Enaya Othman

Gendered Disabilities Project Report

This report presents our yearly progress in the third year of the Gendered Disabilities Project that aims to collect data and create a digital database on the experiences of Muslim women as people with disability or caretakers, including their access to healthcare services. With the outbreak of the COVID-19 pandemic, which has influenced the structure of our research and has strong implications for our research topic, we have integrated the issue into our themes. Meanwhile, we adapted our methodology to the measures and thus conducted the interviews virtually. The remainder of this report first focuses on the integration of COVID-19 research into the project, followed by the statistics of this year, and then concludes with the Disabilities Conference.

Integration of the COVID-19 Research

We have extended our data collection and analysis to include the issues surrounding the COVID-19 pandemic as experienced, interpreted, and viewed by Muslim community members, not only due to its direct link to our core issue of the intersections among health, minority, and gender dynamics, but also due to its immense impact on the social relations among the community. The former link has sought to uncover how the pandemic has been experienced by Muslim community in general in addition to the relations among gender, mental health, and the COVID-19 pandemic. In the same line of our "gendered disability" hypotheses, we have investigated access to health care, coping with mental health issues, community views and stigma, and the like. We have expanded our interviews and questionnaires to cover immediate concerns related to the pandemic. In expanding our research project, we have aimed to investigate the social and familial relations changing during the pandemic and how these influence Muslim individuals regarding their mental well-being, religious perspectives, and gender relations. It delves into the individual views of dealing with disasters such as pandemics from the perspectives of Islamic history and teachings, and how these are shaping the ways they tackle with the contemporary pandemic.

According to data elicited from 22 men and women and examined for this report, Muslim individuals resort to religiosity and spirituality as coping strategies and create meanings with references to scriptural sources that describe catastrophes as tests from God. Religious references are extensively utilized both by community members in individually dealing with the pandemic and by community religious leaders such as Imams for the purpose of guiding, educating, and creating a collective response to the pandemic conditions. Islamic explanations and guidance were used to deal with the psychological outcomes of the pandemic circumstances. Theological opinions on acceptance, fate, precaution, and control of God have been cited as the main pillars of coping with the pandemic. On the social level, religious sources are used to shape the community behavior during the pandemic. For instance, Imams utilized examples from Islamic history and doctrine to create a discourse on individual responsibility in spreading the disease and to align with the measures suggested by the institutions such as WHO. Thus, both individually and as a community, a wide range of issues from rationalization to treatment, social distance to vaccination, and solidarity to economic results are addressed within a religious framework.

Still, changes in religious rituals such as the restricted number and space for Jamaat prayers caused resentment and mild reactions in the communities. Especially, virtual participation in religious events emerged as a significant practice but also a controversial matter. While the majority of participants viewed the transfer to virtual setting positively; others regarded it inappropriate or awkward for certain religious practices such as prayer and funeral. As a response, religious leaders drew on the Islamic principle "necessity may authorize forbidden acts" or "emergencies permit the unlawful." Accordingly, people followed and accepted changes in many areas at the intersection of religious practice and daily life such as accepting condolences, funerals, religious festivities, and the like.

Another major theme is the deficiencies in having access to mental health care during the pandemic both for people with mental disability and for those who struggle with stress due to the pandemic. In this sense, vulnerability among people with disabilities became higher. COVID-19 intensified the difficulties with regard to discrimination, integration, and immigrant experience for people tackling mental health issues. Also, the content of the consultations when available, as one of the health professional respondent noted, may fail in addressing the needs of the Muslim community members. Therefore, especially young members of the community suffering from mental illness face an overwhelming sense of helplessness resulting in suicide attempts.

Statistics

In addition to the 32 interviews conducted last year, we have completed 35 interviews on COVID-19, disability, and caregiver perspectives from February of 2021 till September 2021. Community members constituted the majority of participants while the sample also included Imams and caregivers.

In conducting our study on the impacts of COVID-19, we distributed an anonymous online survey to community members throughout the United States to evaluate the emotional and psychological impact of the pandemic. The following figures visualize the demographic characteristics of the survey's participants (N=83).

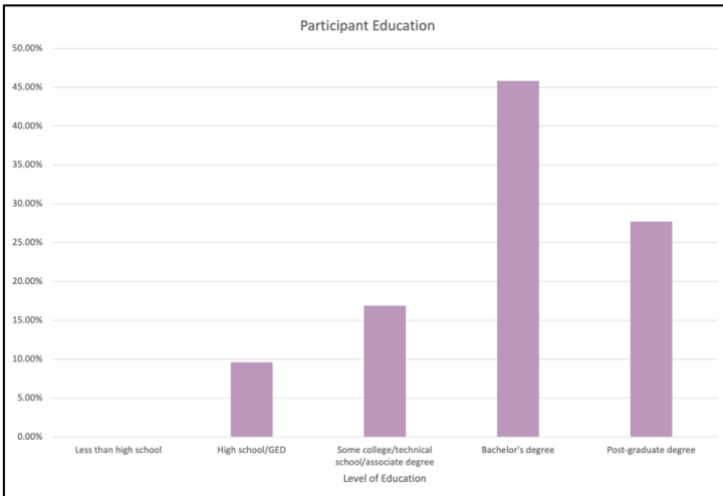

Figure 1: Participant Education (N=83)

74% of our survey's respondents have a bachelor's degree or higher, and every participant has received at least a high school diploma or GED.

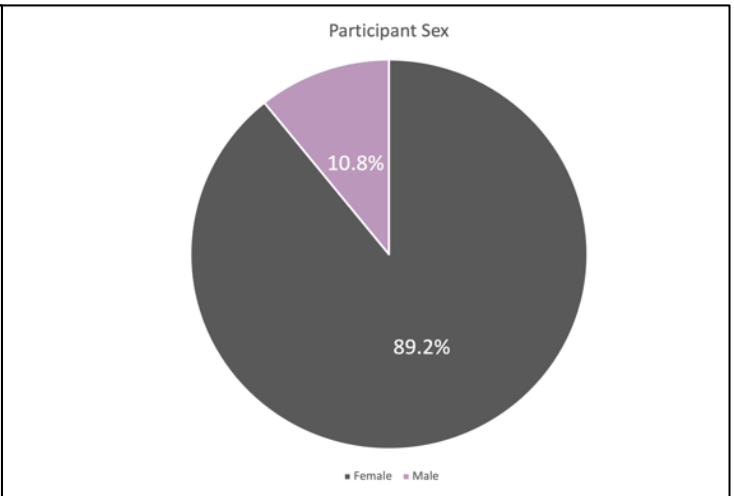

Figure 2: Participant Sex/Gender (N=83)

The majority of the survey's participants were female (89.2%), while only 9 of our 83 respondents were male.

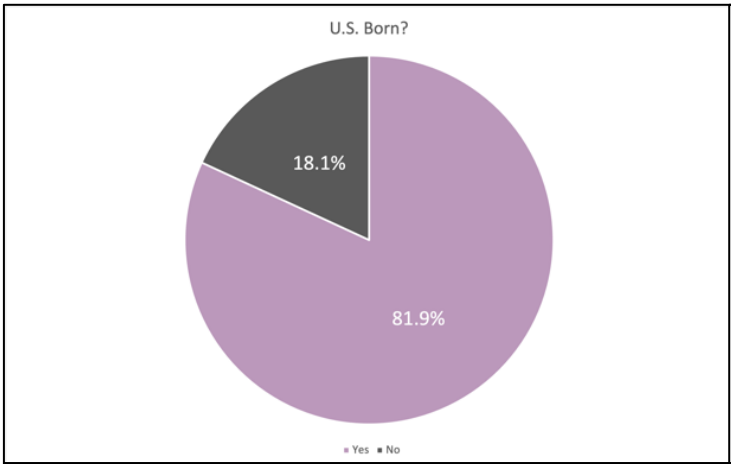

Figure 3: Participant Country of Origin (N=83)

Most of our respondents were born and raised in the United States (81.9%). Survey participants born outside of the U.S. have lived in the country for 20 years on average. Of these respondents, 40% are originally from Palestine. Other represented countries include Pakistan, Egypt, Kuwait, Jordan, Afghanistan, and Chile.

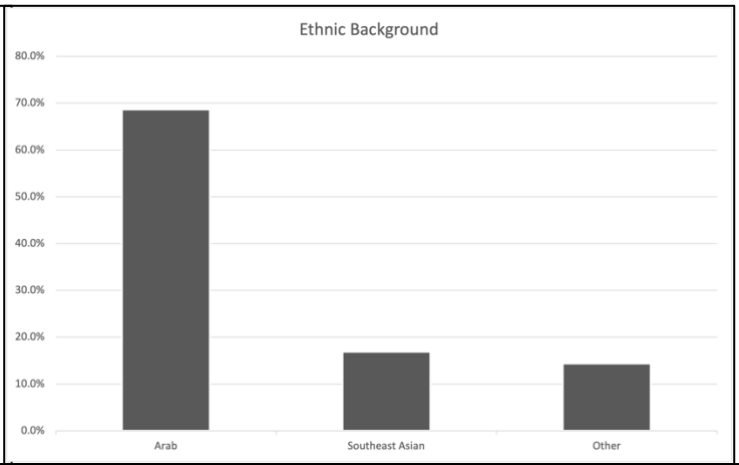

Figure 4: Participant Ethnic Background (N=83)

Many of the participants were of Arab ethnic background (68.7%), with Southeast Asian as the second-most represented group (16.9%). 14.4% of participants were of other backgrounds including Caucasian, African American, African, Asian/Pacific Islander, and Pakistani.

Demographic Data:

Additionally, more than half of surveyed individuals were from the Midwest (54%), with the Southeast being the second-most represented geographic region (24%). 75% of respondents were married or in a committed relationship. 79 respondents had children under the age of 18 in their household, and among these respondents there were an average of approximately 4 people in the home. 95% of respondents have health insurance and 82% had never had a COVID-19 diagnosis by the time of survey submission. 57% of respondents knew an individual that died of COVID-19.

The second part of our survey focused on two scales used to analyze the psychological impacts of the pandemic: the Pandemic Emotional Impact Scale (PEIS) and Muslim Perceptions and Attitudes towards Mental Health Scale (M-PAMH). The PEIS poses a series of questions concerning how much the respondent's wellbeing and functioning have been altered since before the pandemic began.

Pandemic Emotional Impact Scale (PEIS):

On a scale of 0-64, with 64 indicating the greatest level of emotional impact, respondents had a sample mean score of 27.95 with a standard deviation of 12.59. Participants assigned a score of 0-4 to 16 questions based on how much they agree with the given statement on the pandemic's emotional impact. On average, the highest rated statement was feeling "more worried about the health and safety of family members or friends" with a score

of 2.70. The lowest rated statement was feeling "more worried about getting necessities like groceries or medications" with a mean score of 0.41.

Muslim Perceptions and Attitudes Towards Mental Health (M-PAMH):

The questions of the M-PAMH Scale are separated into four subcategories: rejection, beliefs, stigma, and familiarity. Rejection concerns general reluctance towards seeking professional mental health care, with higher scores indicating a desire to deal with one's mental health concerns on their own. "The idea of talking about my problems with a mental health professional is a poor way to solve mental health difficulties" was the least agreed with statement with a mean score of 1.57, while "I admire an individual who is willing to cope with his/her conflicts without resorting to mental health care" was the most agreed with statement at a score of 2.22 on average. Beliefs focused on spiritual and religious components of mental health, with higher scores suggesting a greater degree of agreement. Belief scores ranged from "mental health or psychological problems can be caused by Jinn (spirits)" at 2.12, to "even if I sought professional mental health care, I would also still seek help from a religious figure (e.g., Shaykh) for a psychological difficulty I was facing" at 2.83. The "stigma" section centered on embarrassment or shame surrounding seeking help for mental health issues. The most agreed with statement, "I would feel comfortable contacting a mental health care professional or using psychological services in the future," had a score of 3.07, while the least agreed with statement, "I would feel embarrassed to seek mental health or psychological services because of others' negative opinions," had a score of 1.90. The final section, "familiarity," deals with how confident respondents are in their knowledge of mental health issues and resources for treatment. Scores ranged from 1.25 with "familiarity with the type of conditions that can be treated by professional mental health or psychological treatment (e.g., mental instability, depression, etc.)," to 0.75 regarding "familiarity with the Muslim professionals who practice mental health or psychological counseling within your local community.

Conference: Disability at the Intersection of History, Culture, Religion, Gender, and Health

Research on disability including our Gendered Disabilities Project confirms that disability is not only a medical or biological phenomenon, but it has been continuously constructed by social, religious, and cultural perspectives as well as legal and political regulations. In order to advance our knowledge of how perspectives on disability historically and presently have evolved, we are organizing an international hybrid conference. It aims to encourage open discussion and better understanding as well as to breakdown stigma associated with disabilities. The conference will host Distinguished Professor Lennard Davis from Disability and Human Development, The University of Illinois Chicago. The conference aims to generate inclusive dialogues and interdisciplinary interactions between academia, community organizers, social and legal activists, health care service/providers, and religious leaders. It will serve as a platform to foster collaboration between various groups engaged in understanding and improving disability conditions.

On behalf of my Marquette colleagues who collaborated on this project, as well as AMWRRI and other community partners, we extend our deepest gratitude for the funding that we got from Marquette University Explorer Challenge Grant. The extensive work we did on this project and the information and resources that are now available to various communities in Milwaukee and beyond could not have been accomplished without their support.

Acknowledgements:

Our team members – Jeana Abromeit, Abir Bekhet, Irfan Omar, Lee Za Ong, and Enaya Othman – wish to thank the following individuals and organizations for their faithful support:

Participants – People who were interviewed, completed our survey, or participated in community discussions.

Marquette University research assistant and student researchers – Stefan Reutter, Shaila Wadhwani, Nikki Deep, Nico Salazar, Allie Perry, Kathryn Nadkarni, Jada Vignos, Tessa Miskimen, Lelah Byron, and Celeste Lagman.

Special thanks to the generosity of Marquette University, which funded the project for 2018-2021 through the Explorer Challenge Grant.