art therapy had the largest significant effect on self-reported anxiety symptoms, specifically separation anxiety. All adult women in the yoga class had initially screened positive for anxiety and depression based on self-report data from the Hopkins Symptoms Checklist-25; at midpoint and maintained to post-treatment, all women's symptoms were decreased to subthreshold. Additionally, for PTSD symptoms self-reported through the PTSD Checklist for Civilians for DSM 5, scores were reduced by over 6 points per person; the DSM characterizes a 5-point decrease as indicative of clinically meaningful effect of treatment. For biological measures, we have observed individual decreases in concentrations of inflammatory cytokines over the course of treatment, however larger sample size is required to produce statistically meaningful data. We look forward to incorporating this measure to produce a better understanding of the biological changes that occur and the potential underlying mechanisms of these cost-effective, community based creative arts and movement interventions.

We continue this cohort to evaluate the epigenetic, family, inflammatory, and environmental correlates of changes in symptoms severity among both children and adults.

## **A Best Practice Model of Trauma- And Grief- Informed Assessment Among Culturally Diverse Youth in Underserved Communities**

***Karen Calhoun<sup>1</sup>, Polly Y. Gipson<sup>2</sup>, Benjamin Oosterhoff<sup>3</sup>, Timothy Brown<sup>4</sup>, Christopher Layne<sup>5</sup>, and Julie Kaplow<sup>4</sup>***

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An alarming number of children, particularly those living in underserved communities, experience a range of psychological and behavioral health issues in response to trauma and bereavement exposure such as Posttraumatic Stress Disorder (PTSD) and/or maladaptive grief reactions (Kaplow et al., 2012; Oosterhoff, Kaplow, & Layne, in press). These issues are often magnified from secondary exposure to accumulating traumatic events, including multiple deaths of family members, friends, and tragedy occurring in their current or former communities. Cultural issues play an important role in the mental health outcomes of diverse youth. For example, among Arab American youth, gender, acculturation/identity stress, exposure to intergenerational trauma (e.g., emigration, war, terrorism), and media reporting of world conflict are potential traumatic stressors that may impact their well-being.

Youth who are grappling with maladaptive grief reactions often exhibit a range of other concurrent distressing reactions. Examples of co-occurring distress reactions include disorientation, disappointment, anger, guilt, insomnia, exhaustion, forgetfulness, hopelessness, fear, social withdrawal, and loss of interest in activities or things the youth previously enjoyed.

Although the overlapping fields of childhood grief and trauma are advancing, many healthcare providers lack access to best-practice guidelines and evidence-based assessment protocols to adequately identify maladaptive grief and/or PTSD, increasing the risk for misdiagnosis and inadequate or misdirected treatment planning. Accordingly, this presentation highlighted findings from the Grief-Informed Foundations of Treatment (GIFT) Network, a national practice-research network that provides trauma- and bereavement-informed screening, assessment, case conceptualization, and treatment planning to a variety of settings that serve bereaved youth. These include school systems; school-based and school-linked health clinics; academic institutions; health systems/hospitals; and mental health organizations serving children, youth and their families.

Our community-engagement approach includes the voices of specific cultural groups to allow for cultural tailoring of assessment tools, ultimately helping stakeholders to identify and reduce PTSD and maladaptive grief reactions among children and adolescents of various backgrounds. Lived experiences inform how receptive clients may be to evidence-based assessment for behavioral health issues. Arab American youth living in the US (either born in the US or native countries) manage assimilation, exposure to trauma, intergenerational associations, culture and religion, perspectives on appropriate expression, and guilt and trust. Collaboration is an

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effective mechanism to facilitate sharing the voice of those affiliated and community perspectives. Practice-based team science aims to enhance the processes and outcomes of collaborative, multidisciplinary team-based research.

Culturally diverse youth in underserved communities face alarmingly high levels of exposure to traumatic events. These events include tension between cultures, racial profiling, homicide and violence, changes in federal laws on immigration and customs enforcement, and national/international transmission of trauma (e.g., shootings, terrorism, war, torture, etc.). No studies to date have systematically examined rates of traumas/losses, or associated posttraumatic stress and maladaptive grief reactions among culturally diverse youth in underserved populations. Bereaved youth experiencing grief as a result of traumatic loss are often overlooked. Prior to the current work, developmentally- and culturally-informed measurement tools have *not* been developed to assess grief reactions in bereaved youth, given that existing measures were validated primarily among elderly Caucasian widows. Thus, there is a great need for empirically-validated, culturally sensitive trauma and grief-informed assessment tools to help identify at-risk youth and ultimately inform intervention efforts.

### **Objectives**

The Grief-Informed Foundations of Treatment (GIFT) Network, funded by the New York Life Foundation, is a practice research network of sites across the country (including community clinics, grief support organizations, schools and academic medical centers) that use “common denominator” theory, assessment tools and interventions to address the unique needs and strengths of bereaved youth and families. The project team collaborated to enhance evidence-based assessment of youth. The presentation highlighted:

1. The lack of data to report trauma and loss experiences among Arab American youth in Metropolitan Detroit and other youth from diverse backgrounds nationally.
2. Content validity of two assessment measures: a) Multidimensional Grief Reactions Scale (MGRS, Layne, Kaplow, & Pynoos, 2011), and b) UCLA PTSD Reaction Index for DSM-5 (PTSD RI; Pynoos & Steinberg, 2014).
3. Findings from our work and how it is being implemented nationally.

### **Presentation**

The presentation began with an overview of the background and significance related to trauma- and grief-informed assessment among culturally diverse youth in underserved communities.

- By age 17, 2 out of 3 youth will experience a traumatic event (NCTSN, 2018).
- Bereavement is the most common and distressing form of trauma (Pynoos et al., 2014; Kaplow, Saunders, Angold, & Costello, 2010).
- Evidence-based assessment tools for trauma- and bereavement- exposed youth are lacking, especially for populations of color.

Very few theories regarding the manifestation of maladaptive and adaptive grief in childhood currently exist. Multidimensional Grief Theory (Figure 1) is a developmentally informed multidimensional conceptualization of grief (Kaplow et al., 2013; Layne, 2012; Layne et al., 2017) that suggests that bereavement can produce both adaptive and maladaptive grief reactions. These reactions manifest across three primary content domains, including separation distress, existential/identity distress, and circumstance- related distress.





Figure 1: Multidimensional Grief Theory

The GIFT Network utilizes the following assessment battery to identify youth who may be struggling with trauma and loss.

- Persistent Complex Bereavement Disorder Checklist (Kaplow et al., 2018; Layne, Kaplow & Pynoos, 2014)
- UCLA PTSD Reaction Index DSM-5 (Kaplow et al., in press)
- Short Mood and Feelings Questionnaire (Angold et al., 1995)
- Strengths and Difficulties Questionnaire (Goodman, 1997)

### **Conclusion**

Given the influence of culture on grief and mourning processes, it is essential to identify and clarify culture-specific grief reactions that youth may manifest in the aftermath of the death of a loved one. To ensure the content validity of trauma- and grief-informed measures with specific cultural groups, it is important to allow them to express their thoughts, feelings, and implications of the constructs under study. The GIFT Network provides training in evidence-based assessment with youth and families exposed to trauma and/or loss, and develops and disseminates trauma- and bereavement-informed “best practices” to community providers nationwide. It is helping researchers and clinicians determine best practices to screen, evaluate and, ultimately, treat bereaved youth; while advancing the field of childhood grief.

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## **Factors Impacting Refugee and Immigrant Health**

### ***Belqassem Sabri***

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In this session, panelists discussed several factors which impact mental health of refugees and migrants.

#### **Non-pharmacological interventions**

The research findings have highlighted the importance of **non-pharmacological** interventions in post-traumatic severe disorders. Social and cultural activities, suited to family environment include art activities such as painting, meditation, sport and yoga, and others. These activities have positively impacted patients following coaching in specific centers. Social support from mental health workers plays a crucial role in such exercise. Some coping mechanisms practiced during sessions in the center, were also reproduced at **home**. An interesting debate following the presentation bringing experiences in other socio-cultural milieus. Results were encouraging according to the research findings.

#### **Ethical dimensions of health care refugees:**

The presentation was made by Professor Michel Daher from Lebanon. He highlighted the main ethical concerns related to health care for refugees and migrants. A particular interest should be paid to the vulnerable among refugees including women, children and elderly.

Ethical gaps have been reported in relation to non-respect of patients' decisions and physical integrity (organ trafficking). Efforts should be made to involve ethical and research committees at national level in dealing with refugees' issues.

Partnership with the academia and with the World Health Organization (WHO) is considered necessary in order to raise awareness about the ethical dimensions in responding to refugees' health and social needs and to protect standard human rights.

#### **Maternal and child health care to Palestinian women in Lebanon:**

A presentation was made on a research carried out by the faculty of health science at AUB on maternal health care provided to Palestinian refugees in Lebanon compared to the services provided by UNRWA.

Findings show that health outcomes using some indicators related to women's health were better through MAP (medical aid to Palestinians) compared to UNRWA provided services. Financial constraints affecting UNRWA services in various fields could partly explain some differences.

More research is needed to better address the major determinants of Palestinian women's health registered as refugees in Lebanon. Such efforts could help in designing and in implementing adapted and appropriate responses.

### **Perspectives and long-term plans:**

Mental and social health support should not rely simply on medicines, which could sometimes lead to chronicity while not allowing integration of refugees and immigrants in their new environment.

Addressing the social determinants of maternal health of Palestinian refugees is important. Partnership with academic and research institutions including AUB should be promoted in order to scale up response to refugees needs.

As the number of refugees (economic and political) is growing globally and particularly in the Middle East and North Africa region, efforts ought to be made to develop **innovative approaches** to rehabilitation which should not rely only on medical (pharmaceutical) solutions.

Integration of refugees and immigrants should also promote such tools after being adapted to the specific social and cultural settings.

### **Refugee health:**

The author made a presentation on the social and health needs of Libyan refugees in Tunisia, following the fall of political regime in 2011 and on the major identified responses to these needs.

Despite the efforts made by governmental agencies and ministries, national and international civil society organizations, UNHCR, IOM and other UN agencies, complaints were made regarding limited access of Libyan migrants to health and social services.

The household survey carried out by the national observatory on migration (Ministry of Migration and Social Inclusion) has revealed serious gaps in terms of school drop-out (25 %), non-coverage by health insurance (80 %) in addition to inability to work and obtain permanent residency.

The lack of appropriate **legislation** was considered the major impediment in addition to the absence of **autonomous institutions** dealing with migrants' issues, away from security concerns.

### **Partnership between Civil society organizations (CSO), academia and relief agencies to cater for refugee needs.**

Civil society organizations start to play a growing role in the MENA region following the wave of political transformations referred to as Arab Spring. Efforts were made in many countries to respond to basic humanitarian needs of refugees coming from various social and cultural situations.

A specific interest is being made to improve the social determinants of health of refugees including access to education, adaptation to educational systems, residency, work permits and access to decent shelters.

Response to health needs, and particularly mental health for vulnerable groups, were organized in collaboration with concerned health authorities at national and subnational levels. UN agencies contribute positively in articulating national social and health response to refugee needs.

**Partnerships** with academic institutions and relief agencies including red- crescent and red-cross societies are of utmost importance in responding to refugees needs. Examples from Tunisia, Turkey and other countries were discussed. The role of **community based** and **grassroots organizations** was also highlighted by various presenters and through debate with the audience.

## **Lessons Learned in Addressing the Behavioral Health of Refugees from the Middle East**

***Ali Abazeed and Curi Kim***

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### **Abstract**

In August 2017, the Office of Refugee Resettlement (ORR) and the Substance Abuse and Mental Health Services Administration (SAMHSA) co-hosted a number of subject matter experts from the Washington, D.C. metropolitan area for a discussion on the behavioral health of refugees from the Middle East. The key findings, highlights, and recommendations from the convening constituted the framework of a panel discussion at the 2018 ACCESS Arab Health Summit.

The discussion centered on:

- Helping refugees navigate healthcare and social support systems;
- Using clear and culturally-sensitive language;
- Developing culturally-appropriate services; and
- Training service providers in trauma-informed care.

All five panelists agreed that further research is warranted to effectively address the behavioral health needs of Middle Eastern refugees.

### **Introduction**

More than a third of the world's 25 million refugees originate from the Middle East (1). Refugees from the Middle East encounter significant, place-specific health challenges based on where they are resettled. The problems can vary according to whether refugees are resettled within the region or in European countries and the United States. Many refugees who remain in the Middle East experience adverse infectious disease-related health outcomes stemming from poor infrastructure, sanitation, and nutrition. Conversely, refugees resettled to western countries may primarily confront health issues related to chronic conditions. Both groups, however, may grapple with mental health challenges. The increasing attention to Middle Eastern refugees in the public discourse notwithstanding, further research is needed to effectively address this population's behavioral health needs.

Recognizing this fact, the Administration for Children and Families' Office of Refugee Resettlement (ORR) and the Substance Abuse and Mental Health Services Administration (SAMHSA), both agencies within the U.S. Department of Health and Human Services, co-convened behavioral health experts from the Washington, D.C. metropolitan area in August 2017. At the all-day meeting, practitioners from multiple disciplines and organizations discussed the behavioral health needs of Middle Eastern refugees to facilitate further understanding of their health conditions. The key themes that emerged from the 2017

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convening framed a subsequent panel discussion at the ACCESS Arab Health Summit in September 2018 in Washington, D.C. The panelists were: Dr. Mona Abuhamda, clinical psychologist and refugee service provider; Dr. Husam Alathari, Assistant Professor of Psychiatry and Behavioral Sciences at the George Washington University Medical Center and member of the SAMHSA Planning Group on Iraq Mental Health; Dr. Nahid Aziz, Associate Professor at the American School of Psychology at Argosy University and co-chair of SAMHSA's Afghanistan Mental Health Workgroup; Dr. James Griffith, Chair of the Department of Psychiatry and Behavioral Sciences at the George Washington University School of Medicine and Health Sciences; and Dr. Omrana Pasha, Senior Scientist at Johns Hopkins University. The panel discussion was moderated by Dr. Anita Everett, Director of SAMHSA's Center for Mental Health Services, and Dr. Curi Kim, Director of ORR's Division of Refugee Health. The highlights of the discussion are summarized below.

## **Discussion**

The panelists discussed how the trauma of forced migration can shape the behavioral health needs of Middle Eastern refugees. They noted that although resettlement is often viewed as the conclusion of a refugee's story, for most refugees, resettlement entails a new journey of acculturation and acquiring a sense of belonging in the host country. Responses to refugees' mental health challenges consequently require deliberate consideration of the sociocultural, historical, and political issues unique to refugees and their backgrounds. The panelists observed that addressing refugees' psychosocial needs with a culturally-sensitive and trauma-informed approach may enhance other resettlement outcomes such as employment, education, and social integration. Their discussion centered on the following themes.

### **1. Helping refugees navigate healthcare and social support systems**

Upon arrival, refugees must quickly learn to navigate multiple complex systems such as healthcare and other social services, often with minimal support in overcoming barriers to access. Considering the relatively sparse scientific literature on how refugees learn to overcome these barriers, programs for new arrivals may rely on incorrect assumptions or ineffective interventions. The underlying assumption is that the primary barrier is informational and can be addressed by knowledge transfers or direct assistance. This supposition may challenge community organizations and public health programs seeking to improve refugees' access to care.

Despite this knowledge gap, the panelists agreed that to mitigate the feelings of devaluation commonly experienced by refugees in their initial, formative interactions with providers, we must do more to support them. Providers must recognize that their point of entry with refugees is crucial in making this population feel valued because although the terms describing social services might be foreign, the constructs themselves are not. The resettlement process often seems overwhelming for refugees as they are shuttled between multiple providers from different organizations without receiving adequate explanations of those providers' identities and specific roles. It is thus important to clarify for refugees the roles of different providers. Further, as host communities develop refugee services, it is important that they holistically support refugees contending with an array of concerns, including medical services (particularly ob-gyn care for refugee women), educational matters, and legal issues.

## **2. Using clear and culturally-sensitive language**

Research indicates that individual issues aside, language and communication affect all stages of refugees' access to healthcare—from making an appointment to filling a prescription (2).

Healthcare providers need to humanize discussions of distress and mental illness by using basic, direct (non-clinical) language that fosters an environment predicated on respect for the refugee patient. Examples of using clearer, non-technical language include substituting "PTSD" with "because of the things you have been through." One panelist found it imperative that clinicians, case managers, and administrators assume the role of moral witnesses who explicitly state to the refugee patient: "What happened to you was wrong and should not happen to any person."

Similarly, practitioners should ask refugees, "What happened to you?" before asking "What is wrong with you?" The first priority should be to learn about the circumstances leading to displacement, which means learning about a refugee's country of origin, its peoples, and its political and ethnic struggles. Listening, acknowledging, and witnessing should precede focusing diagnostic attention to commonly occurring symptoms from losses, trauma, or dehumanizing acts.

Focusing upon resilience is a reliable way to restore honor and dignity to a demoralized refugee; it can also help destigmatize mental illness and the use of mental health services. Providers can focus upon resilience by asking refugees specific questions such as:

- What kept you from giving up while facing numerous hardships?
- What sustained your hope during the worst times?
- What are the strengths of your family that have helped it endure?
- What skills helped you get through hard times?
- Are there important religious beliefs or practices, or a religious community to sustain you through hard times?

Some panelists noted that refugees from certain culturally conservative countries such as Iraq or Afghanistan are not opposed to discussing their emotions; however, they reject being labeled "emotional" or "mentally ill." Such examples highlight the need to change practitioners' language and practice in the refugee context.

## **3. Developing culturally-appropriate services**

Building upon the previous theme, panelists discussed the importance of developing culturally-appropriate services centered on participatory care. Refugees of all ages arrive with complex medical and social histories, often involving war, torture, and strenuous migration journeys. Many refugees spend significant time in refugee camps or struggling in urban settings before resettlement. Scarce resources and the stress of encampment can result in myriad acute and chronic diseases which may not be addressed until after resettlement. Acculturation itself may entail increased stress, isolation, and new responsibilities; moreover, refugees' cultural beliefs about healthcare directly affect their expectation of care (3). These factors may contribute to delayed care and affect refugees' short- and long-term health, underscoring the need to practice culturally-appropriate care that is sensitive to all aspects of the refugee experience. However, healthcare professionals in receiving countries are not often not familiar with the various challenges in addressing the healthcare needs of this population. Complex trauma in

refugees, in particular, can make mental health assessments difficult for care providers with limited experience and training in transcultural or trauma-informed care (4). As Vukčević et al. assert, “In order to ensure adequate psychological support [for refugees and asylum seekers], it is necessary to be aware of their traumatic experiences and the hardships they are dealing with (5).”

The panelists agreed that refugee mental health services present a major challenge due to the aforementioned barriers; however, a collaborative model that integrates mental health into the provision of primary care at the first point of entry could prove promising. Highlighting cultural differences that may impede this population’s access to services, some panelists described instances of Iraqi men frequently refusing treatment from women providers, particularly in the realm of mental health; community collaboration, especially working with community leaders, to destigmatize mental health and discuss gender roles can help address this barrier.

Another way of encouraging refugees to feel safe and comfortable is for service providers to share personal stories that normalize mental health distress. Also, the use of telemedicine to address refugees’ behavioral health needs can make mental health services more accessible and less intimidating. One panelist disclosed that with the help of web-based communications, she regularly provides mental health counseling and consultation for clients in Afghanistan. Other suggestions included deploying physician volunteers through programs such as the MAVEN Project, which links a corps of medical experts to providers in need.

#### 4. Training in trauma-informed care

SAMHSA’s “4 R’s” approach to trauma-informed care offers providers important lessons applicable to treating Middle Eastern refugee populations. The approach encourages responders to:

- **Realize** the widespread impact of trauma;
- **Recognize** the signs and symptoms of trauma in others;
- **Respond** with informed policies, procedures, and practices; and
- **Resist re-traumatization** (6)

Panelists reiterated the importance of incorporating trauma-informed care into every aspect of treatment. For instance, providers should recognize that treatment begins with the greeting, rather than the formal treatment session. Through greeting the refugee, the provider initiates a relationship that **realizes** the impact of trauma on the individual’s life, family, and community. As with other social services, the intake process is innately intimidating; the **recognition** of the signs and symptoms of trauma in refugees should thus take precedence over the formal intake session and paperwork, which can safely be deferred. It is also important to focus on recovery. One practitioner noted the alienation and inherent sense of isolation stemming from the refugee experience. Often, as the realization of loss sets in throughout the resettlement process, the individual’s very identity itself is called into question. Recovery occurs as a shift back to the relational world, where the survivor and his or her story are embraced by the community. **Responding** to traumatized populations requires operationalizing trauma-informed care; options include requiring yearly training for all providers, hosting peer-to-peer learning sessions among practitioners, or training other community members, such as taxi drivers and

teachers, to interact effectively with refugees. The multiple ongoing stressors of resettlement (including unemployment, lack of social and community connections, and poverty) can exacerbate existing trauma, which necessitates a systematic trauma-informed approach when interacting with refugees. Panelists further agreed that it is critical to **resist** any form of re-traumatization by being cognizant of potential triggers.

## Conclusion

The 2018 ACCESS Arab Health Summit provided a timely opportunity for convening this panel of experts in Middle Eastern refugee and immigrant health. It enabled them to share key themes from the 2017 meeting co-hosted by ORR and SAMHSA and to further discuss the impact of refugees' resettlement journey on their mental health. Panelists highlighted the importance of helping refugees navigate the complex U.S. healthcare and social support landscape, using clear and sensitive language in a provider context, developing culturally-appropriate services centered on participatory care, and incorporating trauma-informed care into every encounter. In summary, the protracted violence in many Middle Eastern countries continues to create significant refugee outflows and the traumatic displacement of these populations may beget lasting mental health sequelae. Further research is needed to inform a more robust approach to address the behavioral health needs of refugees from the Middle East.

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## **A Diverse Interdisciplinary Approach to the Problem of National Data on Arab Americans**

***Matthew Stiffler***

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**Introduction.** The panel showcased a diverse interdisciplinary approach to the problem of national data on Arab Americans.

**Background.** The changes to the upcoming 2020 decennial U.S. Census may provide an opportunity to gather better data on the Arab American/Middle East North African (MENA) community. This is particularly true if Arab American organizations work with the Census to educate the community on how best to respond to the demographic questions.

**Needs Assessment.** It is important to disaggregate Arab ancestries from the white racial category on both the decennial Census and the American Community Survey. Arab ancestry communities have unique issues (such as age, citizenship status, disability prevalence, and housing situations) that are lost when all Arabs are enumerated as white. There are also unique issues for Arab ancestry groups living in different metro areas including Detroit, Chicago, New York, Houston, Los Angeles, and Washington, DC.

**Current Limitations.** When Arab Americans are not disaggregated from the “white” category, health-related research can be severely impacted (e.g. tobacco and hookah use).

Research funding is a huge issue. Researchers are not able to obtain major funding for MENA communities without linking them to other minority communities. For NIH funding to apply to Arab Americans, there is a need to prove that the community is a “health disparity community” even if they are not a federal minority.

**Strategy.** Arab American local and national organizations should push local and state institutions to collect data on the Arab Americans and MENA community. Currently, even the best demographic studies (like the Census and ACS) do not get at deep psychosocial distress and other important variables.

Census data can be a key tool for working with the Arab American and MENA communities, but given the complexities of the community, Census data should be paired with other local, state, and national data.

**Long Term Plans.** Researchers need to develop a set of standardized categories for collecting data on Arab American and MENA communities. This allows all local level researchers to gather data that can be used comparatively.

**Role of the Arab Community Center for Economic and Social Services (ACCESS).** ACCESS will take the lead on this initiative. We need to be building the workforce of researchers interested in working with these communities in academia. In addition, there is a need for a mentorship program and a pipeline.

## **Refugee Health: The Current Displacement and Emergencies in the MENA Region and Resulting Health and Socioeconomic Conditions**

***Adnan Hammad***

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### **Introduction.**

The Middle East and North Africa Region (MENA) extends from Pakistan in the east to Morocco in the west. Around 646 million people live in these 22 countries which are characterized by diverse socioeconomic status and Health challenges. Violence, conflict, poverty, political instability, human trafficking, child labor, smuggling, and mass internal displacement are some of the realities faced daily by millions of men, women and children throughout the MENA region. These challenges and demands continue to stretch economies, public and social services, and civil and political structures to the limits. The humanitarian crisis facing refugee in the Syrian Arab Republic (Syria) and Yemen remain the largest in the world (Figure 1).



**Figure 1. Photo from a local photographer affiliated with the Sociology Department of Gaziantep University, August 2018.**

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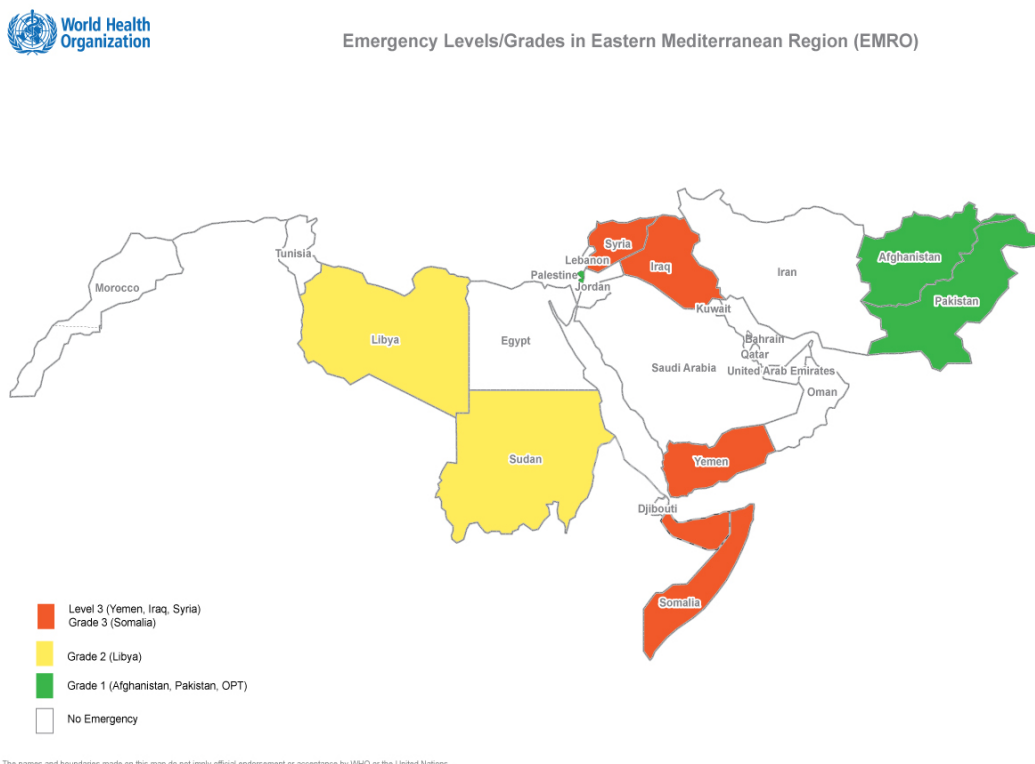
## Objectives

The objectives of this presentation were:

- To review the emerging public health conditions in the MENA region and improve the understanding of how migration, displacement, and the associated socioeconomic deterioration could influence physical and mental health of refugees.
- To share acquired knowledge about collaborative models and strategic thinking that would improve the social and environmental coping mechanisms, and leverage global resources for the purpose of improving health in refugee communities in the MENA region during periods of turmoil.
- To improve capacity building to address refugee and mental health issues in countries that host refugees

## Discussion

For the last decade, the region has faced increasing emergencies that are devastating more lives than ever before. In 2017, close to 76 million people were directly or indirectly affected by political conflict, environmental threats or natural disasters. Consequently, communicable and non-communicable disorders and poor life conditions have intensified to record high levels. In 2015, malnutrition was an underlying cause of 45% of deaths of children under 5 years of age. The increasing environmental risk, including air pollution, contributes to 854,000 premature deaths annually in the region. In 2012, compared with other WHO regions, the prevalence of smoking in men was the second highest at 40%. The Use of water pipe among 13 to 15 year-old youths has grown to an alarming rate of almost 35% (Figure 2).

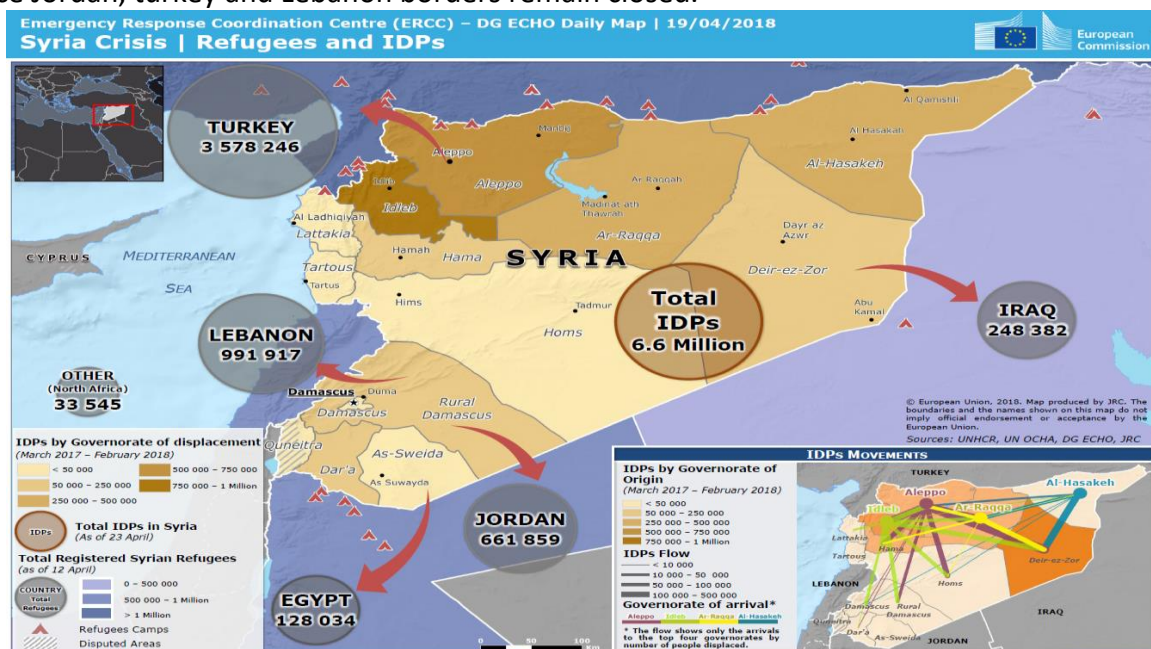


**Figure 2. Graded Emergency Levels/Grades in Eastern Mediterranean Region (EMRO), September 2017.**

The United Nations High Commissioner for Refugees (UNHCR) reports that 51% of refugees worldwide come from the MENA region with over 30 million people (mostly women and children) displaced. The region bears the greatest refugee burden across the globe. As a result, research in conflict-affected populations showed a prevalence of 15.4 % for post-traumatic stress disorder (PTSD) and 17% for depression. In 2016, Malnutrition was an underlying cause of 45% of deaths of children under five years of age.

By the end of 2016, the number of displaced people rose to 65.6 million people, a number greater than the total population of the United Kingdom. Three were 40.3 million people displaced within their own country. Refugees who fled their country make up the second largest group, a record high of 22.5 Million. Every three seconds, an individual is forced from their homes by violence, war, and persecution. Host Communities are affected by the impact of displaced populations.

In 2017, the world hosted nearly 23 million refugees. This does not include people living in internal displacement as a result of conflict in the world who amounted to 40.3 million by the end of 2016. Refugees and forced migrants must await many years of political resolutions, while often contending with the deep trauma of ethnic, sectarian, and political cleansing. This includes the deliberate targeting of hospital and unarmed civilians. Syria, with some 12 million out of 22 million forcibly displaced, represents the single largest source of refugees and Internally displaced people (IDP) in the world (Figure 3). There are Syrian refugees in Lebanon (1 million) Jordan (661,000), Turkey (3.5 million), plus hundreds of thousands of asylum seekers in Europe. There are approximately 6.6 million internally displaced people and the number is increasing since Jordan, turkey and Lebanon borders remain closed.



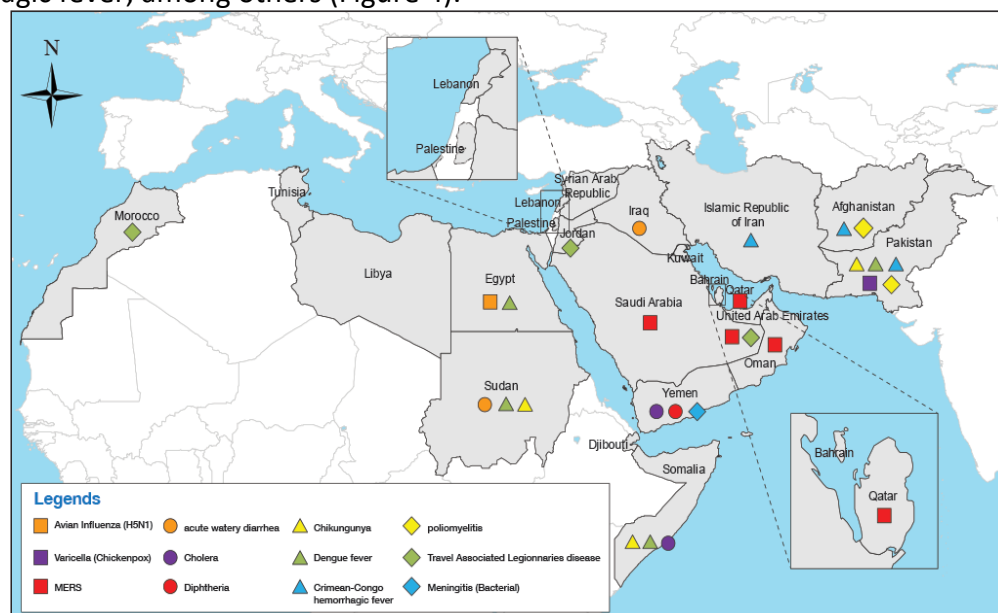
**Figure 3: Refugees and Internally Displaced People, Emergency Response Coordination Center (ERCC) DG ECHO Daily MAP 19/04/2018.**

Moreover, Palestine refugees are persons whose normal place of living was Palestine between June 1946 and May 15 1948, and who lost both home and means of livelihood after the 1948 conflict. Around 5 million Palestinian refugees are officially registered with UNRWA, one third of

whom (1.5 million) live in 58 camps in Jordan, West Bank, Lebanon, Syria and East Jerusalem. UNRWA basic services are available to all refugees living in its areas of operation that meet this definition. There were some displacement implications on Palestinian refugees living in Syria because of the Syria crisis, with no lasting, peaceful solution in the horizon. UNRWA reports that over 280,000 Palestine refugees from Syria (PRS) have been internally displaced, and more than 80,000 have fled to neighboring countries, including Jordan and Lebanon, where Palestine refugees from Lebanon (PRS) have been accessing UNRWA services for years. This has placed additional pressures on camps, schools and health centers with scarce resources. The blockade and recurrent emergencies in Gaza, and the occupied West Bank, remain major obstacles to socioeconomic development of Palestine refugee communities, and on the health-care provision.

The Conflict in Yemen has left 75 per cent of the population (22.2 million), needing humanitarian assistance. An escalation of hostilities in late 2017 resulted in new displacement (another 2 million), precluded safe return and increased demands on emergency services.

Welfare infrastructure including health systems have been stretched to the limit. The health of communities across the region has been negatively affected. A growing number of people are requiring life-saving interventions and treatment of communicable and non-communicable diseases. The high incidence of emerging and re-emerging infectious disease (ID) poses a perennial threat to regional health security, which also has significant impact on Health and economic development with a large number of active disease outbreaks in the EMR as of September 2018 (Figure 4). At least 12 of the region's 22 countries have experienced emerging ID outbreaks in the last decade with potential for global spread. These diseases include ME respiratory syndrome, corona virus (MERS-CoV), Avian influenza A(H5N1) infections, cholera, and hemorrhagic fever, among others (Figure 4).



**Figure 4. Select Infectious Disease Outbreak in East Mediterranean Region. WHO EMRO 2017-2018.**

Mental health disorders are on the rise as well with negative impact on maternal and child health care including vaccination programs. As a result, two thirds of countries in the region are directly or indirectly affected by emergencies (Figure 5). By the end of 2016, out of 140 million people in



need of aid globally, more than 76 million people (59%) lived in countries in the region affected by emergencies.

In light of the above health and socioeconomic conditions faced by the refugee communities in the MENA region, there is an immense need for supporting refugees in with relief and recovery programs. These include pharmaceutical and medical relief as well as basic nutrition supplies for children. In addition, there is a dire need for research, advocacy and education interventions on human rights for refugees.

Global collective efforts must improve the understanding of how migration and displacement and associated socioeconomic deterioration influence physical and mental health and social behaviors. One vehicle to accomplish this goal is conducting specific conferences and workshops aimed at capacity building for research, education, and policy change. Conducting scientific research then sharing acquired knowledge could help identify how collaborative models improve social and environmental coping mechanisms. The ultimate goal is to increase our ability to leverage global resources for the purpose of improving health in refugee communities in the MENA region. Lessons learned can be applied during periods of turmoil to improve capacity building and address physical and mental health issues in countries that host refugees.

### **Recommendations**

The discussion during the refugee health panel of ACCESS 8<sup>th</sup> Arab Health Summit: A Global Call to Action for Health Equity and Social Justice, advocated and adopted the WHO EMRO 64 Session recommendations in Islamabad for supporting health and relief agencies' capacity building, especially those who are affected by graded and protracted emergencies to respond to health emergencies by scaling up response and early recovery.

- To enhance prevention and control of emerging, and re-emerging, and epidemic-prone diseases by improving prevention, containment and control of diseases that are easy to eliminate.
- To support relief and health agencies by supporting their efforts to ensure women's, newborn's, children and adolescents well being by responding to their health needs and enabling them to live healthy lives.
- To provide advocacy to ensure that all refugees and displaced populations, and other vulnerable groups in the region have equitable access to health care needs.
- To advocate for all policies, with a specific focus on the social and environment determinants of health.
- To strengthen public health leadership capacity to meet the global health determinants in the region and as it relates to vulnerable populations.

### **Our Collective Responsibility:**

The panelists advocated for strengthening a culture of research and evaluation and ensure that monitoring and evaluation systems are in place for the interest of refugees and displaced populations. An immediate focus on prevention and control for the dual burden of communicable and non-communicable diseases and disabilities was categorized as a priority area.

The panelists also emphasized the need to build and strengthen academic partnerships to

advance global health research and research capacity to address refugee health challenges globally. Partnerships between academia, government and non-government agencies, and the refugee community in the MENA region and their counterparts in countries with Syrian refugees such as, Europe and North America must involve the refugee community in community-based participatory research (Figure 5).



**Figure 5. A. Hammad. Community- Based Research Model, ACCESS Community Health and research Center, 2014.**

*The audience emphasized the creation of a proclamation of health rights and initiatives aimed at improving the management of mental health and chronic disease conditions and human trafficking prevention in Syrian refugee populations in times of turmoil around the world. This important proclamation took place in the closing remarks of the ACCESS 8<sup>th</sup> Arab health Summit in Washington DC, September 19, 2018.*

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## **American Diabetes Association. Research, Advocacy, and Professional Education for Arab and Arab-American Communities**

***Mary Rife, Linda Cann, LaShawn McIver, and William Cefalu***

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Leaders from the American Diabetes Association (ADA) explained how they address diabetes prevention and treatment through research, professional education, and advocacy. These areas are relevant to both Arab and Arab-American populations in terms of: a) innovative research that refines patient care, including advances in precision medicine; b) educational programs, based on Clinical Practice Guidelines, for providers in the U.S. and abroad; and c) advocacy initiatives to increase access to care, protect patient rights, and eliminate health disparities. The Q and A session focused on implementing these strategies in your communities.

### **1. The Promise of Precision Health to “Revolutionize” Diabetes Care and Prevention**

William T. Cefalu, MD, Chief Scientific and Medical Officer, ADA.

**Learning Objective.** To communicate the potential benefits of precision medicine on the prevention and care of diabetes patients, including those populations disparately affected by the disease.

**Current management strategies** for Type 2 diabetes involve lifestyle management as a cornerstone of therapy combined with appropriate pharmacologic therapy. The goal of therapy is to effectively manage glycemia and associated risk factors to prevent the development or reduce the progression of both micro and macrovascular complications. Currently, recommendations to achieve the proposed clinical goals are outlined in our Standards of Care, published annually from the ADA, traditionally based on data from randomized controlled studies. In this case, efficacy is generally assessed on overall population means.

**Newer Trends.** In the current era, there is a need to individualize therapy in which therapeutic decisions should be made in conjunction with the patient, reflecting his or her preferences, needs and values. This direction has been highlighted in our Standards of Care.

In regard to further refining individualized care, there has been great interest in the concept of “Precision Medicine” or “Personalized Medicine.” Specifically, “Precision Health” is defined as providing the most appropriate therapy for the most appropriate patient at the most appropriate time. Whereas we do have clinical guidelines to suggest a more individualized approach, we are not at a point in clinical diabetes management where we have reliable genomic, biomarker, or other tests that can specifically guide the provider to a specific, individualized treatment strategy for Type 2 diabetes.

**Recent Advances.** During the recent past, there have been remarkable advances in obtaining data on patients at multiple levels. For example, considerable effort has been focused on the genomics/genetics and metabolomic data, as clearly this area continues to inform this field. It is



expected that with more research, genetic correlates relevant to the functioning of the human glucoregulatory network will be identified which will then translate into macro-characteristics of an individual at multiple levels. In addition to the genomic/metabolomic profile, an individual's profile is reflected by a variety of routine lab tests measuring parameters of the glucose dynamics in addition to phenotypic characteristics such as BMI, duration of disease, etc. Finally, we are also now realizing the value of wireless sensors contributing to patient care. For example, a variety of signals from body sensors and consumer electronic devices are now routinely available and typically gather relevant data by a wearable hub (e.g. smart phone). Thus, in addition to the traditional definition of "precision medicine" on genetic/genomic terms, the complexity and availability of health data on individual patients is expanding exponentially due to the utilization of electronic medical records, registries, pharmacy claims data bases, and digital devices/wireless sensors.

**Future Expectations.** With the above expected advances, we can, therefore, expect that data from lab tests combined with data from EHRs, wireless sensors, etc., will create a data "ecosystem" that can support a variety of treatments, including risk assessment, predictive analytics, decision support, and closed-loop control. Given the high rates of diabetes in many countries and in individuals of Arab descent in the U.S., a more focused approach to treatment and prevention to achieve clinical goals that is proposed with precision medicine would be a huge advance.

#### **Sample Resources.**

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NIH funds precision medicine with a focus on health disparities, News Release, July 28, 2016, at <https://www.nih.gov/news-events/news-releases/nih-funds-precision-research-focus-health-disparities>.

Abuyassin, Bisher & Laher, Ismail. (2016). Diabetes epidemic sweeping the Arab world. *World Journal of Diabetes*. 7. 165. 10.4239/wjd.v7.i8.165.

Jaber LA, Brown MB, Hammad A, et al. Epidemiology of diabetes among Arab Americans. *Diabetes Care*. 2003;26:308–13.

## **2. ADA Domestic and International Diabetes Education Programs for Providers**

Linda Cann, MSED, Senior Vice President, Professional Services, ADA (ADA)

**Learning Objective.** To describe the range of professional/continuing education opportunities offered by the ADA to health care providers worldwide.

**Introduction.** The ADA has conducted international professional/continuing education programs for the past 13 years. The Association and its Clinical Practice Guidelines are recognized as the authoritative source for information related to diabetes and its complications and form the core content of the vast majority of professional education programs conducted worldwide.

**Background.** ADA develops its international programs in collaboration with local medical societies and individual health care providers and leverages the expertise of the ADA and that of local diabetes experts to establish the social and cultural relevance of the material.

Programs can be tailored to meet the needs of individual countries.

**Current Programs.** Two examples of highly successful program formats are.

- “Best of ADA International” – This program presents the latest in clinical research related to the prevention and management of diabetes translated into practical clinical strategies. Topics are selected from ADA’s most recent Scientific Sessions or Postgraduate Course. The faculty includes representatives from ADA and those from the host country. This program has been conducted twice in Dubai, as well as in India, China, South Korea, and Spain over several years.
- Train the Trainer – This type of program is tailored to meet the needs of individual countries. Content is developed by the ADA, with the case studies developed by the local diabetes society. Upon completion, these health care providers then educate general practitioners in local areas, using a standardized slide set and materials.

**Proven successful formats include:**

- A 1.5 day didactic and cased-based program with collateral materials presented to diabetes specialists and/or those who see a significant number of patients with diabetes.
- An in-depth, intensive educational program, with both Core and Advanced content presented to cohorts of 70-100 physicians at various levels. The Core program focuses on the basic information needed to improve practice. The Advanced program is presented to the same cohort approximately three months later, with topics that include the managing the complex patient and the complications associated with diabetes.

Both program formats have been successfully conducted in several countries in Southeast Asia, including the second format as a five-year program in Indonesia, and a four year program in Vietnam.

**Future Goals.** ADA can collaborate with a country to develop a diabetes educational program that is culturally competent and addresses the unique needs of the providers, the patients and a region’s health care system.

### **3. From Research to Policy. Tackling Diabetes through Domestic and Global Policy Initiatives**

Lashawn Mclver, MD, MPH, Senior Vice President, Government Affairs & Advocacy, ADA (ADA)

**Learning Objective.** To share the types of advocacy strategies and issues that ADA employs to support individuals with diabetes that could be replicated, with some modification, within the US and abroad.

**Introduction.** The ADA is the largest voluntary health organization that advocates on behalf of the needs of all people with diabetes.

**Priority Areas.** The main advocacy priority areas addressed include advancing diabetes research and programs, increasing access to adequate and affordable health care, diabetes prevention and treatment, eradicating diabetes disparities, and eliminating discrimination against people with diabetes. In addition, the Association’s efforts to drive domestic and global policies impacting ethnic and racial minority populations including initiatives to address diabetes in Arab populations were discussed.

## **Informal Health Services for Syrian Refugees in Lebanon**

***Fouad M. Fouad***

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The Syrian crisis is perhaps the largest refugee crisis in recent history. A key feature of the Syria crisis has been the displacement of highly skilled workforce cadres – including healthcare workers (HCWs) – from a country that before the outbreak of conflict had a highly educated population by comparison with many regional neighbours (1,2). Neighboring countries including Lebanon, where this study was conducted, faced major domestic economic, social and political challenges due to the influx of large number of refugees (14). This was an unprecedented situation that took the neighboring countries by surprise and little was known on how to stipulate policies to manage this inflows (3). With this poor understanding of the labour market, Lebanese law restricted the labour market to Syrian refugees to three domains: agriculture, construction and cleaning services. Thus, under these circumstances, refugee Syrian HCWs who attempt to practice had no choice but to work informally (4).

Currently, the majority of health services in Lebanon are provided in primary healthcare centers (PHCCs) and hospitals, both supported by the Lebanese Ministry of Public Health (MOPH), Non-Governmental Organizations (NGOs), and United Nation (UN) agencies for refugees registered with the United Nations High Commissioner for Refugee (UNHCR). They receive primary care consultations for a fee of 2-3 USD and pay 25% out-of-pocket of hospitalization fees (5). The exponential increase in demand not countered back with increase in supply for human and non-human resources led to inadequate access to health services for both Lebanese and refugees alike (6). It is estimated that 74% of Syrian refugees reported difficulty accessing the formal healthcare, with some returning to Syria in order to receive services (5).

Given the presence of HCWs among SRs and the inadequate access to the formal health sector, the emergence of an informal sector of healthcare provision among refugees was highly probable.

Our study showed that the motivational factors that led SHWs to practice informally were personal (e.g. source of livelihood), societal (cultural competency), and formal health services factors (filling a health service gap). Being connected to a network of IHCWs facilitated initiation of the informal practice until eventually becoming part of an informal community of practice. The challenge was the informal aspect of their practice and its negative consequences. Most were afraid of being persecuted by the government once identified yet some indicated that the government was aware of their

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informal services but kept *a blind eye* and most indicated being discriminated against by the host society in the form of differential wages and tense interpersonal relationships. Almost all recommended change in policy allowing them to practice formally under a temporary registration until their return to Syria.

The picture of informal healthcare provision revealed by participants in this study has similarities with that described elsewhere in the literature, but also important points of difference. Much of the existing literature on informality in health care provision originates from settled low or lower-middle income country contexts, where “informal” health workers are understood as having received training outside a formal institutional setting or curriculum, receive undocumented payment, operate without oversight and may be members of professional bodies that do not have formal regulatory functions (7). The participants in this study, however, do not meet the first criterion in this definition: they possess formal qualifications from Syria, and their informal status derives instead from legal, regulatory, administrative or other barriers to registration in Lebanon.

On the other hand, the fact that IHCWs are part of a larger community of informal workers, who promote each other’s services through referrals and use of social media to connect is also in line with the broader literature on informality in healthcare, which indicates that the work of informal healthcare workers is always tied to the community and is dependent on their trust (7). Where IHCWs work also mattered. we found that IHCWs deliver services to Syrian refugees in all health sectors: the public, private, and humanitarian. However, work conditions were diverse, such that NGOs providing equal pay, while the Lebanese-run private hospitals and pharmacies had differential wages between IHCWs and the local ones. This inequity is widely present across the labor market, and is not only restricted to the health sector, where SRs are being paid lower wages than their Lebanese counterparts despite longer working hours and lack of social benefits(8).

### **Policy recommendations:**

Based on our findings, it is recommended that the Lebanese government consider issuing a short-term license for Syrian health workers that allows them to provide healthcare to their compatriots (9). It will serve the health workers on a personal level by providing them with formal employment and a legal source of income(35, 39). In addition, it will integrate the advantages of informal healthcare provision, mainly affordability and cultural competence, into a formal regulated system. Moreover, it will decrease the load on the primary healthcare centers and other healthcare workers in the most overcrowded and understaffed areas of Bekaa (9). Finally, it will allow healthcare workers to retain their professional skills in order to build the future post-conflict Syrian healthcare workforce (10).

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## **The City, Refugees and University: The Case of Gaziantep**

***Şehmus Demir***

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### **Abstract**

This paper generally outlines and focuses on the distribution of Syrian refugees in Turkey, and their utilization of education and health services. It also mentions the higher education opportunities that Gaziantep University offers to young Syrian immigrants in addition to the key role and importance of Gaziantep regarding immigrants. This paper also considers scholarships, grants and a range of educational programs offered by Gaziantep University, which are among the best in Turkey and in the world, for Syrian immigrants.

**Keywords:** Syrian refugees, Turkey, education, Gaziantep University

### **Introduction**

Gaziantep is one of the most important cities in the Fertile Crescent with 2.1 million inhabitants, advanced industrial complexes, a cosmopolitan structure and ancient history. While its proximity to northern Syria, ancient history and cultural features make the city the most important and strongest door of Turkey opening to the Middle East in the pre-war era, it was elevated to a key position in the post-2011 era with the war in Syria and the refugee crisis. In the space of eight years, Gaziantep University came to the forefront through its exemplary provision of health and educational services for the Syrian immigrants, just like the City did.

The year 2011 marks a cornerstone for the Middle East, of which the city of Gaziantep is a major part through different networks. However, no one, including politicians, academics, strategists or journalists could foresee the beginning of the process which was first described as “spring” in 2011 but later escalated into an “uprising” due to the harrowing scenes of horror that ensued (1-4). The humanitarian crises, violence, war, forced migration and refugees affected Gaziantep and dozens of other countries including Turkey and it is not easy to argue that it all has settled peacefully. There is one truth in this complex web of events that stands out. The war in Syria, and the refugee, migration and humanitarian crisis that came with it, seriously changed the Middle East as well as the entire world (5,6). There were certainly many humanitarian reasons for this transformation. Problems that riddle the rural agricultural structure and peasantry become ever more chronic. Productivity became negatively affected by globalization and neo-liberalism, the ever-rising presence of armies in political, economic and cultural aspects of many countries, corruption, decay, and non-fulfillment of the promises given to the poor communities. In addition, the non-fulfillment of the demands of young people, whose share in the population is on the rise, prodded by modernization and urbanization, for work, education and democracy coupled with populist policies all together caused people to revolt (1,2). However, the multi-layered and multifactorial structure of the Middle East put forth the course of the uprisings and

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its consequences in different ways. The historical, cultural, political and geo-strategic structure of Syria has taken the uprisings in this country to a whole new level. On the other hand, there are no clear answers as to where or how the process that started in 2011 will be concluded.

Turkey is foremost among the countries most affected by the climate of war and violence in Syria that started in 2011. Starting from the middle of the same year, cities which shared a border with Syria faced an influx of Syrian immigrants streaming into the border, first in hundreds and then thousands. The cities of Kilis, Gaziantep, Şanlıurfa and Hatay tried to provide shelter for refugees in the city centers and borders. The number of Syrian refugees, which was hundreds of thousands in the beginning, then rose to 1 million towards the end of 2013, then to 1.5 million at the end of 2014, 2.83 million at the end of 2016 and then to 3.644 million in February 2019. According to the updated records of Turkey's Ministry of Interior in February 2019, there are currently 3.644 million registered Syrians in Turkey who have been granted a Temporary Protected Status. It should be noted that Turkey's 81 provinces have the Syrians in various numbers. That figure includes all refugees registered by the cities and the Governorships. When official records are taken into account, Syrians make up 4.4% of the Turkish population. This general average of the population rates hits exponential levels in certain cities. Registered Syrians make up more than 20% of the population in cities such as Şanlıurfa, Hatay and Gaziantep. Kilis is an exceptional case, as registered Syrians make up about 80% of the town's local population. On the other hand, 45% of the Syrians registered in Turkey are under 18 indicating that we are faced with quite a young population.

According to February 2019 data (7), there are 425,000 Syrians in Gaziantep. Indeed, the reason of the intense population of Syrian refugees in Gaziantep is the city's historical, economic and cultural ties to Aleppo and its surrounding areas as a city and as the region (8). Also, one of the main factors is Gaziantep's position as a vital industry, trade and production center in Turkey and the region. Due to all these factors, more than 21% of the population of Gaziantep is made up of Syrian refugees. The "open doors" policy of the Turkish government for Syrians, and the availability of both national and international humanitarian aid made Gaziantep a place of attraction for Syrians eight years after the war. While this in itself provides a myriad of opportunities for cultural, economic, commercial and human encounters and interactions, it also puts strains on infrastructure, education, transport, health services, and jobs market as well highlighting language challenges. However, it can be said with some degree of certainty that despite the unfavorable circumstances, Gaziantep has found clever ways of reaping benefits from the existence of Syrian immigrants by accordingly making policies in various areas.

As of February 2019, 142,000 Syrian refugees were living in the camps in Turkey, especially in southern border cities (temporary accommodation centers). However, according to the figures in early 2018, this corresponds to a reduction of 85,000 people as the camps are being gradually closed, and accommodation opportunities are being offered for refugees in city centers. In parallel with changing internal and external conditions from 2011 to 2019 and considering that millions of Syrians came to Turkey as a route to travel to other countries, it is possible to foresee that Gaziantep is located on quite a busy route. In the course of these eight years, there are also cases of refugees returning to Syria. According to February 2019 data of the Ministry of Interior 313,000 Syrians returned to their country (9).

The challenges faced by Syrian refugees in Gaziantep such as housing, accommodation, employment, work, health, language, social rights and adaptation are being addressed with the active participation of Gaziantep University, especially in critical areas such as higher education and language learning. Demands relating to basic education, vocational training and higher education of the younger population with more than 400,000 Syrians in the city can no longer be delayed and will play a crucial role in the future integration process of immigrants. Recent data clearly reveals the existence of problems on the education front that have been neglected for several reasons for the last eight years or cannot be fixed through constructive policies. Even though the school attendance rate of school aged migrant children has increased since 2017 through more realistic policies, data from UNICEF and the Ministry of National Education of Turkey show that at least 400,000 children are out of school or unable to continue their basic education due to various reasons. According to February 2019 data from the Ministry of Interior Directorate General of Migration Management, 45.5% of the 3.635 million Syrians registered in Turkey are aged between 0 -18. In other words, the most recent data indicate that 1.658 million Syrian children live in Turkey. In spite of the considerable socio-economic support from the government, national and international NGOs and international organizations, data from UNICEF and the Ministry of National Education show that only slightly more than 600 thousand students (almost all of them in state schools) continue their education, as mentioned earlier. It is also possible to say that a significant number of Syrian children between the ages of 0 -18 are involved in vocational learning or have already begun to work (10). Because when the age ranges and the generations are taken into account, the number of Syrian children out of school becomes obvious.

The current state of basic education and schooling should not preclude promising prospects for higher education of immigrants. The role of Gaziantep University at this juncture should be mentioned. On account of its global presence over the last thirty years and through the use of opportunities and platforms it has put to the use for the Syrian students over the last eight years, Gaziantep University sets a unique example, not just in Turkey, but for the entire world.

Founded in 1973, Gaziantep University is today the largest higher education institution in Turkey's southern border with 54,000 students. With sixteen faculties, eleven Vocational Schools, one of which is located in the Syrian city of Jerablus, five institutes, and four academies, Gaziantep University is the only university in Turkey offering education in three languages. A significant portion of the health services provided for the Syrian refugees during the war at its peak until now has been delivered through the two hospitals of the university, which still provide healthcare for refugees. Besides the courses it has been offering in Turkish and English for many years, the university also added Arabic to its course languages after 2011 with the increase of the Syrian population in the city and the lack of accredited centers teaching Arabic. As of 2019, the university has around 4000 international students, of which around 2500 are Syrians. Around 500 students continue attending Arabic courses certified by the Council of Higher Education. Undoubtedly, in addition to the Arabic courses, the policy that encourages ever more Syrian students to attend university still postulates certain requirements for acceptance whilst offering places as part of its unique understanding of public service. First of all, it should be noted that every year, no fewer than 10,000 Syrian students queue to be admitted to a higher education



institution and only very few of them are offered a place, which is a great loss in terms of human potential. On the other hand, offering a quality university education can be considered as a measure taken by the university against the high rates of unemployment among the young Syrian young population. It is obvious that the integration of this human potential into the social, economic and cultural life of Gaziantep and Turkey will contribute to the harmonization and coexistence of the populations. This also represents a case of risk management that the university can undertake and manage in urgent humanitarian matters, such as war and immigration. Undertaking a great responsibility in the inclusion of Syrian students in the higher education system, which is second to none in Turkey and even in other countries except Syria, Gaziantep University also boasts significant international partnerships in terms of overseas scholarships and academic visibility. Likewise, as well as providing courses in three languages, it also publishes academic journals in Turkish and Arabic.

Furthermore, another issue that needs to be mentioned is the health services that are provided to Syrian refugees, in addition to the opportunities provided by Gaziantep University to access health services. At present, a health system operates that is accessible to nearly four million Syrians despite the shortcomings or problems. All Syrians under Temporary Protected Status have free access to basic health services. At the same time, the Turkish Ministry of Health gives roles to Syrian healthcare professionals in the delivery of certain health services to Syrian refugees. Healthcare professionals with an equivalency certificate have undertaken critical roles in the process. For example, only in May-July 2017, more than 500 Syrian healthcare professionals who completed the required orientation training program started to offer their services in various areas as specified by the Ministry of Health. Similar programs involving Syrians continue. Syrian doctors, nurses and other healthcare professionals who received their equivalency certificates are currently undergoing training before providing service to both Syrian and Turkish citizens. It is also useful to note that as of 2018, more than 250,000 Syrian children in Turkey and approximately 63,000 people in Jerablus, Syria were vaccinated.

Finally, despite all the setbacks refugees experience in education, health, work, cultural orientation and social rights, Gaziantep, Turkey and Gaziantep University play extremely vital roles in rectifying the process. Especially, the support given by Gaziantep University for the education of young generations in Gaziantep and Jerablus is unequalled in scope. Undoubtedly, the conditions and traumas experienced by Syrians in different walks of life ranging from education to health and daily business life can be alleviated through harmonious and coordinated policies and activities. Gaziantep University is trying to do just that, integrating young Syrians into the higher education system who wish to have a university education by pushing the boundaries and enabling great achievements.

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## **Be Hookah Free: A Mobile App to Promote Hookah Cessation**

***Corey Beckwith and Mariam Akhdar***

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**Introduction:** In 2015, ACCESS received funding from the Blue Cross Blue Shield of Michigan Foundation to develop and pilot a mobile application designed to help hookah smokers quit tobacco. A lack of culturally competent, hookah-specific resources was identified as a barrier to smoking cessation in focus groups with Arab American young adults conducted by ACCESS. A 2017 Michigan Department of Health and Human Services study of Arab American tobacco use in the Detroit area found that 40.6% of Arab American/Chaldean adults currently smoke hookah.

**Objectives:** The Be Hookah Free project sought to test the feasibility of a mobile smoking cessation app specific to hookah.

**Methods:** The Be Hookah Free app was developed for Android and iOS platforms by a mobile web development firm with input from ACCESS staff. The app tracks the user's days without smoking hookah and money saved as a result of not smoking.

The app addresses the social nature of hookah smoking by including a calendar that is automatically populated with events.

ACCESS staff recruited 53 Arab American young adult hookah smokers to participate in a pilot test. The pilot included a baseline survey along with one, two and three-month follow up surveys. All surveys were conducted using Google Forms. Participants were expected to use the Be Hookah Free app throughout the process, even if they experienced a relapse. Participants received a \$10 Amazon gift card each time they completed a survey.

Participants were recruited using a convenience sample at three Detroit-area colleges and universities (Wayne State University, University of Michigan – Dearborn and Henry Ford College). Arab and Muslim student groups helped in identifying Arab American students who qualified for the pilot.

**Results:** The app had a positive impact on participant reports of smoking during the past 30 days. At baseline, 42% reported smoking hookah 14-30 days during the past month (frequent smoking). That figure fell to 17% at one month. At three months, only 7% reported smoking 14 or more days. After three months, 78.6% of respondents reported using the app "somewhat often" or "very often". Prior to participating in the Be Hookah Free project, only two pilot participants reported ever using any smoking cessation resource while trying to quit hookah.

The share of participants who reported 0-2 days of hookah smoking in the past 30 days steadily fell over the course of the pilot period. Just 17% reported this level of use at baseline. At one month, the figure rose to 22%, 28% at two months and 57% at three. Again, month three had a smaller sample size over-represented by individuals dedicated to quitting. Despite this, the trend of less hookah smoking when engaged with the app continued.

Throughout the pilot period, the app's tracking features (days smoke free and money saved) ranked as the most popular component. Support ranged from 80% at one month to 64.3% at three months. After three months, 28.6% found the milestone badges most useful. No participants found the event calendar useful at any stage of the pilot.

Most participants (85% at baseline) indicated health concerns as their main reason for quitting hookah.

Pilot participants responded favorably to the app in general. At one month, 97.8% said they would recommend the app to a friend or family member trying to quit hookah smoking. After two months, the rate dropped to 85.7%. Participants reported 78.6% favorability at three months. Similarly, after three months 78.6% stated that the app made them feel more prepared to quit smoking hookah.

At one, two and three months after baseline survey, most pilot participants reported using the app "somewhat often". The highest percentage of participants reporting "very often" or "somewhat often" use, came at three months (78.6%).

**Discussion.** Lower reports of frequent smoking while using the app suggest that engagement with Be Hookah Free helped participants limit hookah smoking.

Limited prior use of smoking cessation resources by pilot participants reveals a need for increased hookah-focused cessation options. Future incarnations of the app should attempt to increase awareness of existing smoking cessation resources to hookah smokers. This could come in the form of push notifications encouraging app users to talk to a doctor about Nicotine Replacement Therapy, medications like Chantix or group and individual counseling. The app should also include information on state tobacco quitlines.

Based on the results of the Be Hookah Free pilot project, a more formal study of mobile apps for hookah cessation is recommended. Participant feedback revealed opportunities to improve the app before any further testing. The event calendar can be eliminated, as this feature was completely ignored by app users. The resource library was similarly unpopular, and participants overwhelmingly reported quitting hookah because of health risks, suggesting that potential app users may not need additional resources to understand the health concerns related to hookah smoking.

## Health, the Syrian Conflict and Global Health: A perspective from the Lancet-AUB Commission on Syria

***Samer Jabbour***

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The conflict in Syria, now in its eighth year, has had profound consequences in Syria, the region, and beyond, precipitating one of the largest humanitarian crises since World War Two. In this summary, I reflect on the approach taken by *The Lancet-AUB Commission on Syria: Health in Conflict* (thereafter the 'Commission') (1), in engaging in the health-related issues and challenges raised by this conflict.

This Commission, hosted by the Faculty of Health Sciences (FHS) at the American University of Beirut (AUB) is the first Lancet commission to be led by an academic institution of the Global South. Founded in 1954, FHS/AUB, the leading school of public health in the Arab region, has lived through the various conflicts in Lebanon and the region. FHS/AUB has had many contributions to the understanding of health challenges of conflict (and instability more broadly) and displacement, and to the response to such challenges. In response to the Syrian conflict and the challenges of large-scale flow of Syrian refugees, FHS/AUB launched several research and practice initiatives at the faculty level and made major contributions to AUB-wide efforts in responding to the crisis. The LCS, the most global of such efforts, was established as a joint collaboration between the Lancet and FHS/AUB, a collaboration that builds on prior joint efforts including the Lancet series on Health in the Arab World, which addressed the health implications of the monumental changes that gripped the Arab region starting in 2011 with the onset of the Arab uprisings (2).

The Commission has sought to bring a strong Syrian and regional voice to weigh on the global discussions on the subject and to bring the health-related issues of the Syrian conflict to global health attention through facilitating a global multi-disciplinary collaboration represented in the Commissioners and related network of researchers. The Commission's objectives are to study the health-related impact of the conflict, both within Syria and across countries of refuge including impact on host communities; critically examine the



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international and global response to the conflict; develop policy and practice options to address the profound toll of the conflict and the shortcomings of the global response including of global health; and launch a network of researchers, practitioners and thinkers to advance discussions on health in the Syrian conflict and health and conflict more generally.

The Commission research is carried out through six Thematic Groups examining the context of the conflict, framing health in relation to the conflict and the conflict itself in relation to global health, and placing both health and conflict in Syria in historical perspective; health impacts of the conflict inside Syria; health issues of refugees and host communities; conflict impact on the health systems both inside Syria and in countries of refugee; the international response to the conflict, with a particular focus on aid and violations of international law; and policy options for health protection in Syria and for advancing the response of global health to armed conflict. The Commission secretariat and an affiliated network of researchers also pursued work in other complementary research streams.

This Commission has also focused on key topics deemed central and urgent in any health inquiry on Syria. We can illustrate this clearly in the example of health protection. On the 5<sup>th</sup> anniversary, the Commission released the results of a preliminary inquiry into the plight of health workers in the conflict, proposing the concept of weaponization of healthcare to discuss a comprehensive strategy, largely employed by pro-Syrian government forces, of attacking health facilities, targeting health workers, criminalizing medical neutrality, and cutting medical aid to besieged areas and forced besieged medicine there (3). Building on evidence generated, the Commission has developed knowledge resources on the subject (4) and used both the evidence and knowledge translation tools to facilitate and contribute to policy dialogue on the subject. The Commission did so through organizing a high-level side event at the UN General Assembly on the subject of 'Protecting Health Care in Armed Conflict' partnering with four UN member states, Canada, The Netherlands, Spain and the United Kingdom and an advocacy network, the Safeguarding Health in Conflict Coalition (5). The event had a global scope looking at policies and measures to advance protection of healthcare in conflicts everywhere. The recommendations of the side event were summarized in a follow-up call to action issued shortly afterwards in the Lancet, which was lead-authored by the Canadian Minister of Health (6). Another call to action (7) followed the offensive by pro-Syrian regime forces on Eastern Ghouta, near Damascus, where large-scale attacks on civilians and healthcare were reported. Accountability, and measures to achieve it, were key to these calls.

Building on the study of health and the Syrian conflict, the Commission has identified a need to advance collaboration on health and conflict globally and strengthen representation and leadership from the Global South. The Commission is now spearheading efforts by FHS/AUB to establish a global network on health and armed conflict. The aims are to advance this as a serious field of inquiry and practice, create a global platform for collaboration among researchers as equals, and contribute to

helping people at risk for or who are affected by conflict. This is envisioned for launch in 2020.

Whether through focusing on Syria or through engaging in global collaboration on health and armed conflict, the Commission is attempting to address one of the most pressing issues of our time: the threat to people affected by the un-relenting global menace, war.

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## Manualized Psychosocial Support for Cancer

*Francesca Gany, William Breitbart, Mark Lazenby*

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### Summary

**Introduction.** Cancer diagnosis has significant impact on the psychosocial milieu of patients. Often, patients face distress, emotional and mental health issues as a reaction to cancer. In 2015, 20% of the 1.5 million Americans who were diagnosed with cancer belonged to an ethnic minority group. Despite being one of the fastest growing populations in the country, Arab-Americans receive little attention in health and mental research. Arab Americans are at risk for poor cancer and quality of life outcomes, due to language, socioeconomic barriers and lack of social support. Evidence-based and manualized psychosocial intervention can contribute to the improvement of emotional and quality of life outcomes in Arab American communities.

**Manualized Psychosocial Interventions.** Culturally tailored manualized psychosocial interventions are more effective than interventions provided to groups consisting of participants from a variety of cultural backgrounds. There is a critical need for the development of culturally-tailored psychosocial interventions for Arab cancer patients.

**Meaning-centered psychotherapy.** Dr. Breitbart discussed Meaning-centered psychotherapy (MCP) which is a manualized seven- or eight-session psychotherapeutic intervention to help patients suffering with loss of meaning around illness. It is designed to help diminish cancer-associated feelings of despair by helping patients focus on the importance of creating, reconnecting with, experiencing, and sustaining meaning in life. Researchers at Memorial Sloan Kettering have adapted these concepts to create the manualized MCP intervention, which has been empirically validated and is adaptable to both group and individual therapy formats. Therapists providing MCP work to help broaden the scope of possible sources of meaning through a combination of didactic teaching, experiential exercises, homework assignments, open-ended discussion, and interpretative comments. These practices help promote emotional expression and facilitate patients' adoption of a meaning-focused perspective.

**Palliative Care Intervention for Muslim Patients.** Dr. Lazenby discussed the development of a palliative care intervention for Muslim patients who are in treatment for advanced cancer in the United States, aimed at helping patients with a cancer diagnosis deal with the questions of mortality. The distress of these questions can be compounded by being from a minority (and often misunderstood) religion.

Additional discussion ensued regarding the status of manualized psychosocial interventions in the MENA region. The panel allocated generous time for audience participation and discussion resulting in opportunities for potential collaboration and capacity building.

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## **Challenges and Lessons Learned from Preventing Non-Communicable Diseases (NCD): Review from the Tunisian Case**

***Hassen Ghannem***

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Tunisia is currently undergoing an epidemiological transition characterized by a decrease in mortality and birth rates, increase in life expectancy and a decline in infectious diseases. In contrast, there is a constant increase in chronic noncommunicable diseases. This change also affects the lifestyle of Tunisians who are adopting the new so-called "Western habits" characterized by physical inactivity, changes in dietary habits and leisure means, and others. Thus, Tunisia is now facing the pronounced emergence of noncommunicable diseases NCD, increasing the need to prepare an integrated prevention strategy to address common risk factors and major determinants shared by NCD.

For this presentation, we prepared a recent bibliographic search in PubMed using the MeSH structure that covers mainly cardiovascular diseases CVD and their risk factors in North Africa for the last 5 years. Estimation of the burden of CVD and their risk factors in North Africa was also based on the consultation of other sources (WHO, GBD of the Institute for Health Metrics and Evaluation, Global Health Observatory and Atlas of African Health Statistics).

North African countries are currently undergoing an epidemiological transition characterized by a decrease in mortality and birth rates, increase in life expectancy and a decline in infectious diseases compared to CVD that are progressively increasing. This change also affects the lifestyle with the rapid increase of urbanization. Thus, North African countries need to prepare an integrated prevention strategy to address common CVD risk factors and major determinants shared by NCD. Four preventable risk factors play a dominant and often synergistic role in the development of CVD like other NCD. These include tobacco use, unhealthy diet, physical inactivity and harmful use of alcohol. Consequently, integrated actions against these risk factors implemented in the social context can lead to the reduction of major Cardiovascular Diseases.

Most of what we know about the prevention of NCD comes from the experience of developed countries where many of these diseases have been the object of successful interventions. The available evidence supports the feasibility and effectiveness of large-scale prevention in the population intended to increase the proportion of people at low risk for these diseases. The concept of integrated NCD prevention as an essential component of existing health system with

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a focus on health promotion at the population level could be the way that our country must take to significantly reduce the future epidemic of these diseases.

The project "Together in Health" in Sousse, Tunisia is an example of an integrated chronic disease prevention programme in an intersectoral approach that goes beyond the health care system. The implementation of this project in the region of Sousse in Tunisia highlighted the following challenges and lessons learned that are shared by other countries with similar context:

1. Among the main challenges encountered we can cite the following:
  - i. The growing urbanization, the environment and economic pressures may result in poor diet choices and limited physical activities.
  - ii. Lack of resources and low interest among major health development funds.
  - iii. Lack of capacity of the public health workforce
  - iv. Lack of responsiveness of the health systems to the multidisciplinary approach
  - v. Lack of performance of the health information systems to shape evidence-based policy
2. Among the lessons learned we can cite the following:
  - i. Need for NCD policies development and implementation
  - ii. Need for global assessment of the implementation of the WHO Framework Convention on Tobacco Control (FCTC) and Global Strategy on Diet, Physical Activity and Health
  - iii. Need for a better control of Cardiovascular disease risk factors (Hypertension & diabetes) in primary care and need to target the youth generations
  - iv. Need to implement structural change through public policy to impact the environment
3. Long term plans
  - i. We need more community-based interventions to generate local evidence. Most of the evidence is coming from developed countries, this may not provide the relevant information to guide decision making in developing countries.
  - ii. We need capacity building to impact NCDs through the development and implementation of Community coalition-building, health education and structural change
  - iii. We need multisectorial approach to target the social determinants of Health
  - iv. We need common research proposal in multi countries context to strengthen networking

## **Health Rights Under Occupation: Palestinian Health Rights in the Occupied Palestinian Territories**

***Maen Hammad***

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Amnesty International research revealed unlawful practices by Israeli authorities in regards to the right to health for Palestinians living in the occupied Palestinian territories.

Sweeping restrictions on the freedom of movement for Palestinians with significant health issues has created a reality where there are record-low numbers in Gaza Medical Permits, resulting in the death of 54 Palestinians in 2017 that were waiting for an Israeli permit to leave the besieged Gaza Strip. This record-low rate of permits issued by Israel for Palestinians seeking vital medical treatment outside Gaza underlines the urgent need for Israel to end its decade-long closure of the Gaza Strip. For the last two decades, and especially since 2007 when Israel imposed a land, air, and sea blockade on Gaza, Israel has kept Gaza mostly closed, unlawfully depriving its population of basic rights.

Further, in the context of mass killings and injuries during recent demonstrations in the Gaza Strip, Amnesty International research suggests that many demonstrators were deliberately killed or injured, while posing no imminent threat to Israeli soldiers and snipers. Israeli forces have used high-velocity military weapons and ammunitions to disperse protesters, injuring over ten thousand Palestinians, including men, women and children— a shocking and appalling number. Many who have not died have suffered life-changing injuries, and will likely face further complications, infections and some form of physical disability. Others, such as health workers, including Razzan al-Najar, a volunteer medic who was shot and killed by an Israeli sniper, have fallen victim to these violations. Hospitals are struggling to cope with the volume of serious injuries without adequate resources and chronic shortages of fuel, electricity and medical supplies caused mainly by Israel's illegal blockade.

Our team at Amnesty International has launched campaigns targeting Israeli authorities and the international community in order to stop human rights violations and to seek justice. These campaigns allow us to reach our targets and goals of stopping the violation of human rights, to do this we target a global audience by utilizing our 7 million members, thus giving a voice to the voiceless. Amnesty International has a number of mechanisms to do this campaigning: some have come in the form of petitions, letters to governments, online- and offline activism, while there are a number of others. This discussion will cover an array of Amnesty International campaigning, especially in the context of human rights in the occupied Palestinian territories.

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## **Health Securities**

***Kashef Ijaz, Kim Curi, Dalia Samhouri and. Jennifer Nuzzo***

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### **Abstract:**

Diseases know no boundaries. A health threat anywhere is a health threat everywhere. New viral and bacterial pathogens continue to emerge and in today's tightly connected world, a disease can be transported from an isolated rural village to any major city in as little as 36 hours. The recent Ebola epidemic demonstrated that a majority of the countries (at least 70%) are not prepared to respond to disease events. It also emphasized the overdue and urgent need to implement core capacities of WHO's International Health Regulations (IHR, 2005). This would help countries have the ability to prevent, detect and respond to public health threats at source, which will not only reduce morbidity and mortality but also the economic and social impact for the developing countries as well as globally. The Eastern Mediterranean Region consists of 21 Member States with an estimated population of 644 million (8.6% of the World population in 2016). The region also consists of countries that are facing protracted crisis and conflicts including complex humanitarian emergencies and have a particular need to develop, strengthen and maintain IHR capacities as part of health system strengthening to detect, assess, notify and respond to any events of national and international concerns regardless of their prevailing situations. The fragile and weak health system, substantial number of internally displaced populations, influx of foreign populations as refugee/migrants, absence or inadequate administration of public health services inside these countries are key concerns as they make these countries vulnerable to potential public health threats. Though the complexity in crisis countries poses its own challenges, it should not prevent conducting an evaluation of public health capacities that identifies critical gaps and ways to improve them, which may not necessarily follow the same path as in the non-crises countries.

### **Panel Objectives:**

The following objectives were addressed by the panel:

1. To provide an overview of importance of Global health security
2. Implications of global health security in terms of capacity building capacity to mitigate health emergencies
3. Importance of global health security related to migrant health issues and refugees
4. Importance of global health security as economic health security

## **War, Displacement and Radicalization**

***Hisham H. Ahmed***

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Good afternoon. Evoking some humor, let me start out by saying that if you want to punish or torture a professor, just limit their time when he/she talks to 10 minutes only. I have been negotiating with the moderators of this panel and the other presenters to sell me their time and they promised me to think about it.

First, I would like to extend my deepest gratitude to Dr. Adnan Hammad and to the entire Access team for inviting me to participate in this phenomenally significant Arab health summit. Access has my profound admiration for what it is doing.

Second, I kind of thought that I will be viewed as an outsider or intruder on this summit. Afterall, I am neither a physician, nor a professional in the healthcare service or public health field. Originally, I prepared to spend a good deal of the short time allotted to me to justify my presence and participation here, for I am a political scientist by training and profession. To my pleasure, however, during the reception I sat at a table with, among other people, Dr. Nazar Elfakhi who is from Sudan and who works in the field of public health in Oman, and who skillfully reflected on the inter-connectedness between healthcare policies and the surrounding political environment. With my luck maximizing that evening, His Excellency, Minister of Health of the Sultunate of Oman, Dr. Ahmed Alsaïdi eloquently spoke of the interplay between policies regarding healthcare in a given state, with Oman being an example, on the one hand, and the impact of political determinants, on the other. Both Dr. Elfakhi and Dr. Alsaïdi made my job much easier. But then Dr. Iman Nuweihid during the first plenary session of the first day of the conference gave another boost to my involvement as he spelled out in detail the impact of different spheres of influence on public health in Arab societies, most notably, the political sphere of influence. Then this morning, at the second plenary session, the link between the politics of health and policy as a determinant of health was well established and nicely elucidated.

To all experts who recognize the inseparability between politics and health goes my deepest gratitude and respect. To them, I am truly grateful, for they make my job as an advocate for public health; but with an orientation in politics, easier.

The title of my research is WAR, DISPLACEMENT AND RADICALIZATION.

In pursuing this ongoing research, my objectives are multifold:

1. To highlight the impact of war and displacement on the education of refugees. It is a well-known painful fact that war and displacement disrupt the educational process for many victims, and in some cases, as has been the situation in the Arab World, they may hamper it completely.

2. To discuss the ramifications of the lack of education for refugees on their behavioral and social characteristics. For any individual or group, education becomes an important tool of socialization. Equally true, when formal education becomes dysfunctional due to war and displacement, another form of socialization, or what you may call mobilization and indoctrination, which is less favorable to stability, may take place. In other words, radicalization may find its way through the alleys of de-education.

3. Due to its prime importance and pivotal relevance to questions of overall security and stability, my overarching objective is to bring to the attention of concerned policy makers the urgency of addressing the unbreakable relationship between displacement as a consequence of war and the likely resultant radicalization.

In pursuing this research, I am motivated by the sense of urgency to highlight the ramifications of the ferocious assault of displacement on the rights of the refugees, particularly those pertaining to education. At the same time, I am also motivated by my own background as a Palestinian refugee who was born and grew up in a refugee camp, Deheisheh near Bethlehem: every time I read about the plight and the agony of new refugees, I cannot help but reflect on my own upbringing and observation of the effect of deprivation on the lives of so many people around me, as well as on my own life and that of my family. Without indulging in personalization, suffice it to say that I have learned only at the age of 25 that the cause of my blindness and that of my brother was the bi-product of life in the refugee camp. When no ophthalmologist in Palestine, Egypt or the United States could ever confirm the exact cause of my blindness, a Palestinian-American nurse, Alan Odeh Nassab whom I was interviewing for the record because she was dying of cancer after her brother, Alex Odeh was killed in a boobytrap attached to his office door in Los Angeles because he was an excellent representative of the ADC, Arab-American anti-discrimination committee. Having never seen me before or after, or known that I was from Deheisheh and that I was blind, as I was conducting the interview with her on the phone, Alan narrated, to my surprise, that while she was working as a nurse at the UNRWA clinic in Deheisheh before and during the 1967 war, one of the most disturbing problems she and the healthcare team was dealing with then was the lack of certain vitamins among many pregnant women, which caused blindness for some of their babies. You cannot imagine the shock that befell on me as Alan mentioned my late mother by name as one of her patients: the news fell on me like a thunderbolt falling from the sky. You can imagine then that this is in part why I am devoting myself to the question of refugees, whoever and wherever they are.

Some consequences of war are tangible in as much as they relate to physical destruction and human casualties. However, war also results in many intangible consequences which can have more far-reaching effects on societies than can be immediately observed. Psychological, behavioral and cultural ramifications of war usually take many years to surface. Especially in a troubled area, like the Middle East, the many crises that have developed over the years, have contributed to the deepening of extremist tendencies among some groups and organizations. By all accounts, the displacement of many Syrian, Iraqi and Palestinian refugees in the most recent conflicts during the past few years has widened the base of radicalization in the region. My study examines the impact of war and displacement on the education and potential radicalization of Syrian, Iraqi and Palestinian refugees, especially in, but not limited to, Jordan, Lebanon and Turkey. I chose these countries because they are relatively speaking the most stable politically in

the Middle East at this stage, at least for now, and because most of the displaced refugees ended up in one of them.

My main hypothesis in this study is that radicalization becomes inevitable during wars unless alternative solutions are considered, i.e., unless some robust, systematic international programs of aid to alleviate the suffering and to replace despair with hope are introduced.

In carrying out this study, I have conducted extensive literature review, and have thus far visited Jordan and Greece where I met with and interviewed many refugees. As this study is ongoing, I also plan to visit Lebanon, Turkey and other countries where refugees ended up going. Greece was chosen because it was the hub for many refugees crossing to other European countries. I have also interviewed refugees living in other locations of refugee concentrations and dwelling, such as some communities in Michigan where the largest Arab-American community lives. By meeting with many of the refugees, my goal has been to firsthand understand the impact of displacement on their behavioral tendencies and social characteristics.

Some preliminary conclusions of this conceptual study are formulated. First, in essence, radicalization of individuals can be viewed as a form of abnormalizing the minds of those who fall victim to this tendency. Secondly, more broadly, when radicalization spreads in a group or community, it can deform the social structure and lead to behavior which lacks balance: we may call this “the imbalancing” of communities. Third, creative and innovative policies are required to tackle the underlying root causes of radicalization. It is not enough to look at the symptoms, but rather to get to the stem cell, to use some jargon from the world of healthcare. Finally, for now, the specifics and particularities may vary from one case to another, depending on the particularities of several political determinants affecting each case. I believe this study should be of immense benefit to scholars, policy-makers and the public at large. The scenes of hundreds of thousands of refugees flooding European highways recently to escape the killing and destruction make this project even more compelling.

Before I close, an important word of caution is in order, inescapable and necessary. One may leave this presentation carrying some kind of stigma or stereotype of the refugees, that they are all radical or amenable to radicalization. Nothing is farther from the truth. Their displacement may result in feelings of bitterness, frustration, and even betrayal by the international community. But when given the chance and the opportunity, refugees are the most sensible, as their journey through the trail of suffering and pain makes them more sensitive to human and social injustice. The task and the obligation are to make the balance tip away from radicalization and in favor of hope and innovation. Most refugees who are given a chance in life have exceeded the average contributions of their peers to human development. Political leaders who understand this, no doubt can make a difference.

This is the time to heed the call for human justice and dignity for refugees. This is the time when perspicacity should over-ride narrow political considerations. This is the time to prevent more seeds of radicalization from being planted.

## Assessment of the Health Status, Behaviors, and Needs of this Arab and Muslim Americans in the Chicago Metropolitan Area

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**Introduction.** There are scarce data on Arab and Muslim American health. Arab Americans are a silent minority in the U.S., in large part because the U.S. Census Bureau classifies those of Middle Eastern or North African (MENA) descent as white. Most studies that do investigate the health of this population come from Michigan, where there are more concentrated areas of Arab American communities. Identifying common health conditions and behaviors of Arab/Muslim Americans is the first step toward designing programs to reduce health disparities affecting our communities. Partnerships among community organizations and academic institutions could facilitate efforts aimed at understanding and addressing health care needs of invisible minorities.

**Objectives.** The purpose of this presentation was to describe findings from a community health survey that was conducted during a health fair held by the Arab American Family Services, a nonprofit social service agency serving South Suburban Chicago area residents.

**Materials and Methods.** A total of 137 Arab/Muslim American adults completed a questionnaire with items on sociodemographic characteristics, language use, access to health care, screening behaviors, and health conditions. Health fair participants were also offered various health screenings including measurement of height, weight, blood pressure, cholesterol, and glucose. We used SAS 9.4 and conducted descriptive statistics based on the completed questionnaires.

**Results.** The mean age of participants was 39.5 years and about 75% were female. The majority of participants were currently married (~76%) and had minor children (~68%). Most respondents listed their ethnicity as Arab (80.9%). Among all participants, 25.8% were born in the U.S., 64.4% were born in an Arab country, and 9.8% were born in other non-Arab countries. The use of Arabic language among participants was more common than the English language.

One quarter of participants stated they had no insurance. Half of the sample cited Medicaid or Medicare as their primary insurance. Sixty-two percent of respondents had a routine check-up in

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the previous year, but more than one third stated that they could not get needed medical care from a doctor in the previous year because they could not afford it.

Despite a high prevalence of risk factors for heart disease, fewer than 7% of respondents stated they had heart disease. More than one quarter of participants stated that they had high blood cholesterol, about one fifth had a diagnosis of hypertension, and approximately 13% reported a history of depression. Diabetes was a significant health problem, with 13.1% of respondents stating that they had been diagnosed with diabetes. Approximately, 47% of participants felt that they were overweight but 75% of participants who had their BMI calculated were overweight or obese. Nearly 40% of participants did not exercise regularly. Twenty-two percent stated they had ever smoked 100 cigarettes, 11.4% were current smokers, and 9.9% reported smoking waterpipe (hookah). Around 65% of women reported never having a mammogram and almost 90% of participants reported never undergoing a stool blood colon cancer screening test.

**Conclusions.** This survey provides a rare opportunity to assess the health status, behaviors, and needs of this Arab/Muslim Americans in the Chicago metropolitan area. Insurance and access to care appeared to be a significant issue in this population. The findings suggest that depression, overweight/obesity, and smoking are common in this population, and cultural perceptions of risk factors (e.g., increased BMI) may differ from established medical classifications of risk, such as what constitutes a healthy weight. This study calls for a more thorough and representative health assessment of this population and for the development of community-based strategies for screening, prevention, and treatment.



## **Health Research System - From System Analysis to System Strengthening: A Case of State of Palestine**

***Mohammed AlKhaldi***

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The importance of a Health Research System (HRS), as an instrument for developing and enabling health systems, is increasing, particularly in developing countries. HRS is the mind of the health system, which feeds proven knowledge to decision-makers to help them in making sound decisions. Therefore, building a robust and effective HRS is one of the most important contemporary approaches for strengthening health systems. As a consequence of this growing awareness also within the World Health Organization (WHO), there are many new approaches and initiatives to ensure the national HRSs be strengthened and well functioned to address the countries' health needs through formulating and analyzing these systems particularly in fragile and resources constraint countries. A holistic analysis, both quantitatively and qualitatively, is a fundamental step which leads to three tracks: understanding the status quo of HRS, creating strengthening and developmental solutions, and proposing a structural road map for HRS building. Assessing the perceptions of system performers is an essential part of this comprehensive system analysis, which seeks also to recognize a system's strengths and limitations across these three tracks.

The present research focused on investigating five key pillars of the system in Palestine as a unique case of a developing country. First, it assessed the HRS concept and its importance among systems performers. Second, it evaluated their satisfaction with overall HRS performance and political attention towards health research. Third, it examined the stewardship functions, governance, policy, and priorities, as a central pillar of this system. Fourth, it analyzed stakeholder's' roles, involvement, and contributions and then, fifth, it explored the status of research capacity with regards to resources, research quality, and knowledge transfer and translation. Based on these five axes of analysis, key gaps and avenues of solutions towards achieving a comprehensive HRS strengthening in Palestine were identified. The research targeted three sectors, namely relevant government institutions, schools of public health and major local and international health agencies. A qualitative analytic approach was used where data was collected through 52 in-depth interviews and 6 focus group discussions with 104 policymakers, academics, directors, and experts.

In the first part, the research found the level of understanding of HRS concepts among health experts in Palestine is inadequate and not sufficiently conceptualized for the application. The second part found that the HRS in Palestine is remarkably underperforming with a significant lack of political support and engagement. The third part revealed that the stewardship functions are problematic, meaning that a system for health research in Palestine is still not embodied mainly due to a missing structural and regulatory framework and dispersed HR work. It is also found that the Ethical Review and Clearance (ERC) is weak, a policy or a strategy dedicated to health research is lacking, and low levels of knowledge and experience in research prioritization amid of lack of consensus. The fourth part found key findings: low involvement of society, private, local and the

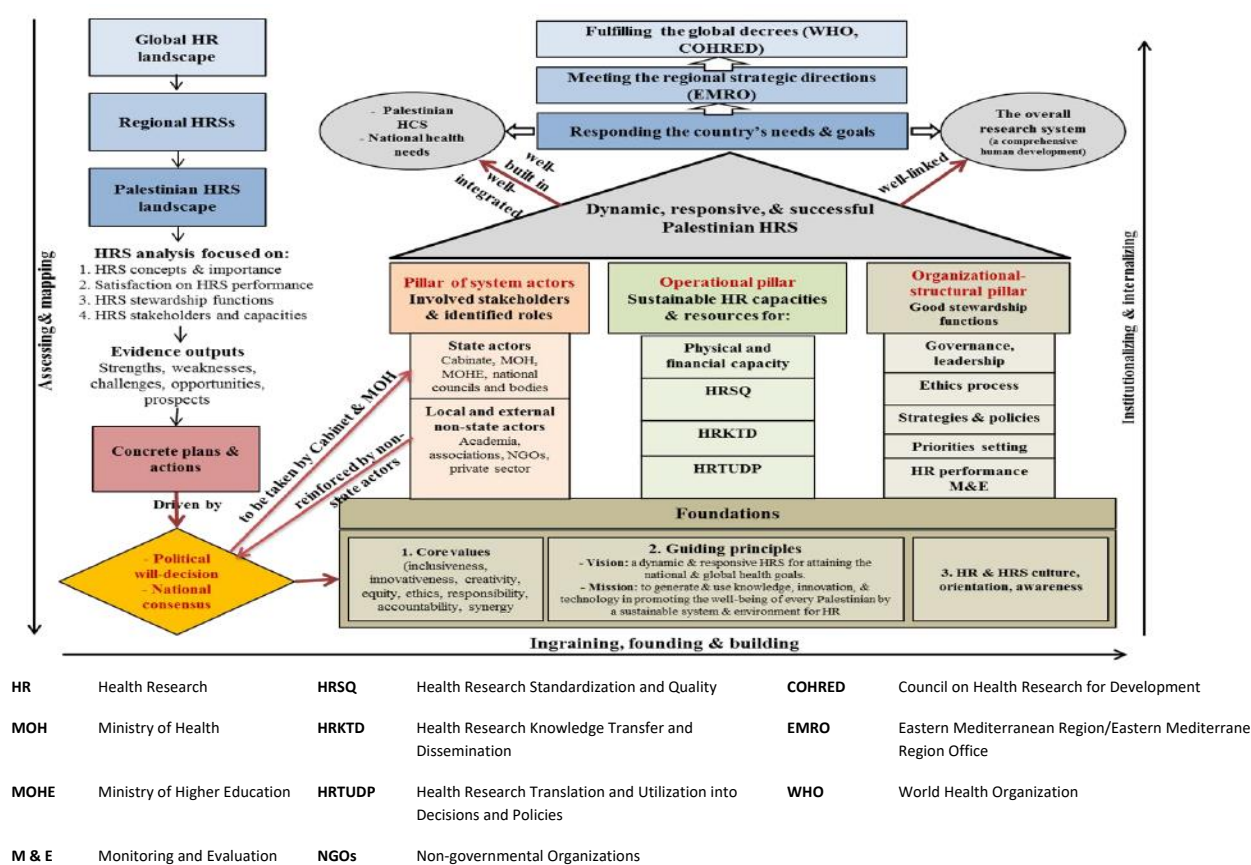
international sectors; a substantial weakness in the role of international agencies in supporting health research. The fifth part demonstrated a significant deficit in HRS resources and capacity. This deficit is due to the fact that research in Palestine is externally and individually funded, limited and unsustainable, and importantly, moderate research quality, as well as knowledge transfer and translation are not well-conceptualized and inappropriately performed. The research also identified main further common gaps as follows: lack of HR culture, systems values and principles; structure; policy; resources; defined roles; connection and network; evidence-informed concepts; and politic impacts.

This analysis has recommended further empirical research to be investigated whether in Palestine and could be so in other similar settings or in the region. Understanding the reasons behind the apparent lack of knowledge on HRS concepts and assessing the HR performance and impact, based on defined quantitative indicators, are essential research. Moreover, assessments on HR stewardship functions with regards to the institutional functionality and applicability, as well as a national HR capacity assessment using qualitative and quantitative measurements deserve to be implemented. Once the HRS is structured, a national comprehensive system analysis is required to investigate inputs, processes, and outputs dimensions.

Crucial actions were offered to be translated into policy-making levels: launching a strategic dialogue on HRS strengthening among actors to ensure a solid commitment, a collective involvement, and a national consensus. This move should pave the ways towards two substantial actions, building a unified national HR body and formulating a national strategy, both are integrated into the structure of Palestinian Healthcare System (HCS), that has to include conceptual, regulatory, legal, technical and ethical aspects. Under this body and through this strategy, actions to improve HR prioritization, ERC, HRS awareness, HR performance, HR resources and capacity e.g. research quality, knowledge transfer, and translation, are fundamental components must be integrated and improved. In doing so, operational policies for HR resources and capacity have to be established, along with guidelines, indicators, and mechanisms for HR prioritization, performance, quality, knowledge diffusion and utilization that essentially required to be formulated and adhered. Also, effective networks communications, dynamic coordination, and systematic education and training programs are further feasible actions towards achieving a comprehensive HRS strengthening.

This research proved to be very worthwhile because it met a longer-standing local demand, as well as was aligned with regional and global strategic directions. To move forward from system analysis to system strengthening, the research portrays, in the Figure 1, a comprehensive picture of the holistic building architecture of HRS considering global, regional, and national spheres, and depicting three strategic trajectories: (1) the analytical and assessment trajectory of HRS, (2) the structural constructivist trajectory, and lastly (3) the strengthening and institutionalization trajectory. Consequently, getting the system pillars well-enabled is possible and yields meaningful benefits to the HCS and other development sectors in Palestine and any settings. This system analysis attempt opened up new avenues for any future endeavors and for the new generation of health research, HRS, and HCSs strengthening in Palestine, in the region, and in the global in general.

Figure 1: A macrocosm illustration of HRS from the perspective of current analysis.



## Promoting Partnerships between Academic Institutions, NGO's and Relief Agencies

**Miles McNall**

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This panel included a distinguished panel of experts from around the world, each of whom shared their perspective on the role of partnerships in promoting health equity in light of current challenges in the MENA region and the U.S. Before introducing the panelists, Dr. McNall made a few remarks about his perspective on the importance of partnerships in achieving health equity. He spoke as a member of the Office of University Outreach and Engagement at Michigan State University who for the last eight years has facilitated research partnerships between Michigan State University and the ACCESS Community Health and Research Center.

He began by making the obvious point that none of the five summit objectives can be accomplished without partnerships. Not one that can be achieved by a single sector working alone. For instance, objective four relates directly to partnerships. It reads:

**To establish** links between researchers and other academic, governmental and non-governmental, organization stakeholders in the United States and in the Arab world as well as their counterparts in countries with Arab immigrants

Dr. McNall noted that objective four uses the term “links” instead of partnerships and argued that links are necessary, but not sufficient to achieve this summit’s other four objectives. What are needed to achieve these are genuine, robust, and sustainable *partnerships*. He added that as he had listened to our distinguished speakers over the past two days, he noticed that once their discussions moved from the particular health problem they were highlighting to solutions, a key element of those solutions was invariably some form of intersectoral partnerships.

Only the combined commitments, expertise, and resources of universities, communities, NGOs, and governments will enable us to achieve these objectives, but the exact mix of partners and roles will vary depending on the particular issue and local circumstances. Each partner in this mix has something extremely valuable to contribute.

**Communities.** Every effort to promote the health of members of Arab communities worldwide will be less effective if it fails to draw on the assets and effectively address the needs of communities themselves. Communities are rich sources of information about health needs of their members and the feasibility and appropriateness of particular health interventions. Communities know the history of past interventions and the reasons for their successes and failures. Communities are sources of highly committed individuals who will work tirelessly to improve the lives of their members. And most importantly, no effort to improve the health of individuals in communities can succeed (or should be undertaken) without their enthusiastic participation.

**Universities.** Universities are able contribute deep expertise in a wide range of disciplines related to human health, including medicine, nursing, public health, behavioral sciences, health

care administration and knowledge of evidence-based interventions. In addition, they can contribute skilled researchers who are increasingly well-versed in community-based approaches to research and are often eager to find partners for their research efforts. Through their research with communities they can generate valuable knowledge about the nature, extent and causes of health conditions, and the effectiveness of interventions. Working in partnership with communities, they can build the capacity of communities to address the health needs of their residents.

**NGO's/Nonprofits.** Whereas universities represent broad expertise across a wide range of disciplines, NGOs typically bring deep expertise in a particular issue, highly committed staff, and strong connections to the communities they serve. NGOs often provide the critical link between universities and communities. I can think of no better example of a nonprofit that plays such a role than the ACCESS Community Health and Research Center, which brings to every partnership deep cultural knowledge and medical expertise, extremely committed and competent staff, and strong connections to Arab American communities in Michigan and throughout the world.

**Governments.** Government health agencies are often essential partners in efforts to promote health equity. In my state, Michigan, the Department of Health and Human Services provides the public with a wealth of information on a variety of health-related topics; initiates evidence-informed prevention efforts related to a number of communicable and chronic diseases; and funds a variety health services from birth to old age. In the U.S., government-supported community health centers provide a large share of health and mental health services to low-income individuals. Government health agencies often have the resources and reach necessary to implement interventions across large geographic areas. They also employ highly trained epidemiologists to monitor health indicators and investigate disease outbreaks.

**Philanthropy.** Finally, let's not forget the role that philanthropy plays in contributing funding to health promotion, prevention and treatment efforts. In addition, government and philanthropy often play an agenda-setting role, and in the absence of partnerships may set agendas that are at odds with community aspirations, are disempowering, or are simply ill informed.

As an example of how partnerships can make things possible that would not have been possible otherwise, a partnership between the Michigan Department of Health and Human Services, ACCESS and researchers at three universities – Michigan State University, Wayne State University, and Saginaw Valley State University – fulfilled a long-standing goal among the partners of gathering accurate statewide health data on Arab and Chaldean Americans through a probability sample-based health survey.

As a result of the 2013 Arab-Chaldean Behavioral Risk Factor Survey, we learned about three important health challenges facing Arab-Chaldean Americans in Michigan. Compared to the general population, Arab/Chaldean adults aged 18-64 years were significantly more likely to report no health care coverage, lower frequency of colorectal cancer screening, and ever using a hookah (Hekman et al., 2013). Each of these challenges would come to serve as a focus for ACCESS's health programming efforts.

To make this survey possible, the ACCESS staff contributed its cultural expertise to the design and translation of the survey, and essential social capital that helped the survey reach respondents who might have otherwise been unwilling to complete it. The Michigan State

University office of survey research contributed its expertise in advanced population sampling techniques and used its established infrastructure for administering the statewide Behavioral Risk Factor Survey, which was modified to be more appropriate to an Arab and Chaldean American population. Dr. Kendra Schwartz from Wayne State University contributed her Arab surname algorithm to the effort, which increased sampling efficiency substantially and made the survey affordable. Dr. Rosina Hassoun of SVSU contributed her cultural and methodological expertise to the design of the survey. Finally, the Michigan Department of Health and Human Services (MDHHS) funded the survey, analyzed the data, produced the statewide epidemiological report, provided the data to researchers, and advised researchers on their analyses.

Dr. McNall noted that as a facilitator of the ACCESS-MSU and other partnerships between Michigan State University, communities, government agencies, and local non-profits, he had observed that several factors are critical to the success of such efforts. His observations were consistent with the principles of best practice for community-based research identified by Kerry Strand (2003) and colleagues. According to Strand and colleagues, in successful partnerships for community-based researcher, partners:

***Agree about goals and strategies.*** One of the reasons that the partnership to conduct the 2013 Arab-Chaldean Behavioral Risk Factor Survey succeeded was shared goals. In the first meeting of the ACCESS-MSU partnership Dr. Adnan Hammad stated quite clearly that accurate statewide data on the health of Arab-Chaldean Americans were urgently needed. We discovered shortly thereafter that MDHHS, which routinely commissions oversamples of particular ethnic and minority groups in Michigan, had the same goal in mind, providing us the opportunity to work together to achieve this goal.

***Have mutual trust and mutual respect.*** One truism in partnerships is that their success depends on a certain level of trust among partners, and that building relationships and establishing trust takes time. To understand this process a little more clearly, it is worth taking a moment to unpack the concept of trust. According to Tchanen-Moran and Hoy (2000), trust is a multifaceted concept that includes the following key elements:

- Confidence
- Competence
- Reliability
- Honesty
- Openness
- Benevolence

Dr. McNall argued that the absence of any of these elements in a partnership creates a challenging environment for that partnership to succeed. In his experience, one especially serious threat to a partnership is a lack of openness and a failure to fully disclose motivations. Because candor is so important to the healthy functioning of partnerships, it is important at the beginning of each partnership for partners to engage in an open and honest discussion about their motivations, interests, and what each needs to receive from the partnership for it to be considered successful from their perspective.

***Share power and resources.*** In the ACCESS-MSU partnership, power was shared through a collaborative consensus-based decision-making process. For each stage of the partnership, partners contributed expertise and resources available to them, and when additional expertise and resources were needed, they brought others into the partnership who possessed them.

***Communicate clearly and listen carefully to each other.*** In community-academic partnerships, faculty and PhD students who are not experienced in partnership work can sometimes be overly generous in sharing their expertise, overlooking the need to carefully listen

to and learn from their community partners. A failure to listen carefully to community partners can communicate disrespect and a devaluing of their knowledge; it can also miss critical information about the context of the work, jeopardizing its chances of succeeding.

***Understand and empathize with each other's circumstances.*** In community-academic partnerships, partners operate on very different time scales with competing professional priorities. Academic research tends to be a slow, laborious process, which can frustrate community partners who want quick answers to questions about the populations they serve or the effectiveness of the services they provide. At the same time, faculty need time to conduct research in a manner that can withstand the exacting scrutiny of peer review. Acknowledging these tensions at the start of a partnership can help to mitigate conflict among partners.

***Remain flexible throughout the partnership.*** Because partnerships operate in complex, dynamic environments, where new opportunities and unexpected challenges present themselves it is often necessary to adjust course, and abandon planned lines of action. This should not be taken as a sign of failure, but intelligent adaptation to changing circumstances.

Finally, successful partnerships are characterized by three things:

- Mutual benefit: Partners' primary interests or needs are met
- Capacity building: Partners' organizational capacities are enhanced
- Long-term perspective: Partners adopt shared, long-range social change perspectives

It is worth pointing out that the principles shared were developed by researchers in the U.S. who conduct community-based research. Panelists and audience members were invited to reflect on the extent to which these principles are universal, or in need of adaptation to fit the many unique contexts of the MENA region, including those currently experiencing conflict.

One truism in partnerships is that their success depends on a certain level of trust among partners, and that building relationships and establishing trust takes time. How does this work in situations where time to engage in relationship building is an unaffordable luxury? How are agreed upon goals and strategies developed in contexts high uncertainty? These questions and many others are raised as we consider partnerships for health in the diverse geographies and political and social landscapes known as the MENA region, as well as Arab communities in the U.S. and Europe.

Additional insights on best practices in partnership for health in the MENA region and the U.S. were also shared by the various panelists.

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## The Behavioral Health Needs of Refugees from the Middle East

**Anita Everett and Mary Fleming**

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This panel discussion was co-hosted by the Substance Abuse and Mental Health Services Administration (SAMHSA) and the office of Refugee Resettlement (ORR). This was an all-day meeting to discuss behavioral health needs of refugees from the Middle East with experts from the DC area who work with these refugees. Here are “lessons learned,” highlights from that meeting:

### **Lessons Learned**

**1. Use clear language that is culturally sensitive, no jargon**

Providers “need to humanize discussions of distress and mental illness” (Dr. Nahid Aziz, Co-Chair, SAMHSA Workgroup on Afghanistan Mental Health) and “use basic, direct (non-clinical) language and create an environment of respect for refugees” (Nouf Bazaz, Johns Hopkins). For example, avoid “PTSD”; instead say “because of the things you’ve been through. Also, persons from Iraq and Afghanistan are open to talk about their emotions but they don’t the label of “emotional” or “mentally ill (Dr. Hadi al-Khalili and Dr. Husam Alathari, members, SAMHSA Planning Group on Iraq Mental Health). “We need to change our language – and our practices.”

**2. Help the refugees understand US clinical care and refugee support systems, and understand how they feel like outsiders**

Participants agreed that refugees feel devalued, and a first session with refugees is often dominated by their feeling disrespected by providers because, although the constructs are not foreign, the words used to describe them are. “Distinguish between voluntary and involuntary treatment and how these play out for refugees” (Cecily Rodriguez, US Committee for Refugees and Immigrants). Clarify the roles of different providers for the refugees (Dr. Anita Everett, SAMHSA). Dr. Linda Wright (SAMHSA Workgroup on Afghanistan Mental Health) noted that legal issues, ob/gyn services, and help with school problems must be considered as services are developed for refugees from the Middle East.

**3. Refugees often present with psychosomatic illnesses**

“Anxiety is described as a ‘fire in my chest’ by persons in Pakistan” (Dr. Omrana Pasha, Johns Hopkins, who developed a 38 item tool while in Pakistan to assess distress in patients).

**4. “Refugees’ strengths and resilience need to be recognized, celebrated and built upon” (Nouf Bazaz)**

Resilience is built in community and family structures (and extended family structures) in these cultures (Omrana). Providers should engage refugees where they are (“I just want a washing machine”), recognize their resilience, and understand that they have experienced trauma (Mary Fleming, SAMHSA). Focus on refugees’ resilience and proactively prevent and normalize problems (“this is what to expect”). Focus on family and community services, and acknowledge understandable mistrust (Nahid). Neema Sheth (Georgetown) noted the need to normalize

refugees' experiences, not to pathologize normal reactions to abnormal situations and stated that services should start with therapy, then to help with sleep.

Resilience is a process that is context dependent, not an additive effect (Dr. Suzan Song, GW). Dr. James Griffith, GW, stated that the definition of resilience is the "capacity to flourish despite exposure to violence." He also noted that "when assessing strengths, assess at the time of struggle. It will tell you what the strong suit is – and go there!"

## **5. Religion and family are central to the refugee**

**Religion:** The role of religion – and of faith leaders – is key to helping refugees (Husam). Need outreach to religious leaders re: mental health and trauma, and they need to be connected to mainstream initiatives on these issues (Cecily). In the clinic, "religion is a potent avenue for emotional regulation. Facts of religion have much to do about how to show respect, but the spiritual center of the refugee (what was, is and will happen is meant to be) is more fundamental" (James).

**Family:** In these cultures, a person is a family member, not an individual. ORR and providers should focus on family-centered care and distinguish distress from disorders (James). James noted the importance of family-centered care for refugees, engaging with the family as a group and offering family therapy as well. Suzan underscored the importance of taking a life cycle approach, covering both development and resiliency, and stated that the family can be a source of strength – and stress. To engage with the family, ask, "How do you know when your family is doing well?" She also noted the importance of working with schools, identifying community liaisons to help the family understand how children are viewed and treated in America and how there will be power shifts due to quick language acquisition by children.

## **6. Develop culturally appropriate services for refugees from the Middle East**

Participatory care, involving the community and key leaders, is important to shaping culturally appropriate services. The primary care model in low and middle income countries can be a model for high income countries (Sonali Gupta, Heartland Alliance). Incorporate screening of refugees from the very beginning of the process (Sein Tuma, SAMHSA Planning Group on Iraq Mental Health). Seattle has a collaborative model integrating primary care and mental health services (Faith Ray, ORR). Nahid underscored the need for service providers to tell personal stories ("I am not immune"). Sonali noted that stigma can prevent access; for example, Iraqi men often will not see women providers, and she called for community collaboration to reduce this kind of stigma that limits access to services.

Nahid and Anita both suggested that telemedicine can be used to address refugees' behavioral health needs; Nahid regularly provides mental health counseling and consultation for providers in Afghanistan. Anita also suggested the use of physician volunteers through programs like the MAVEN Project that links a corps of expert physician volunteers to clinics and organizations in need, [www.mavenproject.org](http://www.mavenproject.org).

## **7. Provider cultural and trauma training is critical**

Noof noted that treatment begins with the greeting, not when the formal session starts. Through the greeting, the counselor starts building relationships. Forms and intake, very intimidating, come later. James stressed the importance of focusing on recovery. The refugee experience leads to alienation, a sense of isolation and "I don't know myself" – the way normal people shift

to deal with an altered world. Recovery is the shift back to the relational world, where the survivor and his or her story are embraced by the community.

Suzan asked how we can operationalize this. Should all providers be required to take training yearly? What about peer-to-peer training? Should groups that refugees interact with be trained – such as taxi drivers, teachers, etc.?

#### **8. Refugees from the Middle East are often highly skilled professionals who aren't able to practice in the US**

A path is needed to use refugees' expertise and skills here. Perhaps an internship program in ORR could help (Hadi). Another approach may be to train them to act as social workers to provide these services (James). "Career Pathways" at [www.career-pathways.org](http://www.career-pathways.org) is an approach that may enable these refugees to find jobs more geared to their experience. ORR has just issued a FOA for a Career Pathways Program that can help highly skilled refugees seek jobs closer to their in-country skill sets (Tim Kelly, ORR). Montgomery College has welcomed refugees and helped them financially (Linda Wright). Canada has several routes available to international medical graduates so they can practice medicine in Canada (Tim).

#### **9. ORR'S Mental Health Role And Services**

ORR efforts on mental health include support for services **through ORR's Services for Survivors of Torture (SOT) grant program**, which emphasizes a holistic, integrated, trauma-informed, and strength-based approach. As part of their State Plans submitted to ORR, states must describe the domestic refugee medical screening services in their states, including whether **MH screening** is provided. In addition, ORR has formed a **Refugee Mental Health Workgroup** composed of members from NIMH, SAMHSA, CDC, and OGA that meets twice yearly.

ORR also coordinates **Mental Health First Aid (MHFA) training** to refugees and refugee serving groups. As of July 2017, over 1,000 people have been trained, 60% of whom are refugees. Nahid noted that WHO has Psychological First Aid training available from its website for free. James added that the basic idea of MHFA is that it is urgent to get the level of arousal down and assess risk and resilience. Anything to bring security and comfort is MHFA. Participants agreed with Sonali's concern that we may be imposing western ideas of mental health and illness unless we take specific steps to work with various refugee groups to adapt the trainings.

#### **10. ACTION ITEMS:**

- ✓ Operationalize the recommendations from this meeting ☐ Provide/require **yearly training for providers**, including peer-to-peer model training
- ✓ **Focus on the ethics governing the provision of BH services** to refugees in all trainings
- ✓ Look into using WHO's Psychological First Aid training for refugee service providers
- ✓ Ensure that **refugee-serving staff working with refugees get Mental Health First Aid (or WHO's Psychological First Aid) training**
- ✓ **Introduce e-psychiatry for refugee clients**
- ✓ **Share key documents** with this group and more widely:
  - Share SAMHSA's summary, "Implications of the Iraq Experience for US Service Providers"
  - Distribute Omrana's chapter on violence and public health to this group
  - Share information on Theresa Bettancourt's home visitor program using bilingual staff

- ✓ Ensure there is **behavioral health training at the 2018 North American Refugee Conference in Portland, OR, June 7-9, 2018**. Develop/support/attend a webinar on bullying and Muslim youth.
- ✓ Check to see if a **HRSA/SAMHSA Integration Grant** can support work with refugees, including the integration of behavioral health and primary care services for refugees.

**ORR-SAMHSA MEETING ON THE BEHAVIORAL HEALTH OF  
REFUGEES FROM THE MIDDLE EAST, 8/9/2017**

**PARTICIPANT LIST**

|  |   |
|--|---|
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## Psycho-Socio-Economic Inequalities and Risky Behaviors Among a North-African Youth Population

**Hajer Aounallah-Skhiri<sup>1,2,3</sup>, Afef Skhiri<sup>1,3</sup>, Nada Zoghlami<sup>1,3</sup>, Fatma Lassoued<sup>4</sup>, Mohamed Hsairi<sup>2,3</sup>, Mounira Garbouj<sup>5</sup>, Nabil Ben Salah<sup>6</sup>**

**Introduction.** The political and socio-economic changes experienced particularly in the Arab world have significantly influenced the frequency of youth health risk behaviors. The identification of high-risk groups is one of the fundamental steps in the targeted prevention.

**Objectives.** to study psycho-socio-economic inequalities in drug use among high school students in Tunisia.

**Methods.** We used data from a national high school survey (Mediterranean School survey Project on Alcohol and other Drugs (15-17y) Tunisia 2013 (n = 3482) using anonymous self-administered questionnaire. Socioeconomic variables were: relationship with social environment (family, peers, and school staff), drug use social environment, awareness about legal aspects related to drug use, educational situation (performance, absenteeism, relationship with school). A psychosocial well-being score was calculated using a principal component analysis based on level of satisfaction in terms of relationships with family members, friends, school and family atmosphere, perceived well-being, perceived quality of relationship with school staff. Illicit drugs represent all drugs except tobacco and alcohol.

**Results.** Two thirds of the study population were female, the average age:  $15.8 \pm 0.04y$ . The prevalence of lifetime of cannabis use was about 1.4% (male: 3.5%, female: 0.2%). About 16% of respondents reported breathing fuel (16.5% of boys and 15.2% of girls,  $p = 0.45$ ), 13.0% (15.4% of boys versus 11.7% of % of girls,  $p = 0.043$ ) breathed the glue and 4.2% breathed other substances.

### Prevalence of some drugs use among 15-17y high school students (MedSPAD I Tunisia 2013)

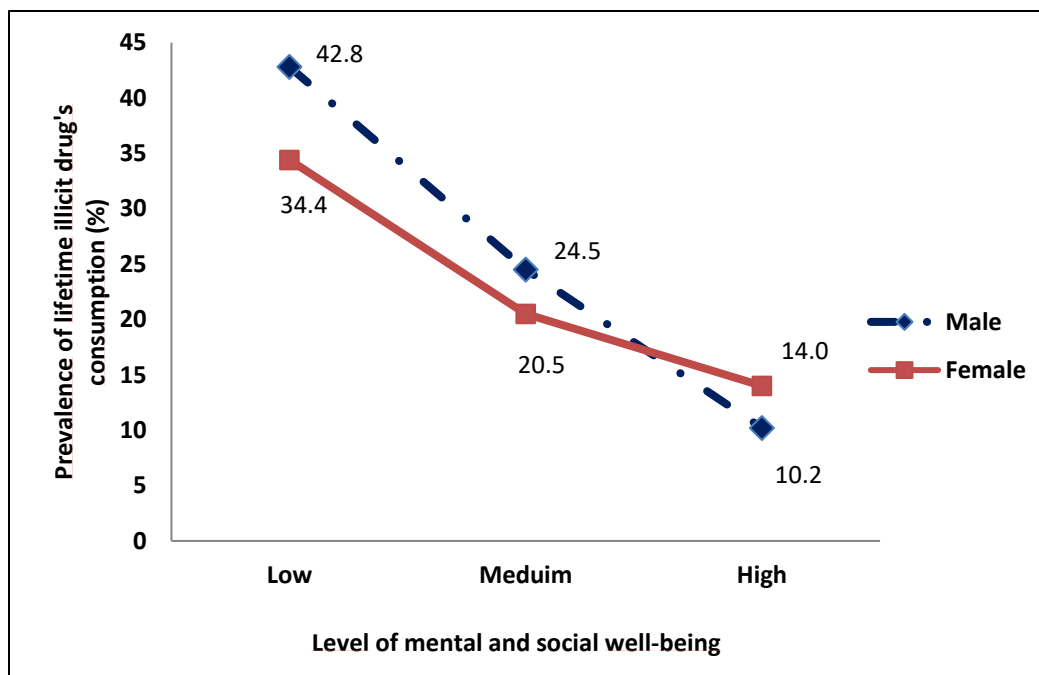
| Alcohol | Tobacco  | Cannabis | Medications | Cocaine | Ecstasy |
|---------|----------|----------|-------------|---------|---------|
| LT=5,8% | LT=22,2% | LT=1,4%  | LT=2,1%     | LT=0,5% | LT=0,2% |
| LY=3,5% | LY=11,1% | LY=0,7%  | LY=1,1%     | LY=0,3% | LY=0,2% |
| LM=2,2% | LM=8,0%  | LM=0,4%  | LM=0,7%     | LM=0,2% | LM=0,2% |

\*LT: lifetime, LY: last year, LM : last month

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A quarter of high school students aged 15-17Y (24.6%) reported having used (or inhaled) one or more psychoactive substances, other than tobacco and alcohol, during their lifetime. This prevalence was significantly higher among males than females (27.7% versus 22.8%,  $p = 0.037$ ). The prevalence of lifetime illicit drug use (except tobacco and alcohol) was higher among students who spent at least one night outside home within the last month (38.0% vs. 22.3%;  $p < 10^{-3}$ ) or having a working mother (28.1% vs. 22.9%;  $p = 0.04$ ) or unsatisfied about their relationship with their mother (60.8% vs. 23.6%,  $p < 10^{-3}$ ; association remaining significant after adjustment on mother professional status: adjusted OR: 4.9[2.4-10.0],  $p = 0.000$ ) or being not satisfied with the family atmosphere (from 19.3% : very satisfied to 60.1% very unsatisfied) or having problems with school administration (47.0% vs. 27.5%,  $p < 10^{-3}$ ). This prevalence increased proportionally with the decrease of psychosocial well-being level for both gender: -boys: from 42.8% (low) to 10.2%(high); girls: from 34.4% (low) to 14.0%(high);  $p < 10^{-4}$ ).

#### Prevalence of lifetime illicit drug's consumption according the level of mental and social well-being



The prevalence was significantly higher among students who reported peers' lifetime drug use (28.4% versus 8.4%,  $p < 10^{-3}$ ), or a family member's lifetime drug use (30.3% versus 12.7%,  $p < 10^{-3}$ ). The lifetime illicit drug use increased significantly with the decrease of perceived household economic level (HEL) comparatively to other HEL in the country (35.3% (under) vs. 26.2% (above) vs. 23.3% (same),  $p < 10^{-3}$ ).

The prevalence of last year alcohol's consumption was higher among those unaware that alcohol consumption leads to legal proceeding (yes: 8,5% vs. no: 2,6% vs. don't know: 1,8%,  $p < 0.001$ ). Same results for the prevalence of lifetime drug use and knowing legal proceeding (37.3% vs. 25.0% vs 14.7%;  $p < 10^{-4}$ ).

### Discussion and Conclusions:

Drug use prevalence was significantly higher among boys and adolescents with lowest psycho-socioeconomic support and awareness about legal proceeding.

Preventive strategy against drug use should take into account these inequalities and strengthen actions targeting vulnerable socio-economic youth population and focusing on reducing environmental and behavioural risk factors of drug use. Implementing healthy school environment and life-skills training are promising interventions to struggle drug use and addiction as well as many other risky behaviors. Any failure to consider the different risk and protective factors (table 2) of drug use would lead to a vicious circle that will worsens the situation at the National and International levels. While Tunisia has made progress in the right direction in post revolution for surveillance and preventive actions, However, it is crucial to reinforce the efforts of setting up an effective multi-sectoral strategy to promote healthy schools and psychosocial well-being, where the adolescent is considered as an actor. This strategy should take into account the different levels of prevention (1- Three levels preventive actions; 2- Multi-sectoral actions; 3- International collaboration)

**Table2: Risk factors and protective factors**

| Risk Factors                 | Domain     | Protective Factors             |
|------------------------------|------------|--------------------------------|
| Early Aggressive Behavior    | Individual | Self-Control                   |
| Lack of Parental Supervision | Family     | Parental Monitoring            |
| Substance Abuse              | Peer       | Academic Competence            |
| Drug Availability            | School     | Anti-drug Use Policies         |
| Poverty                      | Community  | Strong Neighborhood Attachment |

(<https://www.drugabuse.gov/publications/preventing-drug-abuse-among-children-adolescents/chapter-1-risk-factors-protective-factors/what-are-risk-factors>)

### Acknowledgments.

We thank all the regional teams of school and medical universities and the representatives of the Ministry of Education for their collaboration in carrying out this study in schools. We would like to thank all the members of the various committees who actively participated in this survey and allowed this work to be completed in a timely manner. The study was made possible thanks to the financing of the action plan for Morocco and Tunisia " by the Council of Europe's neighborhood policy".

## **Stakeholder Capacity Building. A Delphi Study on Global Workforce Development**

*Sylvia Nassar*

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**Purpose.** At the conclusion of this session, participants were expected to:

1. Learn critical guidelines for global workforce development
2. Understand basic elements of a Delphi study
3. Recognize differences and similarities among policy, research, and practice stakeholder groups.

**Introduction.** Globally, youth represent 25 percent of the total working population [<http://bit.ly/1leueGJ>]. About one in three youth aged 15 to 24 suffers from a deficit of decent work opportunities [Millennium Development Goals, Goal 1, target 1.B -FAO and YUNGA]. In addition, almost 43 percent of global youth labor is unemployed or working, but living in poverty [International Labour Organization, October 2015, <http://goo.gl/DT3zar>].

Literature across policy, research, and practice highlights gaps in educational and career achievement, earning potential, and psychological risks among global youth. These factors contribute to poverty and to the marginalization of populations. Yet elements of effective career education and interventions remain unidentified, let alone agreed upon across the various workforce development stakeholder groups.

**Objectives.** What is needed is a comprehensive synthesis of policy, research, and practice so that mutually impactful infrastructure and connections among the three domains can facilitate a unified approach to the global challenges of global youth unemployment. In an effort to strive for this consensus, our Delphi study sought to capture the feedback of stakeholders from policy, research, and practice domains through a series of three survey administrations. The Delphi technique is a structured and interactive communication process which relies on a panel of experts, anonymity of responses, controlled feedback, statistical analysis, and multiple rounds of data collection, each of which informs the subsequent round (Dalkey, 1969). Our survey questions were based on six areas identified across the literature of these various domains: holistic, systematic, and comprehensive frameworks; needs assessment; trainer curriculum; participant curriculum; delivery; and assessment.

**Methods.** Through convenience and snowball sampling, we assembled a panel of experts across these domains who met the criteria of having worked a minimum of five years with global youth populations aged 10-35 on employment issues; and that they had made substantive contributions within their self-identified domains of policy, research, or practice. Twenty individuals meeting our criteria chose to participate in the study, with 17 representing policy, 13 representing research, and 19 representing practice.

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**Results.** Within each of these six common denominators, or considerations, our stakeholder-research participants provided rich data and insights on policy, research, and practice. At Round 1, all of the initial survey data were content analyzed, with themes informing a set of statements within each of the six common considerations. In Round 2, participants were asked to indicate agreement with each of the statements and those resulting data were then analyzed, first via Stata to determine whether each statement met an acceptable level of consensus (i.e., through both acceptable median score and interquartile range), and then secondarily via content analysis to incorporate any new comments and feedback into the statements next presented in the Round 3 survey. For the Round 3 data, we applied only Stata to determine whether or not to retain the statements based on their acceptable median scores and interquartile ranges.

The final results yielded 28 different statements across the areas of policy, research and practice that, in essence, represent consensus across the three stakeholder groups. Some of these selected statements are provided in Table A. Implications for implementation across global youth populations will be discussed.

**Conclusions.** The Consensus statements emergent from our Delphi study represent perspectives of policy makers, researchers, and practitioners engaged in global youth workforce development initiatives. In many cases these 20 participant-individuals represented more than one of these three domains. In any case, the need for the policy, research, and practice to reciprocally inform one another is essential, as each of the three need to work synergistically in order to ensure support for empirically validated youth workforce development practices. Thus, it behooves individuals across these domains to carefully study the consensus statements to determine which may be the most relevant and have the most impact within each. Moreover, it behooves individuals to coordinate across domains to ensure that these critical guidelines are comprehensively and collaboratively addressed.

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## **APPENDIX A. SELECTED CONSENSUS STATEMENTS**

### **A. Holistic, Systemic and Comprehensive Framework**

Holistic, systemic, and comprehensive frameworks of career and workforce development programs for youth should.

- be age specific, from primary schools through transition aged youth/young adults [practice]
- be lifelong and progressive [practice]
- provide information and/or access to financial services [policy]
- be culturally appropriate to participants and community [policy/practice]
- provide training and programs that are evidenced based [all]
- build awareness throughout the community and incorporate initiatives to build interest in the community [practice]

### **B. Needs Assessment**

A comprehensive needs assessment for career and workforce development programs should consider.

- diverse and specific goals agreed upon by multiple stakeholder groups
  - labor demand
- Stakeholders groups should include.
- private sector industry
  - parents
  - counselors
  - researchers/ scholars
- There should be a system for communication with stakeholders; including why and how they are involved.

### **C. Trainer Curriculum**

- ❖ Teachers with specialized and focused training can provide career and workforce development programs for youth. [policy/practice]
- ❖ Teachers and specially trained career and workforce development consultants should work together. [policy/practice]

The trainer curriculum development should be influenced by.

- curriculum content experts [policy/practice]
- previous curriculum evaluation [all]

- Aspects of Positive Youth Development (i.e. an ecological approach to global youth development which “engages youth along with their families, communities, and/or governments so that youth are empowered to reach their full potential/incorporates positive psychology [practice/All]
- collaboration between internal and external stakeholder groups
- trainers’ ability to recognize their own preconceived notions, biases, and beliefs [practice]

Psychosocial interventions (e.g. crisis and trauma, substance abuse, disability, etc.).

- are an important trainer curriculum component
- local agencies should provide this support/collaboration
- should be limited to ability to recognize need and referring for mental health support (e.g., need some background in order to enact PYD/positive psych/emotional intelligence, resilience ETC based interventions)

#### D. Participant Curriculum

Effective participant curriculum development should consider. [All]

- labor market demand
- input from parents and other community stakeholders
- Effective curriculum for parents/family members should consider. [practice]
- providing information regarding career specific issues
- providing information about current social, economic, and labor market trends
- providing information about what their child is being exposed to and the implications of the education/work decisions made by the participant
- providing the skills and information to assist their child in making an objective career related decision
- Effective curriculum for other community members/stakeholders should consider.
- the role that community has on influences certain jobs/careers; stereotypes, attitudes, and perceptions
- addressing and developing social/community responsibility
- creating support networks for career and workforce initiatives and participants
- Effective global workforce development programs include.
- career education and guidance
- technical and vocational training
- soft skills training
- transferable skills training

#### E. Delivery

Effective delivery of career and workforce development programs should consider:

- combining different methods and interventions
- accessibility
- information for family members
- Single locations (such as career centers) as standalone locations for career and workforce development programs:

- should work in conjunction with the academic standards/ practices already within the community

#### Group interventions:

- allow participants to learn from each other
- improve participant ability to work in groups
- improve participant's interpersonal skills
- can take the form of small group guidance
- can take the form of whole classroom activities
- promote soft skills such as collaboration and problem solving
- are essential
- Technology:
- is essential
- Peer to peer interactions:
- are essential

#### F. Evaluation

Effective evaluation of a career and workforce development program for youth should:

- use explicit indicators
- use simple evaluation tools
- look at what has been learned
- look at any behavioral differences within participants
- look at how the target audience was engaged throughout the program
- be measurable
- combine progress measures (quality assurance) with program outcomes
- include different forms of data
- match clear and systemic inputs with measurable outcomes

Effective intervention research with regard to career and workforce development programs:

- should look at why something works, as well as if it works
- should include how evidence interfaces with practice and practitioner
- should be targeted to policy makers

Key outputs and outcomes to identify and measure in evaluation of career and workforce development programs should include:

- the extent to which the program addressed the needs of the community/participants
- the extent to which the program is sustainable
- both qualitative and quantitative data
- both indirect and direct measures
- defining terms before collecting data
- determining what the local socio-economic context necessitates job retention

## **Michigan's Model to Prevent Type 2 Diabetes in Underserved Populations**

*Tamah Gustafson, Jan De la Torre and Lauren Neely*

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**Introduction.** According to the Centers for Disease Control and Prevention (CDC), it is estimated that 84.1 million US adults aged 18 years or older (33.9% of the adult US population) had prediabetes in 2015, and in Michigan, only 6.8% were aware of their condition<sup>1</sup>. Prediabetes is a serious health condition where blood glucose levels are higher than normal, but not high enough to be diagnosed as type 2 diabetes. Without intervention, 37% of people with prediabetes may develop type 2 diabetes within four years as their risk of developing type 2 diabetes is four to 12 times higher than it is for people with normal glucose tolerance<sup>2,3</sup>. Several factors increase a person's risk for type 2 diabetes, including being overweight, not being physically active, and having a family history of diabetes. A person's race or ethnicity as well as education level can also increase their risk for type 2 diabetes. Members of some racial and ethnic minority groups are more likely to have diagnosed diabetes than non-Hispanic whites, and a higher percentage of adults with less than a high school education had diagnosed diabetes compared to adults with a high school education or more than a high school education in 2013-2015<sup>1</sup>. In Michigan, it is estimated that the prevalence of diabetes in the Arab American population is 18%, compared to an estimated state prevalence of 10.4% (Michigan adults 18 years and older)<sup>4,5</sup>.

**Objectives or Hypothesis.** The National Diabetes Prevention Program (DPP) is a CDC-recognized lifestyle change program based on research led by the National Institutes of Health. Research showed that people with prediabetes who participated in structured lifestyle change programming can reduce their risk of developing type 2 diabetes by 58% (71% for people over 60 years old). Increasing program availability and access for priority populations by utilizing existing or new partnerships will lead to increased enrollment and participation. Priority populations are defined as those at high risk for type 2 diabetes that experience racial/ethnic disparities, including inadequate access to care, poor quality of care or those living in low socioeconomic communities. Increasing availability and access to preventative care, such as the CDC-recognized Diabetes Prevention Program, will provide opportunities to maximize health improvements, further leading to reducing health disparities, specifically among Arab American communities.

**Materials and Methods.** Michigan is one of 17 states and four large cities to be awarded funding under "State and Local Public Health Actions-1422" through the Centers for Disease Control and Prevention. Michigan set forth to work with local communities to implement a set of comprehensive environmental, health system, and community clinical linkage strategies to reduce chronic disease, including type 2 diabetes. Four sub-awardees, known as Chronic Disease Coordinating Networks (CDCNs) identified geographic areas of greatest need and disease burden, which included Lenawee County, Kent County, Macomb County, and Oakland and Wayne Counties. Using a set of mutually reinforcing strategies, four models were developed to scale and

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sustain the National Diabetes Prevention Program for priority populations and reduce incidence of type 2 diabetes. CDCNs, with technical assistance from Michigan Department of Health and Human Services (MDHHS) used grant funding to support enrollment of priority populations into existing DPPs and started new DPPs in geographic areas where DPP was not available. Through this approach, efforts focused on building capacity of DPPs to effectively enroll priority populations. Capacity building activities included lifestyle coach trainings and support, offering the DPP in accessible locations, and tailoring materials to ensure they are culturally and linguistically appropriate.

**Results.** Since March 2015, more than 1,015 individuals representing the priority population enrolled in the Diabetes Prevention Program, which were supported through 1422 funded efforts. In addition to supporting two existing DPPs, CDCNs were able to initiate four new Diabetes Prevention Programs representing community-based organizations, health systems (including a faith-based nursing approach) and a local health department. CDCNs built the capacity of both new and existing DPPs by training over 125 lifestyle coaches, providing lifestyle coaches with ongoing education and support, and implementing culturally appropriate media and outreach campaigns in their respective communities. Additionally, DPP providers developed supplemental program materials to meet the needs of culturally diverse participants. CDCNs increased the number of partnerships with local organizations which serve the priority population to host the DPP in over 75 host site locations.

**Conclusions.** Our initial findings support that when DPP is available, accessible and tailored appropriately to meet the needs of the participants or audience, it can lead to increased enrollment of populations who are at high risk for type 2 diabetes that experience racial, ethnic or socioeconomic disparities, including inadequate access to care, poor quality of care or those living in low socioeconomic communities. Future research and programming should explore long-term health outcomes of traditionally underserved populations who enroll and complete the Diabetes Prevention Program. Opportunities exist to continue to reduce barriers in recruitment and retention of participants in DPP with a specific focus on underserved populations, including Michigan Arab American communities specifically.

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## **Loss and Displacement in Syrian Refugee Families - From Women's Struggles to Intervention Strategies**

***Leila Asadi***

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This paper addressed the issue of domestic violence among Syrian refugee families newly arrived in the United States after 2011 conflict in Syria. It revolved around the relation of loss and domestic violence to argue that the experience of gender-based violence during the war, in transitional time, or in resettlement period may intensify the sense of loss and displacement and may delay integration of Syrian refugee women in the host country. According to Elizabeth Grosz, “there is no pre-cultural body, but only one that already is the site of social pressures, fantasies, projections, significations, and inscription” (1). The bodies are not ahistorical rather “direct effects” of natural, social, and historical processes. Looking at the human body as a social construct, this in progress research reflected on some observed/witnessed cases of domestic violence in Syrian refugee families to join the conversations on gender-based violence in refugee and immigrant communities and the responses/assurances of local and state level organizations serving refugee communities.

### ***The method of data collection***

Conducting ethnographic fieldwork (not directly related to domestic violence) in Michigan from August 2017- May 2018 with a group of Syrian women, it became apparent that the lived experience of political demise in Syria, displacement, and asylum seeking shifted from center to periphery of our conversation by the women who preferred to speak about abuse in their family or marital relationship. Extracted stories of violence from field work as a segment of data allowed adoption of ethnography as this paper’s research method plus a content analysis of refugee policies responding domestic violence in refugee families. The research consulted the websites of three organizations active in Michigan, journals or posters they published and the annual report they produced. Moreover, interviews with Syrian refugee women, and social workers or activists carried to get a better sense of challenges of the survivors and the intervention strategies.

### ***Multiple Truths***

Among 33 women interviewed, there were 7 incidents of either witnessed gender-based violence such as being verbally abused, interrupted or controlled by their husbands during the conversations, or reported experiences of their abusive relationship. A range of forced marriage, physical abuse, the use of state violence to exert more pressure on the partner in time of revolution and war in Syria, economic and mobility control and even forceful sexual intercourse, all were alluded to in their multilayered narratives of war, displacement and resettlement periods. They actually displayed the reality of “multiple truths” that Nadia Al- Ali refers to as “living in and living with” (2), consisting of personal and collective truths and intertwine of history and biography about war in Syria.

In this presentation, we emphasized our aversion to ‘taking an orientalist approach to power relations in Muslim families.’ We avoided by any means using gender-based violence committed

by family members in an “orientalist gendered framing of the culture” (3) to not overlook the effects of Syrian revolution on women and men equally and to not associate it with the very current anti-Muslim rhetoric through which Middle Eastern men are seen as the fanatic oppressors of women. Perhaps in this critical period that more than ever Muslim identity is at the center of ‘war on terror and Islamic radicalism’ leading to the approval of the ever strict immigration policies in many countries including the United States, it would be harder to raise awareness on domestic violence in Muslim refugee families, but taking a long term approach to embodying displacement and loss in refugee assistant policies, we urge a gender-sensitive analysis of existing strategies or treatments for trauma and loss for refugee women who have experienced gender-based violence.

In this presentation we argue that volatile bodies hardly become the subject of change and social transformation. In time of violence, the spatial and temporal experiences within home significantly impacts one’s experience and emotional relationship to that site as a space of either or both security and insecurity. Home spaces also are important sites of belonging and at times alienation linked to the sense of self and one’s connection to a place within community (4). The home is an essential space of geographic inquiry that must also be included into the study of refugee resettlements. Considering the increase of domestic violence during times of heightened political conflict or war (5) domestic violence in transitional time doubles the sense of displacement in refugee families and creates conditions in which “living bodies are reduced to bare life”. Women who coexist with their perpetrators become weakened in their ability to cope with critical conditions in life. The abusive act and language toward women’s bodies undermines “the self-image of women” (6) related to their body as flesh, as raw materials and the subject to time and space. Also, by domestic violence women see their body as an inferior object, unable to make or negotiate for change. As their body image is distorted and “fragmented”, their self is distorted too. They are unable to “modify their being in the world”. Domestic violence interrupts also in the sense of kinship, love, and friendship and distorts feeling physically and emotionally secure.

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# ABSTRACTS



## **Experiences, Challenges and Coping Strategies for Parents of Children with Autism in the US and Arab World**

***Mariam Ayyash, Mona Alaouie, Alex Blackwood and Marwa Ayyash***

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### **Background.**

Most of the research studying autism has targeted White Americans. Arab parents comprise a unique subset as the diagnosis may be associated with more stigma resulting in diminished knowledge to detect or raise a child with autism.

### **Methodology.**

Participants were recruited via an anonymous electronic survey posted on social media support groups for autism. Parents who chose to participate clicked a link that directed them to the online questionnaire. Submission of the completed survey constituted consent.

### **Results/Findings.**

A total of 400 parents participated. One hundred and sixty-five (165) were from 15 Arab countries and 235 were from 32 US states. Knowledge rating of autism before the child's diagnosis was the same for Arab and US parents. The age of initial concern of the parents regarding their child was also the same for both Arab and US parents (2 yrs). However, the age at diagnosis for US parents was 4 years old vs 3 years old for Arab parents. US parents reported a higher satisfaction in the diagnostic process. In terms of challenges, Arab but not US parents reported "lack of community support" as one of the top 3 challenges. As for coping strategy thought to be most valuable, 13% of Arab parents and 2% of US parents chose a negative strategy such as "hiding the diagnosis", "minimizing outside visits", or "denial of the diagnosis" to be most important.

### **Conclusions.**

Based on this study, it can be inferred that US and Arab parents have similar but low knowledge about autism requiring further community educational initiatives. Arab parents reported a higher level of dissatisfaction in the autism diagnostic process, in which further research is needed to understand its underlying causes. Moreover, given the lack of community support for Arab parents, it is pivotal to address the stigma and shame associated with an autism diagnosis.

## Arab American Perspectives on Intimate Partner Violence and Reproductive Health

*Angubeen Khan, Elizabeth King, Layla Elabed Shivali, Amin Lama, Baddah Yasamin, Kusunoki and Neda Eid*

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**Introduction.** Intimate partner violence (IPV) and reproductive coercion (RC) are significant public health problems in the United States. IPV impacts 1 in 3 women globally and IPV/RC are linked to higher risk of unintended pregnancy. Yet there is virtually no research about how IPV/RC impacts the reproductive health of Arab American women.

**Objectives/Hypothesis.** This study investigated the need to address IPV/RC and the role of religion and culture in shaping attitudes and beliefs around IPV/RC among Arab Americans.

**Materials and Method.** A mixed-methods design and a community-based participatory (CBPR) approach were used. This encompassed ongoing meetings with community partners at the Arab Community Center for Economic and Social Services (ACCESS) in Dearborn, MI, two focus group discussions with ACCESS providers and community stakeholders, and interviews with Arab American women in the community. Approximately 8-10 providers and stakeholders participated in each of the two focus groups sessions. Fifteen Arab American female clients at ACCESS (age 18 years or above) were recruited for interviews. We conducted qualitative data analysis of the focus group and interview findings using NVivo software.

**Results.** Initial findings indicated that providers and stakeholders and most community women believed that IPV/RC is often accepted or dealt with privately and most community women believed IPV/RC was more prevalent in the older generation. In addition, several community women reported prevalence of verbal abuse, and cited it as a potential precursor to physical violence. In regards to reproductive health decision-making, many community women felt that there was pressure from their families and the community to have more children. Providers, stakeholders, and community women also discussed the best ways for conducting a quantitative assessment of IPV and RC prevalence and related beliefs and attitudes, along with the effectiveness of using a CBPR approach given the sensitivity of the topic in the community.

**Conclusions.** The findings regarding norms and attitudes in the Arab American community suggest that there is a need for an IPV/RC needs assessment that examines prevalence, attitudes, and factors that influence IPV/RC experiences and reproductive health decision-making. The findings also highlight the importance of integrating a CBPR approach to research when working with the Arab American community as this can foster trust and strengthen the relationship between community partners and academic institutions.

## Social Determinants of Health for Arab Americans in California: Results from a Population-Based Survey

*Nadia Abuelezzam and Adolfo Cuevas*

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**Introduction.** On January 26, 2018, the U.S. Census Bureau decided not to include a Middle Eastern and North African (MENA) identifier on the 2020 Census despite years of advocacy by the Arab American community. Changes in the social capital of Arabs immigrating to the United States since World War II has created diversity in the lived experiences of Arabs in the United States. The majority of studies examining Arab American health have been performed in Michigan where there is a large ethnic enclave. Population-based samples of Arab Americans are rare and, as such, little is known about the composition and health needs of Arab Americans in California.

**Objectives.** To describe the social determinants of the Arab American population in California using acculturation, health, and sociodemographic variables collected in a population-based survey representative of California's population.

**Methods.** Data in this study were extracted from the California Health Interview Survey (CHIS). CHIS is a series of cross-sectional random-digit telephone surveys (2003-2016) that are representative of California's population. We identified Arab Americans in the CHIS sample by noting if respondents indicated that they spoke the Arabic language at home or that they or a parent were born in one of 22 Arab League countries (N=1607). Population-weighted percentages were calculated.

**Results.** The majority of Arab Americans in California were born outside the United States (60.8%), were naturalized or U.S. born citizens (85.3%), are college (or higher) graduates (52.2%), live above the poverty line (87.2%), own their homes (55.4%), married (52.3%), have resided in the U.S. for over 15 years (78.3%), and have excellent or very good general health (62.3%). A large proportion of Arab Americans in California are uninsured (21.1%), are overweight (53.4%), were never smokers (61.0%) and have consumed alcohol in the past 12 months (42.1%).

**Discussion.** The demographic, geographic, and lived experiences of Arab Americans in California is diverse. Without a designated racial identifier, Arab Americans in the United States are difficult to isolate and identify and therefore are not likely receiving specialized and targeted care. Population-based surveys allow for robust examination of Arab American health needs in places where ethnic enclaves may be wide spread or non-existent.

## **Generalizability of Arab American Health Outcomes. Results from a Population-Based Survey in California**

***Nadia Abuelezzam and Sandro Galea***

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### **Introduction.**

On January 26, 2018 the U.S. Census Bureau decided not to incorporate a Middle East and North African (MENA) identifier on the 2020 Census making the study of Arab American (AA) health outcomes difficult. In place of an identifier, a number of strategies have been used to identify AAs from hospital, state, and national databases including using surname algorithms, identifying place of birth, and using Arabic language as a marker for heritage. Little work has been done to understand the generalizability of the inferences from each of these strategies.

### **Objectives and Methods.**

Using data from the 2003-2016 California Health Interview Survey (CHIS) we examined differences in prevalence in self-reported diabetes, hypertension, heart disease and other social determinants of health among AAs identified by place of birth, parents' place of birth, and language spoken at home. We compared prevalence estimates to results from non-Hispanic Whites in CHIS and other population-based surveys.

### **Results.**

AAs identified by parents' country of birth have lower overweight and obesity (43.2 vs. 61.2%), unemployment (22.1 vs. 35.9%), living below the federal poverty line (FPL) (6.2 vs. 17.2%), and hypertension (11.4 vs. 17.6%) prevalence than those who were born in an Arabic speaking country suggesting potential disparities in health outcomes based on immigration generation. AAs who are identified by Arabic language use at home tended to be economically disadvantaged (16.2 vs. 6.2% living below FPL) and have higher diabetes prevalence (8.7 vs. 8.1%) when compared to those with a parent born in an Arabic speaking country. Self-reported hypertension (11.4%-17.6%) and heart disease prevalence (3.3-4.6%) among AAs is consistently lower than prevalence in non-Hispanic Whites in CHIS (29.6% and 8.2%, respectively) and lower than data on heart disease among AAs from the National Health Interview Survey (8.8%).

### **Conclusions.**

The methods used to identify AA populations from hospital, state, or national databases may not be generalizable to the wider AA community in the United States. Understanding the needs of and identifying solutions for this population relies on our ability to identify AAs appropriately. Without the MENA identifier on the 2020 Census, AAs remain a difficult population to identify in public health research.

## Multidrug-Resistant Organisms in the Middle East. A Global Concern

*Hind Hadid, Zohra Chaudhry and Marcus Zervos*

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### Introduction.

With massive efflux of civilians from violence-stricken countries, the high rates of colonization with multidrug-resistant organisms (MDRO) amongst the refugee populations is an emerging global concern. Our report describes two Middle Eastern patients who suffered severe traumatic injuries in their home countries, subsequently developing chronic wounds. Upon arrival to the United States, the patients sought treatment in our institution for wound infections with MDRO.

### Objectives

1. Describe the patients' clinical characteristics and risk factors for MDRO colonization.
2. Elucidate the susceptibility pattern of bacterial isolates from our patients, highlighting how our experimental studies helped in choosing antibiotic therapy.
3. Describe the treatment and clinical outcome of the patients.

### Materials and Methods.

The patients' clinical data were collected from the patients' charts. MALDI-TOF established the identification of the organisms cultured from the patients' wounds. A combination of Vitek2, Kirby Bauer, and manual broth dilution tests revealed the antimicrobial susceptibility pattern of the isolates. In vitro synergy time-kill experiments on a highly resistant *Pseudomonas aeruginosa* strain from one patient were done to assist in the selection of antimicrobial therapy in this patient.

### Results.

Patient 1 came from Syria, and patient 2 from Yemen. Both patients' infections were healthcare-associated and involved underlying chronic osteomyelitis. Both had multiple risk factors for MDRO, including multiple prior surgeries, repeated hospitalizations and numerous antibiotic courses. Patient 1 cultures grew Carbapenem-Resistant Enterobacteriaceae (CRE) *Klebsiella pneumoniae* and MDR *Morganella morganii*, and on a later date, Extended-Spectrum Beta-Lactamase (ESBL) *Escherichia coli*. Patient 2 cultures grew *Pseudomonas aeruginosa* sensitive only to colistin. Patient 1 was treated with ertapenem. Patient 2 received a rifampin, meropenem, plus colistin, the only antibiotic combination that demonstrated synergistic killing in our experiments. Both patients required prolonged intravenous antimicrobial therapy, and on follow-up were doing well.

### Conclusions.

Colonization with MDRO amongst Middle Eastern immigrants is an alarming phenomenon. In vitro experiments with available antibacterial agents may assist in the choice of therapy for MDRO strains when conventional options are exhausted.

## Knowledge Assessment and Screening Barriers for Colorectal Cancer in Arab Americans from the Dearborn Community

*Hiam Hamade, Alex Blackwood and Mariam Ayyash*

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### **Background.**

Colorectal cancer, CRC, is the second leading cause of cancer related deaths in the United States in both men and women and the third most common cancer in both genders. Screening tests have been successful in detecting precancerous polyps. Early detection and removal for polyps have been shown to reduce colorectal cancer diagnoses. Unfortunately, about one third of adults aged 50 or older, the age group at greatest risk of developing colorectal cancer, have not been screened as recommended.

### **Methodology.**

In this study, we targeted particularly the Arab American community in Dearborn, MI. We aimed to assess the knowledge of this community regarding colorectal cancer and screening methods. Moreover, we attempted to better understand the main screening barriers faced by the community, which prevented them from undergoing CRC screenings. Our study was conducted at the Arab Community Center for Economic and Social Services (ACCESS) in Dearborn, MI. We here include survey results for 150 Arab American participants.

### **Results/Findings.**

We identified significant knowledge deficiencies in multiple domains including general knowledge on what CRC is or risk factors or screening modalities. Additionally, our results highlight deficiencies in patient-physician interactions and discussions around CRC. Lastly, we identified barriers to CRC screening which included costs, lack of awareness, fear, insufficient physician education and insufficient understanding for screening modalities.

### **Conclusions.**

Being more aware of specific areas of knowledge deficiencies, we hope this study would allow physicians to provide better education regarding colorectal cancer and the value of screening. Additionally, knowing the more prominent barriers to screening, we hope to break such barriers as physicians and healthcare providers further address colorectal cancer screening.

## Hope, Life and Legacies - Organ Donation in Islam

*Lesley Compagnone*

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**Introduction.** The majority of American Muslims believe organ donation is not only objectionable but forbidden. For centuries, they have been taught, incorrectly, that organ donation in Islam is haram. It is a topic plagued with stigma, confusion and fear. These stressors cause thousands of American Muslim families every year to experience an entirely avoidable infusion of stress and anxiety into a time they already feel shattered – the unexpected, often shocking, death of a loved one. According to the Uniform Anatomical Gift Act of 1968, a representative from a federally-designated organ procurement organization (OPO) is required by law to discuss the option of organ donation with the decedent's family and/or legal next-of-kin. For several years, Family Service Specialists with Washington Regional Transplant Community (WRTC), an OPO, have documented that these conversations with Muslim families, which require an expedited decision, often surprise the unprepared family, and are extremely difficult and upsetting for them. The organ donation decision is one that a Muslim living in the United States will HAVE to face at some point in his life. Whether deciding for oneself to become a designated organ donor at the DMV or needing to make that decision on behalf of a loved one, most American Muslims don't know where to go for information, or who to talk to for guidance. The donation and transplantation community of practice in the United States has been ineffective in its outreach to American Muslims ... until now.

**Objectives.** WRTC is leading a national education effort to provide American Muslims with the most recent, relevant and reputable information on organ donation in Islam. This information will empower Muslims to make informed decisions and eliminate additional stress and anxiety.

**Materials.** A multimedia educational toolkit that includes videos, literature, a lecture series, Webinars, an App, press materials, photographs and talking points.

**Results.** This is an ongoing education and outreach initiative, but since the project's inception in 2015, results have been.

1. The nation's first Fiqh Forum on organ donation hosted by the International Institute for Islamic Thought (IIIT). Titled, Reaching Consensus on Organ Donation. A Call to the American Muslim Community, the forum brought together the country's leading donation and transplantation professionals and some of the world's most influential Muslim academic and religious scholars. It was the foundation for the current and important national conversation about organ donation in Islam.
2. Numerous panel presentations at national conferences and conventions, including Islamic Society of North America and Islamic Circle of North America.
3. Individual members of the Fiqh Council of North America have issued public statements in support of organ donation; the Council's official fatwa of support is expected this Spring.
4. Other OPOs throughout the country have replicated and implemented WRTC's Muslim outreach initiative, thus reaching hundreds of thousands more American Muslims.
5. More Muslims are registering to be organ donors for the very first time.

**Conclusion.** Organ donation is permissible in the Muslim faith.



## Impact of Home Visitation on MCH Outcomes in Refugee Settings

*Martine Najem and Noor Jaber*

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**Introduction.** Sixty percent of preventable maternal deaths and 53% of preventable deaths for children under 5 take place in settings of conflict and displacement where the availability of basic reproductive health services, including accessibility to family planning and basic and emergency maternity and newborn care is highly compromised. There is evidence that Maternal Child Health (MCH) interventions help decrease maternal morbidity and neonatal and perinatal mortality, increases immunization rates among infants and enhances positive interactions and healthy attachment behaviors in the family. In fact, Home-Visitation (HV) programs in specific are one of the most commonly practiced MCH interventions that accommodate for the compromised access to services among displaced populations. In Lebanon, UNRWA provides clinic-based MCH services that include regular checkups, screenings, vaccinations, etc. The Medical Aid for Palestinians (MAP) complements those services with a MCH Home-Visitation program. The program aims to enhance the care offered to pregnant and postpartum Palestinian women and their infants residing in camps in north and south Lebanon, and consequently reduce the impact of dire living conditions on their families' health.

**Objective.** Our evaluation study aims to assess the impact of MAP's MCH Home-Visitation intervention in complementing UNRWA's medical services that target Palestinian mothers and their children residing in camps. The evaluation covers MCH outcome indicators, perceptions around benefits of the intervention, and the overall value of the MAP HV program.

**Methods.** Both quantitative and qualitative tools were utilized as part of a mixed method approach to compare the variety of outcomes in women receiving both UNRWA and MAP services versus women receiving UNRWA services only in camps in north and south Lebanon.

**Results.** Preliminary results of the quantitative analysis show that women receiving both MAP and UNRWA services generally have better MCH outcomes than those receiving UNRWA services only. Such outcomes include birth weight, breast-feeding, birth spacing, and infant prematurity. Qualitative data that provide further insights on mothers' perceptions with regard to the value of the home visitation intervention as well as midwives' feedback on the overall experience are being analyzed and will be presented.

**Conclusion.** Based on the preliminary findings, in refugee settings where services are overburdened and resources scarce, going beyond the walls of health care centers into the community maximizes the benefits for vulnerable populations. In particular, Home-Visitation programs targeting high-risk pregnant refugee women bring added-value to MCH services and consequently enhances mother and child health outcomes.

## **Knowledge, Attitudes and Practices toward Antibiotics Misuse among Arab Countries Population. A Systematic Review**

*Khaled Al-Surimi and Abdulrahman Binyaish*

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### **Background.**

Arab countries have turned out to be background lands for bacteria that cannot be controlled by the usual antibiotics. A few of researchers are trying to track this problem and we hope they could put a stop to it.

### **Objective.**

To assess the current state of knowledge, attitudes, and practices towards antimicrobial misuse in Arab countries, and identify gaps for future research.

### **Methods.**

We conducted a systematic literature review, searching two databases, between 1990 and 2017, focusing on knowledge, attitudes and practices toward antimicrobial misuse in Arab countries. Databases were searched using both 'free terms' and 'index terms' funneled using Boolean operators and truncations. Inclusion and exclusion criteria were set, and included papers were scrutinized, employing a critical appraisal tool to find the best available evidences to support the study purpose.

### **Results.**

Evidence from 24 articles included in this review showed that general knowledge and awareness of the Antibiotics use, its resistance, and control and preventative measures were generally found to be lacking amongst both the general public and healthcare professionals. In addition, the study shows that Inappropriate use as evident by using antibiotics for future and sharing antibiotics with family or friends was also identified in this study population as major risk factors.

### **Conclusions.**

This review suggests the importance of increasing health awareness, mobilizing the local or community healthcare professionals, for prevention as well as early detection and effective treatment of misuse among people who are at risk. Antimicrobial resistance is also associated with poverty and socio-cultural factors. Therefore, strong political will, wider partnerships between health and non-health sectors, and strengthening technical and managerial capabilities of health systems are needed at all level.

### **Keywords.**

Antibiotics Use, Antimicrobials Resistance, Misuse, Arab World, Systematic Review.

## **How Does eEvidence-Based Capacity Building Impact Education of Refugee Children?**

*Jomana Kalot and Martine Najem*

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### **Background.**

UNICEF Lebanon has been supporting the Ministry of Education and Higher Education (MEHE) in the Reaching All Children with Education (RACE) response Plan to provide both formal and informal education opportunities to all children affected by the Syrian Crisis in Lebanon. While this allowed an increase in affected children's access to quality educational opportunities, a lot of them still quit school and become at risk of child labor and early marriage. In order to increase enrollment of 450,000 Syrian and Lebanese children in formal education by 2020-2021, MEHE adopted the "BACK TO SCHOOL, STAY IN SCHOOL (BTS-SIS)" initiative that aims to increase enrolment in MEHE's formal and informal education mainstreams. The Faculty of Health Sciences' Center for Public Health Practice (CPHP) at the American University of Beirut partnered with UNICEF Lebanon to support the above initiative led by MEHE. Our program aimed to improve capacities of frontline field workers and community mobilizers working in the education sector within refugee settings.

### **Methods.**

The presented program aimed at equipping field workers with necessary skills and information for motivating refugee parents to enroll their children in school. It was based on CPHP's competency-based workforce development framework using the Communication for Development participatory approach in humanitarian settings, and led by a multidisciplinary team of expert trainers. A package of messages to respond to barriers and misconceptions around school enrollment was developed and piloted with parents of refugee children and parents of children from host communities in addition to fieldworkers from UNICEF's partners. Front liners/community mobilizers were trained on communication and community mobilization with simulations on the specific use of messages.

### **Results.**

Within a period of six weeks, CPHP trained 352 field workers from 56 NGOs equipping them with needed skills and resources to guide outreach activities. UNICEF and MEHE data revealed an increase in enrollment rates for 2016-2017 exceeding 2015-2016 rates by around 22% in the first month of the BTS-SIS campaign.

### **Conclusions.**

This project showcases the power of academic-community partnerships in putting evidence-based approaches at the service of international and local agencies' development and humanitarian programs. The added value of this work lies in the adaptability of the methods and techniques used to other sectors in the humanitarian response.

## **Adverse Childhood Experiences and the Social Determinants of Health**

*Marijata Daniel-Echols*

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### **Introduction.**

Over twenty years ago, Drs. Anda and Felitti conducted the CDC – Kaiser Permanente Adverse Childhood Experiences Study (ACEs). Their sample consisted of over 17,000 people from southern California. The longitudinal findings of their work have been replicated over time and have had large impacts on the social service industry – for example, early childhood, mental health, social work, and pediatrics in the United States. Beyond its roots, this research can inform health interventions within any population where poverty, childhood trauma and adverse events are realities. The ACEs work has drawn a link between experiencing toxic stress as a child, disruption of normal neurodevelopment, and subsequent behavioral, mental, and physical health problems that can lead to early death. While ACEs have been shown to be common – that is they are present across all levels of socio-economic status, genders, and racial-ethnic groups, what is also true is that poor communities, people of color, and racial-ethnic minorities suffer disproportionately higher levels of ACEs. Indeed, poverty in and of itself can be considered an ACE. Thus, an understanding of the impact of ACEs requires the use of an equity lens that considers the social determinants of health and root causes of inequality – structural racism, gender discrimination, and class oppression. Understanding ACEs as an equity issue demands an interdisciplinary, multi-sectorial approach. In this session the universal and yet disparate nature of ACEs will be used to introduce targeted universalism as one way to promote equity.

### **Materials and Methods.**

This will be an interactive session with a presentation using PowerPoint slides and group discussion as well as an opportunity for participants to calculate their own ACEs score.

**Results.** Not applicable

### **Conclusions.**

While the ACEs study was conducted on a predominantly white, privileged, American sample, the lessons that can be learned about the connections between toxic stress and life outcomes are fully applicable to communities of color and poor communities around the world.

## Colorectal Cancer Screening Among Arab Americans. Community Members Perspectives

*Claudia Ayash, Redwane Gatarny, DalaBadreddine, Zeinab Alward, Minlun Wu, Nicole Roberts, and Francesca Gany*

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**Introduction.** Colorectal cancer (CRC) is the third most common cancer diagnosed and the third leading cause of cancer-related death in both men and women in the United States. CRC is the second-most commonly occurring cancer in the Middle East. CRC prevalence is rising in Arab countries as Arabs adopt a more Westernized diet and obesity rates increase. Studies have shown high CRC incidence and mortality among Arab Americans. Little is known about CRC screening among Arab-Americans in NYC.

**Objectives.** This study's primary objectives are to 1) assess knowledge of, and perceived susceptibility to, CRC among Arab Americans; 2) assess the association between socioeconomic factors and CRC screening; and 3) explore the influence of cultural, religious and spiritual beliefs on seeking CRC screening.

**Materials and methods.** This is an observational cross-sectional study conducted in religious and community-based organizations. 40-minute interviewer-administered surveys were conducted in Arabic and English with a convenience sample of 100 participants, recruited from 2014-2017, who were compensated with a \$15 gift card. Inclusion criteria were. 50-75 years old, live in NYC, immigrants who migrated at age 12 or older, and are proficient in English or Arabic.

**Results.** Participants recruited were 50% males and 50% females. Average age was 59.68 (SD=7.03). Only 8% of participants did not have any form of health insurance.

Regarding CRC screening (FIT/FOBT and/or Colonoscopy), 77% of participants received the recommendation from their doctor to do one of these tests; however, only 57% of the participants received the test. There was a significant association between having health insurance ( $p < 0.05$ ) and education level ( $p < 0.05$ ) and being prescribed and having completed the screening test for CRC. There was a significant negative association between spiritual and religious beliefs and completing CRC screening. Participants who believed they can stay healthy through God or by leading a spiritual life, and with prayer had a lesser probability to be screened for CRC ( $p < 0.05$ ). There was no significant difference between spiritual and religious beliefs among the various religious groups.

**Conclusions.** Results show lack of health insurance status and lower education levels are barriers to screening access. Religious and spiritual beliefs were shown to be important to participants' decisions to complete the CRC screening tests. Additionally, providers may not be recommending these screenings consistently. The confluence of these issues points to the need for culturally-tailored education in the community; and training for providers to promote age-appropriate cancer screening.

## Insights from NIMHD's Research Framework on Individuals of Arab Ancestry

*Sherine El-Toukhy*

Although estimates of individuals of Arab ancestry vary widely from 1.5 million according to the Census Bureau to 3.7 million according to the Arab American Institute Foundation, it is a growing and diverse population. The number of Arab households increased by 91% since 1990 according to the American Community Survey, 2006-2010 and individuals of Arab ancestry have ties with 22 countries and religious backgrounds.

The US Census Bureau defines White race as “a person having origins in any of the original peoples of Europe, the Middle East, or North Africa,” thus including individuals of Arab ancestry in the non-Latino White majority. However, research shows that these individuals experience health disparities in several health outcomes such as tobacco use, hypertension, and obesity.

The National Institute on Minority Health and Health Disparities is the leading authority on minority health and health disparity populations. This presentation provides an overview of research opportunities with individuals of Arab ancestry guided by NIMHD's research framework, which identifies five determinants of health (i.e., biological, behavioral, physical environment, socio-cultural environment, and healthcare) and four levels of influence within these domains (i.e., individual, interpersonal, community, societal). The presentation will cover examples of current funded research with minorities and health disparity populations that can be applied to individuals of Arab ancestry. Finally, the presentation will cover recent requests for applications (RFAs) that represent potential funding mechanisms for research to reduce disparities among individuals of Arab ancestry.



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## Mental Health Challenges among U.S. Syrian Child Refugees

*Cynthia Arfken, Luay Haddad, Haifa Fakhouri, Samantha Sonderman, Farah Alani, Zainab Alrawi, and Arash Javanbakht*

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### **Introduction.**

The Syria Civil War has exposed millions of civilians to extreme physical and emotional trauma. However, little is known about the mental health impact on the children, including the extent their mental health is impacted by that of their parents.

### **Objectives.**

To determine the prevalence of PTSD and anxiety among Syrian refugee children resettled in Southeast Michigan and impact of parents' mental health on them

### **Methods.**

All resettled refugees (both adults and children) must have an initial health assessment at a limited number of contracted primary care clinics soon after arrival. Our bilingual/bicultural team 1) recruited participants (age 6 – 65) by families at two of the four clinics located in Southeastern Michigan, 2) obtained consent, and 3) screened children using the Screen for Child Anxiety Disorder (SCARED) (internal reliability=.90), UCLA PTSD questionnaire, and Mood and Feelings Questionnaire (MFQ) (internal reliability=.95). For adults, the PTSD checklist (PCL) and Hopkins Symptom Checklist were used.

### **Results.**

We recruited 128 children (age 6 – 17 with mean age=11.03, 42% female) from 50 families with 82% having 2 parents present. All of the children reported their health was “good” or better. Using established cut-offs on the total SCARED and subscales, 52.9% had possible anxiety disorder and 77.0% had separation problems. The prevalence of possible PTSD was 6.3% (all males) and 10.5% for possible depression. In bivariate analysis, no demographic characteristics were associated with total SCARED or possible anxiety disorder. Age was marginally associated with separation score. However, there was significant clustering of anxiety measures within families. In analysis controlling for family, age was negatively associated with separation score ( $p=.003$ ,  $\beta=-.34$ ). All measures of maternal distress were associated with higher scores on total SCARED and separation score (controlling for age and family) (all  $p$ 's  $<.01$ ). No measure of paternal distress was associated with either outcome.

### **Conclusions.**

The children presented with very high prevalence of anxiety (especially separation problems) but lower prevalence of PTSD and depression. Additionally, their anxiety whether total score or that for separation clustered within families and was strongly associated with their mothers', but not their fathers', distress. These findings suggest that interventions are needed and will be most helpful if they also assist mothers. The findings also suggest that assistance with transitioning to school may be needed.

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## **Prevalence and Risks Factors of Anabolic Steroids Use among Gym Users. Community-Based Cross-sectional Survey**

*Fares F Alharbi and Khaled Al-Surimi*

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### **Background.**

Anabolic Androgenic Steroids (AAS) use is a growing public health problem. Yet, level of knowledge about AAs in Middle East region is dearth including Saudi Arabia. This study aims to estimate the AAS prevalence and identify its risk factors among community-based Gym users in the city of Riyadh, the capital of Kingdom of Saudi Arabia.

### **Methods.**

This is a cross-sectional study carried out among male Gym users at the Riyadh capital city from March to October 2016. Twenty community gyms were selected randomly using the cluster sampling technique to represent the 4 different regions (North, South, East and West) in the capital city. The data collected by self-administered anonymous questionnaire and data managed and analyzed using the SPSS.

### **Results.**

Out of 482 participants, 141 (29.3%) reported positively using AAS. The mean (SD) age of study participants was 27.2(±6.9) years, 61.0% single, 67.1% had Bachelor and above degree, 35.5% were government employees and 31.1% were students. The use of AAS found significantly associated and more prevalent among who were 25 years old and above, private employees (37.2%), practice weight lifting (40.1%). Multiple logistic regression showed that the significant predictors of use the AAS among Gym users are 'practice weight lifting' OR [95%CI]= 1.93[1.02, 3.67],  $P < 0.044$ , 'using supplementary vitamins, minerals or special diet' OR [95%CI] = 7.80[4.05, 15.03],  $P < 0.000$ , 'knowing anyone about using anabolic steroids' OR [95%CI] = 7.51[3.78, 14.1],  $P < 0.000$ , and those who been asked to take AAS OR [95%CI]= 2.26[1.23, 4.15],  $P < 0.008$ .

### **Conclusion.**

The Anabolic-androgenic Steroid (AAS) use seems is a growing public health problem in Saudi Arabia as its worldwide and associated modifiable risk factors. Thus, the results of this study provide clear and compelling evidence to inform public health policy makers to take the necessary action preventing and controlling the access and use of in order to alleviate the future negative implications of AAS at community level."



## **A Best Practice Assessment Model to Implement Trauma- and Grief- Informed Assessment for Culturally Diverse Youth in Underserved Communities**

***Karen Calhoun, Polly Gipson, Benjamin Oosterhoff, Timothy Brown, Christopher Layne, and Julie Kaplow***

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"An alarming number of children, particularly those living in underserved communities, experience a range of psychological and behavioral health issues in response to trauma and bereavement exposure such as Posttraumatic Stress Disorder (PTSD) and/or maladaptive grief reactions (Kaplow et al., 2012; Oosterhoff, Kaplow, & Layne, in press).

These issues are often magnified from secondary exposure to accumulating traumatic events, including multiple deaths of family members and friends. Cultural issues play an important role in the mental health outcomes of diverse youth.

For example, among Arab American youth, gender acculturation/identity stress, exposure to intergenerational trauma (e.g., emigration, war, terrorism), and media reporting of world conflict are potential traumatic stressors that may impact their well-being.

Although the overlapping fields of childhood grief and trauma are advancing, many healthcare providers do not have access to best practice guidelines, evidence-based assessment and treatment modalities to adequately identify maladaptive grief and/or PTSD, often leading to misdiagnosis and inappropriate treatment planning.

This presentation will highlight findings from the Grief-Informed Foundations of Treatment (GIFT) Network, a national practice-research network that provides trauma and bereavement informed screening, assessment, case conceptualization and treatment planning to school systems; school-based and school linked health clinics; academic institutions; health systems/hospitals and mental health organizations serving children, youth and their families.

Our community-engaged approach includes the voices of specific cultural groups to allow for cultural tailoring of assessment tools, ultimately helping stakeholders to identify and reduce PTSD and maladaptive grief reactions among children and adolescents of various backgrounds.

## Asthma in Arab Populations

*Kamal Eldeirawi and Ahdab Eskandar*

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**Introduction.** Asthma is one of the main chronic conditions affecting populations around the globe. Although people of Arab descent share common cultural, historical, and some lifestyle factors and constitute a relatively homogeneous gene pool spread over a large geographic area, there are significant variations among people of Arab descent in socioeconomic conditions and environmental exposures, some of which are associated with asthma. Yet, data on the prevalence of asthma and asthma related conditions in the Arab world and Arab populations in the United States are lacking. In addition, factors associated with asthma among people of Arab descent are not well delineated. Understanding these factors will shed light on the etiology of asthma among Arab populations and has the potential to inform the development of strategies to prevent and/or control the disease.

**Objectives.** The purpose of this paper is to synthesize existing evidence on variations in the prevalence of asthma and asthma morbidity across Arab populations in the Arab World and in the United States. We will also discuss differences in asthma related lifestyle and environmental factors across Arab populations.

**Materials and Methods.** We synthesized existing literature on asthma and asthma related morbidity as well as factors associated with asthma in Arab populations in the Arab World and in the United States. We searched PubMed to find articles published in English and addressed asthma or asthma related symptoms in Arab countries and Arab populations in the USA.

**Results.** Existing findings suggest marked variations in the prevalence and morbidity of asthma among Arab populations with higher rates noted in Gulf countries and relatively lower rates in Arab countries by the Mediterranean Sea. There is some evidence that the prevalence of asthma has increased over time as countries became more industrialized and with urbanization. Reasons for variations in asthma risk among Arab populations are not well-understood but they might be due, in part, to environmental and lifestyle factors. Some of the factors associated with asthma in Arab populations include family history, exposure to environmental tobacco smoke, exposure to traditional incense, sandstorms, pet ownership, and urban residence. Studies in the United States show positive associations of household environmental risk factors with asthma as well as positive correlation between asthma and acculturation among new immigrants. Data on Arab Americans suggest that the adoption of a more “westernized” lifestyle among new Arab immigrants might be associated with an increased risk of the disease.

**Conclusions.** Although Arabs may share common ancestry, this paper highlights differences in asthma and asthma morbidity as well as factors associated with asthma among Arab populations. These differences might be due to variations in environmental and lifestyle factors and possibly the interaction of these factors with undiscovered genetic variants. More research is needed to better understand factors linked with asthma in Arab populations and guide the development of interventions aimed at controlling and/or preventing the disease.

## Refugees, Migrants and Ethical Responsibility for their Health Care

*Michel Daher*

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**Introduction.** War, conflict and persecution have forced millions of people to flee their homes and seek refuge and safety elsewhere. As of 2015, there were 250 million international migrants, of which 150 million are migrant workers.

Also affected are particularly vulnerable groups of refugees (21.3 million) and internally displaced persons (40.8 million). Of these, 9.1 million refugees and 21 million internally displaced persons (IDPs) originate from the Eastern Mediterranean Region, which carries the largest burden of refugees and IDPs globally.

**Objectives.** What is the result on their health situation? Major problem concerning acute malnutrition, epidemic infectious diseases, non-communication diseases which needed urgent health interventions. Although these interventions are important in emergency and post emergency settings, refugee situations in the 21st century are increasingly diverse and occur in refugee camp and non-camp settings.

**Results.** Recommendations concerning their Healthcare

- Refugees have a right to health care services that must be respected by all States and by the international community. Vulnerable groups (within a vulnerable group) such as women and children should be entitled to special health care services.
- Refugees retain the right to make their own medical decisions or to have an informed surrogate decide in accordance with their known or likely values and preferences.
- Needed health care services must be provided in a non-discriminatory manner.
- There should be no mandatory testing for diseases among refugees or migrants unless there are clear epidemiological reasons to suspect a high incidence of a certain disease among the refugees.
- Protective measures should be taken to prevent exploitation of refugees as organ providers in receiving countries.

**Conclusion.** The condition of refugee should be temporary, lasting only as long as the situation that gave rise to the condition persists. Nobody should be a refugee during his/her whole life. The countries of origin of refugees should make the greatest efforts to ensure their right of return, which is consecrated in the international legislation.

The international community has a duty to help countries in their efforts to bring back refugees, particularly in the cases of war-torn countries. This may be a costly endeavor and funds should be specially allocated to this task.

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## Deliberately Engaging Communities in Decisions about Resources (DECIDERS)

*Susan Goold, Adnan Hammad, Karen Calhoun and Zachary Rowe*

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**Introduction.** Engaging communities most affected by decisions about how limited resources are allocated could make those decisions more just, and more responsive to their needs.

**Objectives.** We will describe a community-based, participatory approach to health priority setting and results from at least two such projects, which included participation and partnership with Arab-American communities in Michigan and provide examples of how the method has been applied in international venues.

**Materials and Methods.** Academic-community partnerships adapted an internationally recognized simulation exercise CHAT (Choosing All Together), a ""serious game"" to engage minority and underserved communities in informed deliberations about health research and health care spending priorities. After an informational video about the decisions being faced, the group's task, and how to proceed through the CHAT exercise, individuals and groups chose from a menu of spending options constrained by limited resources. During CHAT they learn the consequences of their tradeoffs and can change their allocations. Pre- and post-exercise surveys measure demographics, perspectives on the deliberative process, and knowledge about the topic. Some sessions were conducted in Spanish or Arabic, with materials provided in those languages.

**Results.** Participants viewed the exercise and the group deliberations as informative, respectful and said they would trust such a process to inform decision makers about their priorities.

Members of underserved communities, in informed deliberations, put the greatest priority for health research on mental health and child health research. Group deliberations influenced individuals' research priorities. For health care spending, deliberations increased the priority given to mental health care and to expanding the population served.

Deliberations increased participants' knowledge and understanding of health disparities and health insurance but did not significantly improve knowledge about health research. The proportion willing to take part in a research study, high at baseline, did not significantly change after participation.

**Conclusions.** CHAT, which can be tailored to engage communities in setting priorities for various types of health resources, effectively engages minority and low-income community members in making tradeoffs between competing needs for limited resources. Its availability in multiple languages enables engagement and capacity-building in research in many populations that may be considered otherwise difficult to engage.

## **Access of Libyan Migrants in Tunisia to Social and Economic Services - Social and Economic Status of Libyan and Other Refugees in Tunisia**

***Belgacem Sabri***

In the aftermath of Arab spring and particularly following the collapse of Libyan regime in 2011, Tunisia has faced important waves of political and economic migrants which were catered for by both public and private health and educational sectors. Although the response of both health and educational systems was considered acceptable through active participation of civil society organizations, some gaps remained particularly in view of the lack of appropriate legislation on migrant's human right despite the new progressive Tunisian constitution.

Following the influx of more than 2 million refugees in couple of weeks, the response was organized in camps for non-Libyans only composed of expatriate workers from sub Saharan African countries, East Asia and others. The majority of Libyan families and individuals were hosted by Tunisian families as part of human solidarity with generous support from civil society organizations. The public sector, including ministry of health and military, was the main provider of health services with the help of red-crescent society and UNHCR. After the operation of transfer and placement in host countries in Europe and Canada, only 400 (mainly from sub Saharan African countries) remained in Shusha camp in the border with Libya. Syrian and Palestinian refugees (5000-7000) many of them registered with UNHCR receive health care in public facilities and by some NGOs. About 500000 and one million Libyan refugees have established since 2011 in main Tunisian cities in rented or owned houses and apartments.

As concerns were raised over social and economic rights of Libyan migrants, a national random survey for about 1500 Libyans was carried out by the Tunisian observatory on migration with the support of the International Organization on Migration. The survey has revealed several deficiencies in access to health care, schools and other social services. Lack of financial means has led to increasing school drop outs and to reduced access to private health care services. Also, existing labor legislation does not allow Libyans to work in Tunisia in both public and private sectors despite the 1973 treaty related to mobility between Maghreb countries. Such situation has worsened social determinants of health of Libyan refugees and increased their vulnerability. The main gap in relation to services offered to refugees is the lack of appropriate law on asylum which is the making since 2012. An independent authority on refugees is planned to be established as part of the law. The authority shall be in charge of managing asylum seekers and of providing them with basic human rights. The situation is also hampered by the refugee crisis in Europe and lack of appropriate strategy on migration over the Mediterranean. Security concerns of European governments are prevailing in all discussions and lip services are given to social, economic and cultural rights of migrants including education and health care.

Belgacem Sabri, former state minister in charge of migration and social inclusion Tunisia and former director of health systems WHO EMRO Cairo, Egypt.

## Knowledge Assessment and Screening Barriers for Breast Cancer in an Arab American Community in Dearborn, Michigan

*Mariam Ayyash, Hiam Hamade, Marwa Ayyash, Sheena Bahroloomi, Mona Makki, Samar Hassounah and Alex Blackwood*

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### Background.

Breast cancer is the most common malignancy afflicting women, with an estimated 1 in 8 U.S. women diagnosed during their lifetime. Screening for breast cancer has been shown to reduce mortality through early cancer detection. Lack of knowledge has been one of the main barriers leading to low screening rates. Given that the Arab American population has grown approximately 47% since 2000, this study was designed to assess breast cancer knowledge and screening barriers in one of the largest Arab American communities, in Dearborn, MI

### Methods.

Following (Exempt) determination by the Institutional Review Board (Michigan) a survey was distributed through ACCESS, Arab Community Center for Economic and Social Services, in Dearborn, MI. The survey covered a knowledge assessment, risk factors and screening barriers for breast cancer.

### Results.

200 Arab American adults participated in the study. 102 healthy women, 48 women who were breast cancer survivors and 50 healthy men. Deficiencies were noted in knowledge around cancer presentation and racial and ethnic differences in relative risk of disease. 73% of healthy women had a high level of knowledge, compared to 56% in survivors and 48% in men. Additionally, we noted that 51% of healthy women controls over the age of 40 have not had a screening mammogram in the past 2 years with leading causes being. absence of symptoms, lack of health insurance and absence of family history.

### Conclusions.

With the growing presence of Arab heritage in American communities, it is important that local physicians are aware in their medical knowledge gap to better serve this population. This survey highlights some of these deficiencies especially lack of adequate health education to patients and their families while they are undergoing treatment for breast cancer.

## Quality of Home Health Care in Arab World. A Systematic Review

*Khaled Al-Surimi and Malak Al Anazi*

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**Introduction.** Home health care plays an important role in improving patients' lives and their ability to sustain physical and mental functions. Therefore, we need more information on quality of home health care services provided. The objective of this study was to review systematically the studies that have been published on the quality of home health care in Arab World.

**Methods.** The search strategy identified relevant published studies through online literature search using the following electronic databases Embase, Cinhel, PubMed and the Cochrane library. We included studies conducted in Arab countries that focused on quality of home health care. Two reviewers independently verified that the studies met the inclusion criteria.

**Result.** Six (6) out of 214 met the inclusion criteria, giving studies on 3 countries. The country with the most studies was Saudi Arabia (4 articles), then Jordan (1 article) and Iraq (1 article), and no studies from other Arab countries. All included studies were assessed based on three quality indicators (safety, efficient and effectiveness) out of the six's Institute of Medicine IOM indicators.

**Conclusions.** This review shows a clear gap in enough literature on quality of home health care in Arab World calling for more studies on home healthcare, especially for quality studies on quality dimensions of patient-centered-care, timeliness of care as well as equity of care in home care settings.



## **Non-Pharmacological Solutions to Mental Health Challenges among Refugees**

*Lana Grasser*

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**Introduction.** Prevalence of PTSD, anxiety, and depression is high in the refugee population, particularly in women and children. This suggests need for treatment, yet resources for language and culturally informed psychotherapy are limited, and cultural beliefs may limit acceptance of pharmacological interventions. With a focus on the mind-body connection, dance, art, and yoga therapies have shown to be effective in reducing stress, improving mood, and promoting overall well-being.

**Objectives.** To show impact of interventions that address somatic symptoms aspects of stress, anxiety, and depression, and use self-report questionnaires plus biomarkers of cortisol and inflammation to evaluate efficacy of such interventions.

**Methods.** Refugee families (n = 31 individuals) with at least one family member being a primary or secondary survivor of torture were recruited by a partner organization Samaritas. Dance/Movement Therapy (DMT; children), Art Therapy (children), mindful yoga (adult women) and High Intensity Interval Training (HIIT; adult men) were provided to participants once weekly for ninety minutes over the course of 12 weeks. These classes promoted non-verbal emotional expression, cognitive restructuring, and mind-body connectivity. We assessed symptoms during, and after intervention using the following. Hopkins Symptoms Checklist, PTSD Checklist-Civilian, Somatic Symptoms Scale 8 (adults and children), Mood and Feelings Questionnaire (children), and the Screen for Child Anxiety Related Disorders (children). We also collected small sample of blood (adults), saliva (children), and hair samples to measure markers of inflammation and cortisol. Intervention is currently ongoing (at week 9).

**Results.** After 6 weeks of treatment, a significant decrease in anxiety symptoms—specifically those related to generalized anxiety, separation anxiety, and social anxiety—has been observed in children participating in DMT or art therapy. Adult participating in mindful yoga or HIIT also experience a significant reduction in depression and anxiety symptoms, in addition to a 12-point reduction on average PCL score; DSM-5 classifies a 5 point reduction as indication of possible therapeutic effect of treatment. Data will be collected again at the conclusion of the program and compared to matched controls who have not received any intervention during the same time period. Data regarding biomarkers will also be analyzed.

**Conclusions.** Based on participant self-reporting, the interventions are well received by the population and seem to be helpful in improving anxiety symptoms in children, and anxiety and depression symptoms in adults. The program is currently on-going and validate the program with hopes of expansion to address the needs of a wider cohort.



## **Narratives of Refugee Women in Berlin, Germany**

***Sura Shlebah***

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### **Summary**

This study examined the experience of refugee women in Berlin, Germany via a qualitative descriptive approach. Every minute 24 people were forced to flee their homes in 2015.

Global trends reported in 2015 that 65.3 million individuals were forcibly displaced worldwide as a result of persecution, conflict, generalized violence, or human rights violations (Global Trends 2016). Berlin, the second most populous city in the European Union (EU) has become home to many individuals seeking refuge.

The study utilized participant observation, field notes, interviews, and spatial observations in order to explore the issues that plague refugee women in their journey and resettlement in Berlin. From the gathered data several common themes emerged:

- Lack of self-dignity during migration journey,
- Lack of stability in resettlement,
- Language barriers,
- and
- The overwhelming desire for safety

The findings demonstrate that the experiences of refugees cannot be merged together of as a hegemonic, collective experience. Rather there is empowerment in reclamation of one's voice and narrative.

### **Key Words.**

refugee women, identity, qualitative, global refugee, empowerment, oral narratives

### **References.**

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## **Sustainable Cleft Training for Middle Eastern and Northern African Surgeons**

*Christine Jones*

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### **Introduction**

The Lancet Commission on Global Surgery has called for improvements to surgical access in low- and middle-income countries.

In contrast to the 28 cleft-craniofacial fellowships in the U.S., no specialized craniofacial surgery training programs exist to serve the 700 million people in the Middle East and Northern Africa (MENA), of whom 14,000 are born with clefts annually.

Historically, Middle Eastern surgeons have travelled abroad to obtain cleft training, but cost and foreign medical graduate status often make this prohibitive.

### **Objectives**

The purpose was to build a sustainable cleft-craniofacial training program for MENA surgeons.

### **Methods**

Phase I.

Three models for MENA cleft surgeon training were compared based on cost, effectiveness, and accessibility.

Model 1 (M1). Trainee travels to an academic program in a developed country;

Model 2 (M2) Trainee travels to a high-volume surgical center (e.g., Guwahati (Operation Smile) or Hyderabad, India (SmileTrain));

Model 3 (M3) Surgical teams travel to the trainee's location in MENA (e.g., Embracing Life Program).

A cost minimization analysis was conducted using a societal perspective. Effectiveness was judged based on case volumes, duration of fellowship, quality of surgical results, and longevity of cleft-craniofacial career, including mentorship of future surgeons.

Accessibility was determined by competitiveness and amount of travel required for each model.

Phase II.

Plans were drafted to create a sustainable model of cleft training.

## **Results**

### **Phase I.**

#### **Cost.**

Trainee cost. M1 (\$97,806) is expensive, with high costs to both trainee and program to account for travel, cost of living, malpractice coverage, and salary in a high-income country. M2 cost varies with location (avg. \$7,472, without trainee salary); all MENA locations modeled are less costly than Western training. M3 cost to trainees is minimal, beyond usual costs of living; however, overall societal cost is highest (\$133,790), accounting for transportation of a surgical team and lost team productivity at home.

#### **Effectiveness.**

With proven quality, emphasis on staged increases in responsibility, and high case volumes, M1 and M2 are the most effective models. M2 has higher volumes; M1 may offer more coordinated teaching. M3 effectiveness is limited by the short mission duration.

#### **Accessibility.**

M3 is most accessible, as teams travel to the trainee's home location.

Accessibility of M2 lies between M3 and M1; while foreign practitioners have opportunities to train at the current cleft centers, these centers are far from MENA.

M1 is the least accessible model because these fellowships have requirements that cannot be met by most MENA practitioners.

### **Phase II.**

Partnership was created between American University of Beirut (AUB) and the United Palestinian Appeal to build a one-year, fully-funded cleft fellowship at AUB, mirroring M2. One fellow will be trained annually and will receive a monthly stipend. The overall program cost is estimated at \$30,000.

## **Conclusions**

High-volume centers (M2) offer effective training comparable to U.S. craniofacial fellowships yet remain cost-efficient. The location of current centers limits their accessibility to Middle Eastern surgeons.

A readily-accessible center with high cleft volume is being created in MENA. Future research will directly measure the costs, effectiveness, and accessibility of surgical training."

## Pain Relief Is a Human Right

*Michel Daher*

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**Introduction.** For centuries, medical and surgical treatment has emphasized saving the life of the patient rather than ameliorating the patient's pain, particularly when there were few options for the latter. Today at the dawn of the 21st century, the best available evidence indicates a major gap between an increasingly understanding of the pathophysiology of pain and widespread inadequacy of its treatment.

**Objectives.** Epidemiologic evidence has proven that chronic pain is a widespread public health issue. Studies of cancer patients' pain control consistently reveal that up to half of patients receive inadequate analgesia and 30% do not receive appropriate drugs for their pain.

One response to the worldwide under treatment of pain has been to promote the concept that pain relief is a public health issue of such critical importance as to constitute an international imperative and fundamental human right.

**Results.** The importance of pain relief as the core of the medical ethic is clear. Pain clinicians promote the status of pain management beyond that of appropriate clinical practice or even an ethic of good medicine. They advocate a paradigm shift in the medical professions' perspective on pain management, from simply good practice to an imperative founded on patient rights.

There is a need to promote policies which create conditions where human beings can bear even incurable illnesses and death in a dignified manner. This must help health professionals or lay groups to initiate a powerful agenda to reform local statutes. The essential components of such legislation are.

1. Reasonable pain management is a right.
2. Doctors have a duty to listen to and reasonably respond to a patient's report of pain.
3. Provision of necessary pain relief is immune from potential legal liability.
4. Doctors who are notable or willing to ensure adequate analgesia must refer to a colleague who has this expertise.
5. Pain management must be a compulsory component of continuing medical education.

**Conclusion.** For too long, pain and its management have been prisoners of myth, irrationality, ignorance, and cultural bias. We are confident that the National Committee for Palliative Care under the auspices of the Ministry of Public Health is the main promoter of Palliative Care in Lebanon whose main goal is to relieve suffering and improve quality of life of the cancer patients, and advocate pain relief and palliative care as a human right.

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## **Access and Use of Medications among Immigrant Arab-American Women. A Community-Based Mixed-Methods Study**

***Dima Qato***

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### **Background**

Little is known about access and use of medications among immigrant population, including Arab-American (AA) immigrant women. In partnership with the community, we assessed access and use of medications among low-income immigrant AA women to identify key barriers in access and use of medications.

### **Methods**

We conducted focus group discussion and a questionnaire-based survey that utilize social services from a community-based organization (Arab-American Action Network). From October 2014 – February 2015. Focus group consisted of 30 participants and 10 women participated in the survey. Findings.

### **Results**

The median age was 45 years and the median years of immigration to the U.S was 4 years. All participants were non-US. Natives; 40% were uninsured and 40% identified emergency room as the primary source of care. Nearly one-third were using at least 1 medication, and two-thirds reported medication non-adherence. Focus groups identified cost barriers, limited understanding of preventative care, transportation and domestic barriers in accessing care and medications.

### **Conclusions**

Immigrant, Arab-American, low-income experience multiple barriers in accessing and using primary health care and medications. Community-based assessments and interventions are necessary to improve the use of medicines in these communities. "

## Pediatric Muslim Fasting Practices in Southeast Michigan

*Malak Ismail, Emman Dabaja, Khalil Dabaja, Muhammad Haidous, Adnan Hamka, Mustafa Deebajah, Alex Blackwood and Toby Lewis*

**Background.** Fasting during the holy month of Ramadan is one of the primary pillars of Islam. Muslims abstain from all water, food, and medications from dawn till dusk for the duration of the month. The start of Ramadan depends on the lunar calendar, with the dates changing yearly. Fasting is considered obligatory for observant Muslims, including adolescents starting at puberty. Notable exceptions are made for those who are ill, traveling, pregnant, and the elderly. To date, the existing medical literature focuses on adult fasting and health outcomes with little attention paid to pediatric fasting practices.

**Objectives.** The goal of this study is to describe pediatric fasting habits and practices among Muslims in Southeast Michigan, in order to help inform physician recommendations and anticipatory guidance for patients.

**Design/Methods.** An anonymous, digital, bilingual (English and Arabic) survey was conducted using Qualtrics software. Participants were recruited in-person at various community clinics, businesses, and mosques as well as online via social media. To be eligible for the study, participants must identify as Muslim and be parents or guardians of child/ren between the age/s of 7 and 18. The University of Michigan IRB granted exemption status for this project.

**Results.** Between July 2017 and May 2018, 899 people took part in the study, with 70% (508/727) of participants living in Wayne County, MI. About 80% (605/754) of the participants identified as Arab American and 60% (449/749) as immigrants to the US. On a 5-point Likert scale, 82% (613/752) of parents rated themselves as at least 4/5 or “moderately religious” with 65% (562/863) of parents reporting that it was “very important” or 5/5 that their child/ren fast during Ramadan on a 5-point Likert Scale. On average, parents encouraged females to start fasting at 10.26 +/- 2.14 years old (n= 796) and males at 10.92 +/- 2.28 years old (n=809). Most parents, 64% (511/801), reported that their child’s doctor was not aware of that their child fasted. On a 5-point Likert scale, 69% (539/779) of parents reported feeling “extremely comfortable” or 5/5 talking to their child’s physicians about fasting, but less than 25% (517/794) of parents said that their child’s physician gave them any medical advice about <sup>fasting</sup>.

**Conclusions.** Our study is an important first step in helping elucidate beliefs and practices about Muslim pediatric fasting in Michigan. Our unique community-based approach helped survey a large sample of Muslims in Southeast Michigan. Subsequent studies will focus on assessing physician baseline knowledge about pediatric fasting practices and their current clinical practice.

**Key Words:** Muslim, Fasting, Ramadan, Pediatrics

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## The HPV Vaccine Introduction in the MENA Region. Cultural or Financial Barriers?

*Sabrine Hamdi*

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**Introduction.** Vaccination is the best approach with regard to both cost and effectiveness, in order to control infectious diseases, (Nicol, A.F. et al. 2018). Nonetheless, the introduction of HPV vaccines constitutes a controversial issue, primarily due to their connection to sexual activity on one hand and to their cost, on the other hand.

MENA region countries are considered to be conservative regarding sexual behaviors compared to the West, because they have more traditional religious and social norms (Vaccarella et al., 2013). Cases of sexually transmitted infections (STIs) there are thought to be higher than reported. Consequently, there exists a false belief that STIs are rare in that region (Seoud, 2012). In addition, assessment of HPV prevalence is difficult because screening is uncommon and there are insufficient regular national cancer registries (Vaccarella et al., 2013).

Within the context of HPV vaccination introduction and according the World Health Organization (WHO) recommendations, cost-effectiveness assessments are crucial to inform evidence-based decision making.

**Objectives.** The objectives of this review article are to. 1) give an overview on the burden of HPV in the MENA region; 2) explore the religious impact on health decisions and potentially the HPV vaccine introduction; and 3) explore the cost-effectiveness of the introduction of HPV vaccine, examples from low and middle-income countries (LMIC).

**Methods.** This paper is a systematic review of the literature. Data on HPV epidemiology were collected through keyword searches using Science Direct and PubMed as search engine. English and French literature were collated and examined.

Studies and articles published in peer-reviewed in scientific and religious studies journals; reports published by organizations including the WHO and CDC; and books written by anthropologists and theologians were examined.

### Results.

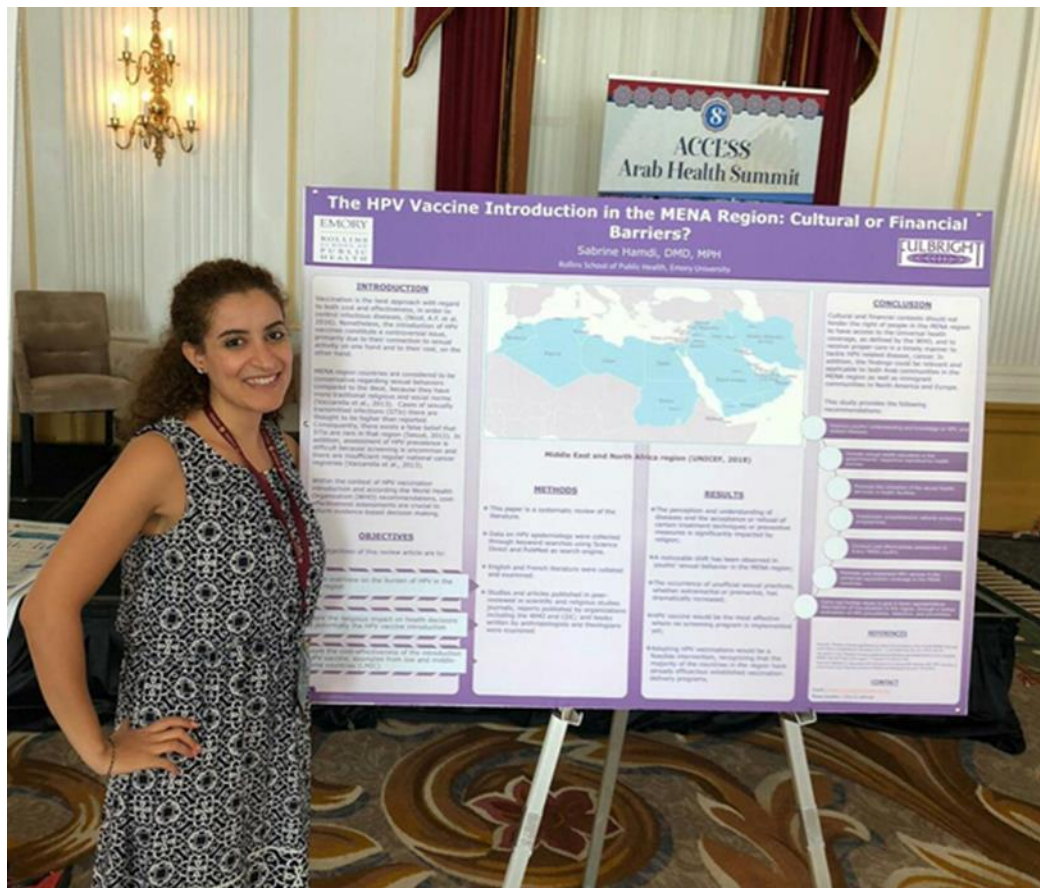
1. The perception and understanding of diseases and the acceptance or refusal of certain treatment techniques or preventive measures is significantly impacted by religion;
2. A noticeable shift has been observed in youths' sexual behavior in the MENA region;
3. The occurrence of unofficial sexual practices, whether extramarital or premarital, has dramatically increased;
4. HPV vaccine would be the most effective where no screening program is implemented yet;

5. Adopting HPV vaccinations would be a feasible intervention, recognizing that the majority of the countries in the region have already efficacious established vaccination delivery programs.

**Conclusions.** Cultural and financial contexts should not hinder the right of people in the MENA region to have access to the Universal health coverage, as defined by the WHO, and to receive proper care in a timely manner to tackle HPV related disease, cancer. In addition, the findings could be relevant and applicable to both Arab communities in the MENA region as well as immigrant communities in North America and Europe.

This study provides the following recommendations.

1. Improve youths' understanding and knowledge on HPV and related diseases
2. Include sexual health education in the governments' respective reproductive health policies
3. Promote the utilization of the sexual health services in health facilities
4. Implement comprehensive national screening programmes
5. Conduct cost effectiveness assessment in every MENA country
6. Promote and implement HPV vaccine in the universal vaccination coverage in the MENA countries
7. Carry out further study to give a more representative description of the situation in the region, through a better evaluation of HPV prevalence, detection, and prevention.





## **The Mental Health of Arab Americans. Findings from Southeast Michigan**

*Sanjana Pampati, Carlos Mendes de Leon, Madiha Tariq, Evette Cordoba and Zaineb Alattar*

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### **Introduction**

A large concentration of Arab Americans, including refugees, immigrants, and U.S. born individuals, live in Southeast Michigan. A growing body of research indicates that Arab Americans are subject to a host of stressors, including discrimination, lack of social support, and economic hardship that could detrimentally influence their mental health.

In addition, Arab refugees and immigrants may be exposed to pre- and post-migration stressors that elevate their risk of adverse mental health outcomes, such as political violence, religious persecution, and acculturative pressures.

### **Objectives**

The purpose of this study was to characterize the mental health burden among Arab Americans living in Southeast Michigan and examine how this burden differs by resident status (refugee, immigrant, and U.S. born). Further, we conducted an exploratory analysis examining how factors related to immigration correlated with depression and anxiety levels.

### **Methods**

A cross-sectional study in a convenience sample of 275 adults who self-identify as Arab living in Southeast Michigan was conducted. Participants were recruited from the Arab Community Center for Economic and Social Services (ACCESS), a non-profit health and social services organization, between August–November 2015.

Data were collected via self-administered questionnaires, using standardized instruments to assess various demographic factors, depression (Center for Epidemiologic Studies Depression Scale Short Form, 8-item) and anxiety symptoms (Generalized Anxiety Disorder Scale, 4-item). Multiple linear regression models were fit to examine if depression and anxiety levels differed among refugees (n=67), immigrants (n=153), and U.S. born Arab Americans (n=55).

## Results

Mean levels were notably higher in our sample compared to national estimates for depression and Detroit metro area estimates for anxiety among African Americans, Hispanics, and non-Hispanic Whites. Among study participants, refugees reported higher levels of depression and anxiety than either immigrants or U.S. born Arab Americans.

After adjustment for age, educational attainment, duration living in the U.S., gender, and marital status, differences between U.S. born Arab Americans and refugees were statistically significant for depression ( $b=2.84$ ; 95% CI. 0.21, 5.47), but not for anxiety. Those reporting political violence and religious persecution as reasons for immigration had the highest mean levels of depression and anxiety, especially if these were the only reasons they listed for immigration.

In contrast, those reporting educational or economic opportunity as their sole reason for immigration had the lowest mean levels of depression and anxiety.

## Conclusions

Arab Americans living in Southeast Michigan, particularly refugees, report high levels of depression and anxiety and may be in need of mental health services. Our results stress the need for more systematic studies of the Arab American population.

Thus, we argue for the introduction of an Arab-origin or MENA identifier in nationally representative epidemiologic surveys (e.g., BRFSS, NESARC, etc.) and on the upcoming U.S. Census.



## **The Prevalence of Obesity among Arab American Adolescents in a Clinical Setting**

*Areeg Zuair*

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### **Background**

There are significant disparities in the prevalence of obesity among African American, American Indian, and Hispanic adolescents compared to White adolescents. The Michigan Department of Community Health considers Arab Americans a minority group and differentiates them from Whites. However, nothing is known about the prevalence of obesity among Arab American adolescents.

### **Purpose**

To determine the prevalence of obesity among Arab American adolescents seeking care in a clinical setting.

### **Methods**

This is a descriptive correlational study design involving the use of medical record data from a community-based health clinic. A nonprobability consecutive sampling strategy was used to identify medical records of Arab Americans seeking care between 12 and 19 years of age from 2013 to 2016. Approximately 476 subjects were required to reject the hypothesis of zero correlation at a 5% level of significance with 95% power. Prevalence was compared with the prevalence from the National Health and Nutrition Examination Survey 2011-2014.

### **Results**

Among 476 of Arab American adolescents, (14.5 %) were at risk of being overweight (> 85th and < 95th percentile for age and sex) and (15.5%) were obese (> 95th percentile for age and sex). Among all adolescents, no difference was seen by sex or age. The prevalence of obesity was higher among Arab American adolescents (15.5%) compared with non-Hispanic white (14.7%).

### **Conclusions**

The proposed research is innovative in that it considers Arab Americans as an independent race and ethnic group. Also, it provides essential primary statistical data for future research about the phenomenon of obesity among Arab American adolescents and helps in developing the appropriate interventions.

## Attitudes to Mental Illness in Arab Muslim Americans

*Shady Shebak, Hussein Tehaili, Henda Albiatty and Taj Elsayed*

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### Purpose

To explore the cultural constructs of honor and shame within the Arab Muslim American Community, while simultaneously devising a culturally appropriate psychoeducational 12-month program.

### Methods

Study participants include attendees to the MOVE – Movement for Outreach – Volunteerism – Education 12-month psychoeducational program, in collaboration with the Islamic Center of America, located in Dearborn, MI. The participants set the topics to be discussed at subsequent psychoeducational groups, as we are utilizing a modified version of the Psychoeducation Responsive to Families (PERF) model in our curriculum.

Participants will fill out the ‘Attitudes Towards Mental Health Problems’ survey, which asks questions pertaining to internal and external shame, reflected shame, and perceived family and community views on mental illness. Each question is answered on a 4 point Likert scale. We also devised several open ended, qualitative questions as follows. What does the concept of honor mean to you? What does the concept of shame mean to you? Have you heard about ‘saving face’? If so, how does this relate or not relate to you? Do you believe that your actions reflect on yourself or do they reflect on the family and community as well? Please elaborate? Are you more private, public, or a mix of both? How so? And Why?

### Results

Currently, we are collecting data and have ongoing psychoeducational groups once per month on the third Friday of each month. We will have collected all of our data for the research portion of this project by December 15. We had 50 participants at the first group. Second psychoeducational group will take place in November.

### Conclusions

By better understanding aspects of Arab culture, such as honor, shame, privacy, and where the stigma regarding mental illness is arising from, we can more effectively work on the problems at hand without assigning guilt or unintentionally belittling a culture. Furthermore, our psychoeducation groups may be replicated in other communities and our results from our study will add valuable literature on honor and shame within the Arab and Muslim American community, as it pertains to mental illness.

## Demographics of Orofacial Clefts Among Palestinians

*Meredith Grogan Moore, Omar Saeed, Moath Tayem, Hassan Zawahrah, Christine Jones and John A. van Aalst*

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### Introduction

Orofacial clefts (OFC) are a common congenital anomaly requiring coordinated pre- and post-natal care to ensure quality of life among affected individuals.

Known OFC risk factors include exposure to smoking, anticonvulsants, chemicals, and radiation, and folic acid deficiency. Surgical repair of the cleft lip is generally performed at 3 months-of-age and of the cleft palate at 9 months-of-age.

Delays in surgical repair may lead to poor outcomes. Little is currently known about natal and post-natal demographics of OFC among Palestinians.

### Objectives

To define unique demographics of Palestinians with OFC and to improve care for these patients.

### Methods

The Palestinian Congenital Anomalies Database was created in 2011 as a REDCap secure web application; it builds on a validated 700-question survey administered in colloquial Arabic to mothers of children with congenital anomalies. Demographics include, but are not limited to, pregnancy history, exposure to teratogens, family and economic history, timing and quality of surgical treatment, and functional outcomes. Quantitative and qualitative analyses were conducted on all data.

### Results

536 patients reported OFC; the most common diagnosis was cleft lip and palate (CLP, 258), followed by cleft palate (CP, 151), and cleft lip (CL, 121), with 6 complex clefts. CLP occurred more frequently in males than females (1.25:1); CP more frequently in females (1.0:0.58). Prenatal. Maternal age at conception was 27 (SD=6.5) and paternal age was 33 (SD=7.8). One-third reported a prior unintended miscarriage. Pregnancy.

Though 84% of mothers received prenatal ultrasound (US), only 13% reported the cleft diagnosed prenatally. Only 28% of mothers understood the diagnosis; only 28% of these mothers received diagnostic information from a healthcare provider. Mothers of patients with OFC had a 4% smoking rate during pregnancy, but 65% lived with a tobacco user; a majority (83%) reported daily exposure to second-hand smoke. Five percent of mothers reported seizures during pregnancy; none took anticonvulsants. Forty-two percent took

medications during pregnancy, generally antibiotics. Toxin exposure was reported by 29% of mothers, generally citing cleaning chemicals. Radiation exposure during pregnancy was reported by 3%. One-third of mothers reported no antenatal folic acid supplementation; 35% did not eat three regular meals per day while pregnant.

Postnatal. Average age at cleft lip repair was 10 months (range 0-180) and for cleft palate repair was 28 months (range 1-348). Two-thirds of mothers reported a speech abnormality in their children at one year-of-age; of these, 44% had not seen a speech-language pathologist.

### **Conclusions**

The distribution of diagnoses among Palestinian patients with OFC is similar to other large reported series. A high percentage of mothers received prenatal US, but with a low rate of cleft diagnosis.

Additionally, a significant number of mothers did not understand their child's diagnosis. Though smoking rates were low, second-hand smoke exposure was significant. A third of mothers did not take folic acid during pregnancy. Both cleft lip and palate repair were delayed compared to established best practice protocols.

Given these findings, improved education regarding OFC is necessary, not only for families of children with OFC, but the health practitioners providing their care.



## Consanguinity Influences Risk of Familial Clefting Among Palestinians

*Omar Saeed and John van Aalst*

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### Introduction

Orofacial clefting (OFC) is the most common congenital craniofacial anomaly, with a world-wide incidence of 0.1%. Though the demographics of OFC are reasonably well-defined, the relationship between consanguinity (intermarriage) and multiplicity (more than one family member with a cleft, generally demarcated as immediate or distant) has not been fully elucidated.

This is due in part to the fact that consanguinity rates in developed nations are low (1%), with negligible perceived impact on multiplicity. By contrast, overall consanguinity rates in the Middle East (ME) are 45%, with a rate of 37% among Palestinians.

Multiplicity rates in the ME are as high as 30%; generally, a lower rate is reported in developed nations. This paper examines the influence of consanguinity on multiplicity and cleft diagnoses among Palestinians with OFC.

### Objectives

To determine the relationship between consanguinity and multiplicity in Palestinian families with OFC.

### Methods

The Palestinian Congenital Anomalies Database is an IRB-approved, validated 700-question survey administered in colloquial Arabic to mothers of patients with congenital anomalies. Survey demographics include a wide array of details including, but not limited to, diagnoses, consanguinity, multiplicity, and family location.

To date 613 surveys have been completed with 536 patients reporting an OFC. Among OFC patients, 352 had cleft lip with or without palate (CL+/-P) and 178 had cleft palate only (CP). All p-values were calculated using chi-squared tests and appropriate Bonferroni corrections for multiple comparisons; level of significance was set at  $\alpha < 0.05$ .

### Results

Among patients with OFC, family consanguinity rate was 53% and multiplicity rate was 50%. The most common consanguineous relationship was first cousin marriage (61%). Based on

diagnosis, rates of consanguinity for CL+/-P (50%) and for CP (62%) were significantly different only for patients with CP. Consanguinity rates in the northern West Bank (20%) were significantly lower than in the south, primarily Hebron (58%). In families with multiplex clefting, the affected individual was most commonly a distant relative (74%).

Cleft diagnoses in multiplex families were CL+/-P (66%) and CP (34%). Differences in multiplex rates in the northern (20%) and southern West Bank (54%) were significantly different. Family history of clefting was more likely to be positive for patients whose parents were consanguineous (56%) than those who were not (42%).

Recurrence of a cleft in siblings was significantly higher among consanguineous relationships (18%) than non-consanguineous relationships (4%).

## Conclusions

Consanguinity rates for Palestinians with OFC were higher than those reported in the ME and among the general Palestinian population; within Palestine, these rates were higher in the southern West Bank, and highest among children with a diagnosis of CP.

Multiplex and sibling recurrence rates were higher than expected, with the highest rates present in those diagnosed with CL+/-P from the southern West Bank.

The risk of OFC may be mitigated with improved education about anticipated genetic consequences of consanguinity in high risk populations such as the southern West Bank."





## **Ethical Issues in End-of-Life Care**

**Michel Daher**

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### **Introduction.**

Ethics is a branch of philosophy that examines rights and wrongs, what should or ought to be done. Clinical ethics refer to application of the science and understanding of morality in the field of medicine and health sciences. The goal of clinical ethics is to improve the quality of patient care, emphasizing the commitment to the well-being of patients. Owing to technical advances in the care of critical illness, physicians, patients, and families are often confronted with ambiguous circumstances in which medical advances may inadvertently prolong suffering and the dying process rather than bring healing and recovery.

### **Objectives.**

The objectives of this presentation are:

- 1) review major principles of medical ethics relevant to the care of terminally ill patients
- 2) explore further the principle of autonomy and its application to advanced directives, informed consent, and medical futility
- 3) characterize the ethical differences between withholding or withdrawing life-sustaining therapies and physician-assisted death
- 4) define a process for communicating bad news and negotiating decisions at the end of life
- 5) examine ethical problems specific to terminal illness in light of these principles. We will discuss how a good palliative care can be an alternative to these ethical dilemmas.

### **Results.**

Patients and their physicians together face a number of challenging ethical issues at the end of life. Although some issues (eg, the role of physician-assisted death in addressing suffering) remain very controversial, there is much common ground based on the application of the 4 major principles of medical ethics, nonmaleficence, beneficence, autonomy, and justice.

### **Conclusions.**

The physician's primary commitment must always be to the patient's welfare and best interests, whether the physician is treating illness or helping patients to cope with illness, disability, and death. The physician must support the dignity of all persons and respect their uniqueness. When ethical dilemmas occur, Ethics Committees must be involved.

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## **Navigating Multiple Community Contexts. Interacting “Positionalities”, Visibility, Resilience, and Well-Being**

*Beth Glover Reed, Odessa Gonzalez, and Larry M. Gant*

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### **Introduction**

Conceptual frameworks draw from critical social theory and intersectionality approaches (Dill, B. T. & Kohlman, 2014). These focus on how societal structures, systems of meaning, and social processes create multiple interacting systems of power which result in differential opportunities and barriers depending on particular mixes of “positionalities”.

Important positionalities vary from culture to culture, and within a culture; in the USA, they are frequently race, gender and gender expression, ethnicity, sexual orientation, economic class, religion, age, and dis/ability (and can include immigration status and others). Everyone has multiple positionalities, and the forces around them work together so that people with different mixes of positionalities will experience different conditions and consequences even in the same environments.

Also their salience, meaning and consequences are influenced by contexts, and all have great impacts on life chances, health and well-being. Intersectionality is not just a means of critique and explanation, but also about transformative practice and furthering health and capacity. [National Collaborating Centre for Healthy Public Policy (2015)]. There are beginning to be some studies using these frameworks focused on Arab and Muslim populations, but less attention to younger populations and implications for health (Rahman, 2017).

### **Objectives**

Explore how a sample of Arab and Arab-American youth and young adults

- understand and experience themselves and their environments,
- identify difficult to supportive environments, and
- engage with and are impacted by these environments.
- Identify what enhances capacities for well-being and growth and promotes resilient individuals and environments.

### **Methods**

Twenty-eight youth (ages 15-18) and young adults (22 to 32) participated in four focus groups. All identified as Arab or Arab-American in varied ways and on other dimensions. They identified

positive, negative and neutral environments, how they navigated and were impacted by these, and what was helpful in promoting positive experiences and coping with negative ones.

## **Results**

Participants report complex positionalities, using many different terms to describe ethnicity (sometimes indicating countries of origin) and/or race, often intertwined with indicators of gender, religion and economic class. Religion provides both sources of meaning and purpose, as well as tensions and risks in particular environments.

Environments included micro, mezzo and macro contexts, and many settings (e.g, mosques, airports, different communities), with external and family roles and responsibilities evolving with age. Visibility is important in the salience and consequences of particular positionalities. Some are always visible (like gender, physical features and skin color, size), while others one can emphasize or minimize. Positive or negative environments influenced whether and how participants emphasized ethnic, religious, cultural and/or gendered selves (e.g., “being a scarfy., length of beard, using

Westernized nicknames). Some contexts allowed them to explore and define themselves while many costs were incurred in others (stress, anxiety, withdrawal, diminished self-esteem with health consequences). Some also described instances of very proactive engagement with their environments to educate others and work for change.

## **Conclusion**

We discuss implications for individual and community resilience and capacity building, and the value of intersectional approaches for examining and addressing interactions among complex positionalities and environments. We also identify some particular issues for youth and young adults.

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## **Human Resources for Health: Pulling and Pushing Factors in the Arab Region**

*Nazar Abdelrahim Mohamed*

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### **Background**

The availability of a sufficient, equitably distributed, skilled, fit-for-purpose and motivated health workforce are key to strengthening and improving health service coverage and achieving better health outcomes.

Yet in many countries in the Arab region health workforce shortages, inequitable distribution, skill-mix imbalances, in addition to other factors related to training and education hinder the attainment of the health-related sustainable development goals (SDGs) and universal health coverage (UHC) [1,2].

### **Objective**

This paper aims to explore the pulling and pushing factors that hinder the achievement of UHC in the Arab region based on the World Health Organization analytical framework that examines effective coverage in relation to the availability, accessibility, acceptability and quality (AAAQ) of human resources for health (HRH) [3].

### **Method**

The author reviewed available literature on HRH in the Arab region and identified key factors that support the progress towards achieving the UHC guided by the analytical frame.

### **Results**

The findings showed that HRH are critical to the expansion of health service coverage and package of benefits, and that HRH strategies in each of the AAAQ dimensions collectively support achievements in UHC.

However, numerous challenges were identified that hinder HRH to accelerate the progress to achieving the health-related SDGs which are complex and often globalized in nature.

The instability and chronic protracted crises, global health labour market and migration, the epidemiologic and demographic shifts, remuneration packages and working conditions, career pathways and professional development, and political leadership were the common among others.

### **Conclusions.**

The findings inform the need of evidence-based policies and strategies that systematically address the deep-rooted HRH problems and synergies. These policies and strategies should avoid piecemeal solutions with long-term perspective and collaboration among many stakeholders and

constituencies. They should also be coupled and brokered by strong strategic leadership and governance.

Country-specific context in the Arab region encourages for more HRH research and evidence-generation to better inform the decision-making process to sustain the health gains and accelerate the movements towards the attainment of the health-related SDGs.

### **Key words.**

Arab region, universal health coverage, human resources for health, sustainable development goals.

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## **A Global Call to Action on Health Equity and Social Justice - International Partnerships. Making Vision a Reality Through an International Lens**

*Karim Ali and Collin Ross*

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### **Introduction**

We describe a program to restore sight and prevent blindness through the healing power of donation, transplantation and research. Our greatest inspiration has come from our work in building a network for cornea donation in Pakistan. Pakistan is a nation of about 200 million people, who suffer from a very high incidence of corneal blindness exacerbated by the effects of widespread poverty. There are about 200,000 people in Pakistan who live in darkness simply because they need a cornea transplant, and they cannot get one. And in that society, to be blind is also to be robbed of one's economic freedom and one's ability to participate in family and community life. Restoring sight restores independence, and dignity, and life itself.

### **Objectives or Hypothesis.**

1. Demonstrate that when we listen to one another, we have the power to save and restore life to those in need
2. Highlight the tremendous immediate and long-term value to be garnered by developing greater global support of international eye-banking as a means of transforming lives in the MENA region and beyond.

### **Materials and Methods**

Through a ten-minute dialogue driven by PowerPoint slides and short video content this presentation explored the significant impact this program (Eversight) is having within the United States and abroad, specifically in Pakistan, where to date a total of four eye bank clinics have been established serving hundreds of local citizens who would otherwise live a life without sight.

### **Results**

Given the vast population of a country like Pakistan the current available medical support to stem the tide of blindness hardly meets the demand. By bringing attention to advances in technology and models of successful international collaboration our presentation created greater collaborative opportunities, as well as emphasized the need to educate the public regarding the current need for this humanitarian work.

### **Conclusions**

Corneal blindness is a significant cause of preventable blindness worldwide. While there is no waiting list for corneal transplants in the United States, there is an extreme shortage of corneas for transplantation globally. Because of this large unmet need, many patients suffer avoidable blindness for years while awaiting their chance for restored sight. Eversight is committed to the development of sustainable community-based eye banking systems, using consented donation models, to address this need by providing tissue and sharing our expertise with surgeons and hospitals for hands-on training with the latest transplant techniques.

## **Models of Grassroots Outreach: Lessons learned from National MOTTEP**

*Karim Ali and Clive Callender*

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### **Introduction**

The “Muslim Life Planning Network (MLPN)” at its inception was an initiative created to assist in educating and increasing the American Muslim awareness and participation in organ and tissue donation. The initiative quickly became one of concern for the life journey of Muslims in America. Currently the predominant thought among Muslim Americans is that organ donation is not permitted [haram]. Interestingly many of the same factors which existed within the African-American community in the late 80’s and 90’s such as bias and misconceptions loom large in the Muslim community today.

### **Objectives or Hypothesis**

1. By utilizing the National Minority Organ Transplant Training and Education Program’s [MOTTEP] model of grassroots education the American Muslim community will over time, experience a transformed perception of organ donation and transplantation.
2. Through robust educational community engagements, the numbers of American Muslims consenting to register and donate will increase significantly.

### **Materials and Methods**

Through a ten-minute dialogue driven by PowerPoint slides and short video content this presentation explored the significant impact Eversight has within the United States and abroad, specifically in Pakistan, where to date a total of four eye bank clinics were established serving hundreds of local citizens who would otherwise live a life without sight.

### **Result**

Presentation will assist in the development of a robust partnership between National MOTTEP and Muslim Life Planning Institute to further grassroots educational efforts nationally.

### **Conclusions**

As part of an ongoing effort to create model communities which enjoy healthcare equity MLPI’s educational efforts will provide much needed understanding and support for those currently seeking organ donations. When communities begin to understand their role in providing a larger context for care and support of less fortunate members who fall ill and who may be in need of financial security, greater civility and pathways to healing will flourish.

## Changes in Palestinian Health Care Pre- and Post-Oslo Agreement

*Rami Abu Khalil, Christine M. Jones, Omar B. Saeed, Meredith M. Grogan, and John A. van Aalst*

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### Background.

Prior to the Oslo Agreement (1993), the Israeli Government was responsible for healthcare in the West Bank and Gaza; after Oslo, Palestinians assumed responsibility for care. Given the complexity of healthcare, established proxies for availability (hospitals, beds, and insurance) and quality of care (infant mortality, IMR; maternal mortality, MMR) are often used to evaluate changes. This study sorts through discrepancies in reporting to determine the value of changes to Palestinian health care.

### Objectives.

This study focuses on health care changes in Palestine after the Oslo Agreement.

Methods. Data were obtained from the Ministries of Health (MOH) and Bureau of Statistics (BoS) in Palestine, Israel and Jordan. Because of significant discrepancies in reported values, data from the World Health Organization (WHO) is used for final determination. Israeli control designates the period from 1967 to 1993; Palestinian control designates 1993 to 2017. Government hospitals and beds are used for calculations.

### Results.

The Palestinian population doubled during Israeli control (See Table I) and doubled again from 1993 to 2016. Government hospitals decreased during Israeli rule from 16 in 1967 to 14 in 1993; they increased during Palestinian control to 27. Hospital beds increased negligibly from 1973 to 1993, then nearly doubled by 2016. Beds/1,000 people decreased steadily from 1967 (1.7) to 0.7 in 1993; since then, the number has not changed. In 1973, the Israelis initiated an insurance system that covered 3% of the population, increasing to 40% by 1980. In 1993, new Palestinian insurance covered 40% of people; by 2016, 69% were covered. IMR in 1967 was 152/1000 live births in the West Bank and 162/1000 in Gaza; by 1993, the numbers dropped to 41 and 37. By 2007, IMR was 12 in West Bank and 34 in Gaza, then decreased further to 10 by 2016. MMR has decreased steadily during both time periods.

### Conclusions.

There have been significant changes in Palestinian healthcare since Oslo. With a doubling of the population, hospital numbers have doubled. Both IMR and MMR have decreased; however, bed numbers have not kept pace with the growing population. Insurance is still not available to a third of the population. Though Palestine compares favorably with neighboring countries such as Jordan, it lags behind healthcare improvements in Israel.



## **Experiences of Arab American Caregivers Raising Children with Autism Spectrum Disorders**

*Serene Habayeb, Sarah Dababnah, Aesha John and Brendan Rich*

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### **Introduction**

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder characterized by impairments in social interaction, communication, and restricted and stereotyped patterns of behavior, interests, and activities and affects one in 68 children in the U.S.

Research has indicated increased levels of stress in caregivers raising children with an ASD, compared to caregivers of typically developing children and children with other developmental disabilities.

However, this research has not been conducted in many specific minority ethnic or cultural groups, such as the Arab American community. The Arab American community is one of the fastest growing yet least studied ethnic communities in the U.S. No research has been conducted specifically exploring ASD in this population.

### **Objectives**

The current study explored acculturation, stigma, stress and coping factors in Arab American caregivers raising children with ASD.

### **Materials and Methods**

Twenty Arab American caregivers raising children with ASD completed an online questionnaire, using standardized measures to explore the main constructs: stress, coping, supports, stigma and acculturation.

Nine participants completed a follow-up phone interview and provided greater detail about their survey responses. Regression analyses were conducted to explore predictors of our main constructs and a grounded theory approach was used to analyze the interview data.

### **Results**

Parents reported that raising a child with ASD felt “somewhat” to “very” stressful overall. They rated the diagnosis, creating and/or finding opportunities for their child, and meeting needs of other children, as top sources of stress.

Significant predictors of stress included dissatisfaction with informal supports and spousal support.

The top coping styles endorsed were acceptance, active coping and planning items. Participants rated having “moderate” to “pretty large amounts” of support from their spouse. Doctors, school staff and ASD societies were rated as the top forms of formal support and female friends, spouse and children were rated as the top informal supports.

The quality of formal and informal supports was rated as satisfactory. Although perceived stigma fell in the low to moderate range, increased stigma significantly predicted increased stress.

Acculturation scales indicated a slight preference for assimilation over separation and a slight preference for integration over marginalization. In addition, during interviews, participants discussed the importance of family and factors related to gender roles.

## **Conclusions**

This is the first study to explore the experiences of Arab American caregivers raising children with ASD.

While many findings were consistent with the literature on stress and coping in caregivers of children with ASD, our study highlight unique circumstances faced by Arab American caregivers.

For example, acculturation data revealed that those who were more separated from American culture were more likely to rely on informal supports such as family and friends, indicating that they may not access formal services in the way that those from the majority culture do.

While stigma was overcome by many participants in this sample, they discussed how salient it still is in the community, and how it impacted them in the past.

Results of this study have the potential to increase clinicians’ awareness and cultural competence in order to support Arab American families of children with ASD."

## Mental Health Challenges among Adult Syrian U.S. Refugees

*Arash Javanbakht, Haifa Fakhouri, Luay Haddad, Hiba Suhaibaun, Mohammed Isam Alsaud, Zeina Alobaidi, and Cynthia Arfken*

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### Introduction

Ongoing Syrian Civil War has exposed millions of civilians to severe traumatic experiences and stress of migration, but little is known about the mental health challenges of adult refugees resettled in the U.S.

### Objectives

To determine the prevalence of PTSD, depression, and anxiety and possible associations among adult Syrian refugees resettling in Southeast Michigan.

### Methods

All resettled refugees are required to have an initial health assessment at selected contracted primary care clinics soon after arrival. Our bilingual/bicultural team 1) recruited participants (age 6 – 65) at 2 such clinics located in Southeastern Michigan, 2) obtained consent, and 3) collected demographic data, medical and mental history, and 4) screened for mental health symptom severity with the PTSD Checklist (PCL) ( $\alpha=.91$ ), and Hopkins Symptom Checklist (HSCL) for depression ( $\alpha=.91$ ) and anxiety ( $\alpha=.85$ ). We used DSM-IV criteria to screen positive for PTSD and previously published cutoffs for anxiety and depression. Data on 157 participants are presented.

### Results

Mean PCL score was 39.5 (SD=15.6) with 32.2% of adults (18 and older) screening positive for PTSD with no gender difference. More women than men screened positive for anxiety (52.7% vs 29.7%,  $p=.01$ ) and for depression (58.8% vs 38.3%,  $p=.03$ ). Comorbidity was common; 76.5% of those who screened positive for PTSD also screened positive for anxiety and depression. Self-reported general health status was negatively associated with depression ( $p=.007$ ), anxiety ( $p=.005$ ) and PTSD symptoms severity ( $p=.01$ ). Screening positive for depression was associated with low education achievement ( $p=.038$ ) in bivariate but not after controlling for gender. Marital status, having young children, medical conditions, and fluency in English language were not associated with any mental health symptom severity. There was no evidence of symptom severity clustering by family.

### Conclusions

Our findings suggest high prevalence of anxiety, depression, and PTSD among adult Syrian refugees with few associated demographic characteristics to guide targeted interventions. These findings, and the impact on self-rated health, in the early resettlement process suggest that interventions are needed to help Syrian refugee resettlement.

## Person-Centered Care Climate Assessment at King Abdul-Aziz Medical City: Health Care Providers Perspective

*Khaled Al-Surimi and Zahra Alhayek*

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### Introduction.

Currently, the health care system is focused more on patient-centered care as a way to improve the quality and patient outcomes for both patients and health care workers. Many care systems suggested person-centered care as a model of choice such in the residential home, oncology, and nursing. The work environment including psychosocial climate is proved to be a major factor in setting the care to the right direction. Few studies were done in the region to measure the extent of the psychosocial climate of the health care organization.

### Objectives.

To assess health care providers' perspective on Patient-centered care at king Abdul-Aziz Medical City context, to explore the correlation between staff characteristics and person-centered care climate perception and to report the reliability of Patient-centered care climate questionnaire at King Abdul-Aziz Medical City context.

### Methods.

The study is a cross-sectional design and self-administered and online questionnaire in English language was used. To explore difference based on staffs' characteristics, independent t-test and one-way ANOVA were used. The reliability of the Person-Centered Climate Questionnaire-Staff version was assessed by Cronbach's Alpha and item-total correlation.

### Results.

The total mean score of person-centered climate was 59.97 (SD 15.36) out of 84. The means values of safety and hospitality and everydayness subscales were 4.45 (SD 0.81), 4.44 (SD 0.84), 3.98 (SD 0.89), respectively. Perceived degree of person-centeredness found significantly associated with staffs' age, gender, nationality, marital status, and type of work and years of experience in the current institution. The Person-centered Climate Questionnaire was had high internal consistency with value of Cronbach's Alpha for the total scale was 0.90.

### Conclusions.

Staff perception of person-centeredness climate are significantly associated with staffs' age, gender, nationality, marital status, type of work and years of experience in a tertiary hospital such as King Abdulaziz Medical City.

### Key words.

person centered care; work climate; psychosocial climate; staff s' perception.

## Medical Students in Gaza Enabled to Train Lay People First Aid

*Anas Ismail, Mohammed Shatat, Maisara Alrayyes, Rajai Al Hafi, Hanne Heszlein-Lossius, Nashwa Skaik, Guido Veronese, and Mads Gilbert*

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### Introduction

People in Gaza suffer acute, time-critical medical emergencies like other populations. out-of-hospital cardiac arrest (OHCA), acute myocardial infarction (MI), stroke, septicemia and breathing difficulties.

Casualties toll from repeated Israeli attacks on Gaza add to the everyday accidents and trauma. Emergency patients need an efficient 'chain of survival. lay bystanders able to recognize emergencies, call for help and capable of providing basic life support (BLS) and cardio-pulmonary resuscitation (CPR) as needed.

Gaza's lay population has had little if any access to systematic BLS- and CPR-training. Hospital staff reports, and clinical studies show that many medical and trauma emergency patients reach hospitals without active BLS/CPR, often with blocked airways and ongoing bleeding.

### Objectives

To examine whether we could recruit local medical students as instructors to train 3000 lay people BLS and CPR in Gaza.

### Material and Methods

We selected eighty-two (82) 3rd, 5th and 6th year medical student volunteers from Al Azhar University in Gaza to train as BLS- and CPR-instructors.

Training included 12 hours BLS/CPR-skills and four hours of didactic skills to enable efficient 1-2 hours basic training. We designed a written questionnaire to explore the student's demographics, prior training experience, motivation and their expectations as to the effects of the training on patient's outcomes.

After completing the instructor course, the students started training lay people. We developed teaching material and methods based on the European Resuscitation Council guidelines and experience from similar training (The Arctic University of Norway).

### Results

#### The instructors.

Eighty-two medical students with mean age  $21.7 \pm 1.25$  completed training, 53.5 % females, 46.5 % males. Response rate to the questionnaire was 86.5% (71/82). Seven percent had

lost family members during Israeli attacks and more than 25% had lost house or property. Nine out of ten students had no previous experience in training lay people, while 65.5 % had never taken a first aid training course themselves.

Over one third (n=29, 40 %) were apprehensive of situations where they would need to give first aid. The majority (85.9 %) wanted to increase personal capacity and skills in BLS/CPR. Nearly half of the students wished to contribute to achieve training 3.000 lay people.

Over 69% described a sense of belonging and duty to the community as their most important inspiration (n=49). Fifty-six students (78.8 %) hoped the training would contribute to increased capacity and skills in the community's response to emergencies, especially during attacks.

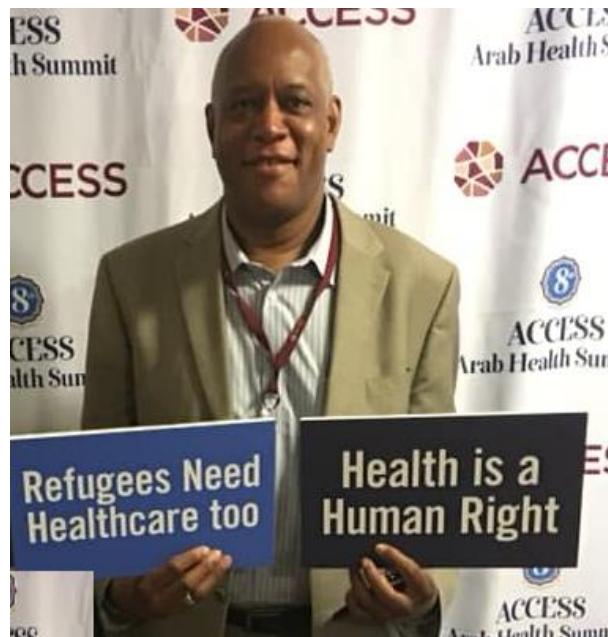
#### The training sessions.

Thirty-five training sessions with 920 lay participants are so far completed. Fifty-seven different student instructors have been active as instructors so far, yielding a ratio of 5.8 lay trainees per student instructor. The majority of lay trainees have been school students aged 13-20 years (70.8%, n= 617). The female/male-ratio of trainees was 1.4.1.

#### **Conclusions**

We have shown that local medical students are willing and capable to be trained as volunteer instructors for BLS/CPR-courses targeting lay people in communities under severe stress from siege and military attacks.

The effects of such training on local resilience and patient mortality need further studies.



# THE WASHINGTON DECLARATION



## ON HEALTH RIGHTS OF COMMUNITIES IN THE MIDDLE EAST AND NORTH AFRICA (MENA) REGION



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## **A. Preamble:**

At the conclusion of the ACCESS 8<sup>th</sup> Arab Health Summit, and based on deliberations of the attendees, Summit organizers identified a need to assert Health Rights of communities living in the MENA region as they continue to struggle with protracted conflict, displacement and strife.

This declaration is based on:

1. Comprehensive review of health conditions of communities in the MENA Region
2. The International Covenant on Economic, Social and Cultural Rights issued by the Office of the High Commissioner for Human Rights

## **B. Background**

1. **The Right to Health.** Article 12 of the International Covenant on Economic, Social and Cultural Rights by the Office of the High Commissioner for Human Rights (1), recognizes the “right of everyone to the enjoyment of the highest attainable standard of physical and mental health”. This does not just include immediate health issues but also deals with preventive, curative and palliative health care. This right does not forget the underlying social determinants of health, such as safe food, potable drinking water, basic sanitation, and adequate housing, as the social determinants of health are the bottom framework for any standard of physical and mental health.

The right to health also must prioritize the needs for groups of people who have specific health needs, for example, women, children, older persons, refugees and displaced persons, and those with disabilities. Every State must encourage an adequate health analysis to ensure those who need specific health needs are having these needs met.

2. **States’ Obligations to the Right to Health**
  - The obligation of States to ensure equitable distribution and access to health facilities, goods and services on a non-discriminatory basis, especially for vulnerable or marginalized groups;
  - The obligation to provide essential medicines;
  - The obligation to formulate a national health plan or policy in a transparent and participatory way, taking into consideration the special needs of vulnerable populations.
3. **The Right to Health During Armed Conflict.** The same State obligations outlined above are the same exact obligations States must meet during times of armed conflict. According to the Committee on Economic, Social and Cultural Rights, in general comment No. 14, para. 34, the committee provides the concrete legal obligations for which States must commit to, even in times of armed conflict (2). This means that when armed conflict arises States still are obligated to provide available, accessible, and acceptable quality health services, facilities, and medicines (3)— most especially to those groups most affected by armed conflict.
4. **Third State and Donor Assistance.** When States have financial or resource limitations to meet their obligations to guarantee healthcare to all persons, third States, donors, and inter-governmental organizations should provide the economic and resource assistance to assist countries to guarantee their right to health obligations. This is especially important for the MENA region as resource limitations are in fact a major hurdle to streamlined healthcare.



This is most often the case with countries in MENA who are recovering or currently engaged in inter and/or intra-State armed conflict.

### **C. The Status of Healthcare in MENA**

The MENA region has been affected by armed conflict for decades, ensuring inadequacy in MENA States' obligations to secure the right to health, especially for marginalized groups and individuals, including women, children, the elderly, refugees and other protected persons. Armed conflict's effect on the right to health is not only immediate but can often have dramatic and long-lasting repercussions. This must be underlined from the outset.

Armed conflict, internal strife, and State austerity have suppressed any real change in healthcare for some decades. For example, conflict has resulted in the breakout of outdated diseases which otherwise were non-existent. For instance, wild polio virus in Syria and cholera in Yemen— outbreaks that only can occur when the right to health is completely sidelined by the State itself of those involved in armed conflict. Another example, according to Amnesty International's research, in the occupied Palestinian territories, three Israeli military offensives on Gaza since 2008 have taken a heavy toll on essential infrastructure and further debilitated an already incapable health system and economy (4).

It is imperative to highlight the most forgotten victim of the right to health in the MENA region: refugees or displaced persons (5). These marginalized groups have fallen into bureaucratic limbo where State authorities' do not provide them with adequate standards of health care—worst of all, this is done casually and under the assumption that it is not their duty or obligation to ensure their right to health, among other rights.

Refugees and migrants have the same right to health as everyone. International law dictates that the right to health extends to everyone, including non-nationals, such as refugees, asylum-seekers, stateless persons, migrant workers, and victims of international trafficking, regardless of legal status and documentation. Governments must ensure that all persons have access to the minimum, essential levels of the right to health and that there is no discrimination in access to healthcare. This is not the case in most, if not all, refugee hosting countries.

The right to health does not forget mental health. For a region which faces the burdens and hurdles which currently stand, the MENA region need not forget this as well. The consequences of armed conflict affect generations. The state of mental health, especially for young people in MENA is formidable. Young people, who hold a majority in the region do not have the requisite tools to foster an appropriate upper-infrastructure to envision positive change. Conflict, displacement, socio-economic turmoil, and no social capital in MENA creates a system where being young coincides with being at-risk for trauma and mental-health diseases or disorders.

This is not something that will happen in the future, but instead something that has been happening for decades. Generations of hopelessness and trauma have created a dangerous and unhealthy system, already on the verge of collapse in many parts of our region.

Where the right to health is not being met in MENA, more often than not, the overarching theme is that armed conflict supersedes this right. Worse yet, this right is being sidelined to those who need it the most such as children, women, the elderly, refugees and other protected persons.

## D. Declaration

To reach full recognition of the inherent right to health in the Middle East & North Africa (MENA), as stipulated by Article 12 of the International Covenant on Economic, Social and Cultural Rights, which recognizes the “right of everyone to the enjoyment of the highest attainable standard of physical and mental health” (4), whereas disregard and inadequacy has resulted in degradation of this right, the below pledge and common understanding is of dire need for the full realization to the right to health.

We call for immediate adoption of the articles outlined in this declaration by all concerned parties including:

- Governments and governmental agencies
- local and international organizations
- community groups
- medical practitioners
- political and militant parties
- and all others engaged in activities in the MENA region that may affect the field of healthcare directly or indirectly

This call for adoption need not be signature without merit, but a goal, to ensure that all efforts in the region are designed to meet the full realization of the right to health. In a time of great need, the people in the MENA region, especially those most affected by armed conflict and marginalization need an adoption so that they could live a dignified life.

Where States have financial or resource limitations to meet their obligations to guarantee healthcare to all persons, it is imperative that third States, donors, and inter-governmental organizations should provide the economic and resource relief to assist countries to guarantee their right to health obligations as articulated herewith.

### 1. Obligations to the Right to Health

- States and state agencies must ensure equitable distribution and access to health facilities, goods and services on a non-discriminatory basis, especially for vulnerable or marginalized groups;
- States and state agencies must provide essential healthcare services, including medicines;
- States and state agencies must formulate a national health plan or policy in a transparent and participatory way, taking into consideration the special needs of vulnerable populations.

### 2. Violations of the Right to Health

- There should never be any discrimination, whether direct or indirect, in access to health care and the underlying, social determinants of health. This is an immediate obligation, irrespective of the resources available to a state.
- Health care facilities, goods and services, including medicines, must always be available.
- Health facilities, goods and services must be accessible to everyone.

- Health facilities, goods and services must be affordable for everybody regardless of their income level.
- All health facilities, goods and services must be respectful of medical ethics and acceptable, that is, respectful of the culture of individuals, minorities, peoples and communities, and sensitive to gender and life-cycle requirements.
- Health facilities, goods and services must also be of good quality.
- States have an obligation to prioritize the satisfaction of the minimum, essential levels of the right to health. The relevant general comments (listed below) provide an indicative list of what these are.
- States have an immediate obligation to take steps to progressively realise the right to health, to the maximum of their available resources.
- Health laws and policies should be designed and implemented in a transparent manner, and with the meaningful participation of people affected by it.
- All health systems must include a robust framework for accountability, which should include access to effective judicial or other appropriate remedies for violations of the right to health.

## E. Citations:

1. International Covenant on Economic, Social and Cultural Rights (ICESCR), 1966, UN Doc. A/6316
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[http://www.unesco.org/education/information/nfsunesco/pdf/SOCIAL\\_E.PDF](http://www.unesco.org/education/information/nfsunesco/pdf/SOCIAL_E.PDF)
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