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### Refugees living with dementia: assessing the barriers to healthcare access in crisis-affected populations in Lebanon and Switzerland, and the role humanitarian actors have on addressing them

Pedro Gomez  
*SIT Study Abroad*

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Running head: DEMENTIA AND REFUGEE HEALTHCARE ACCESS

Refugees living with dementia: assessing the barriers to healthcare access in crisis-affected populations in Lebanon and Switzerland, and the role humanitarian actors have on addressing them

By *Pedro Gomez*

Spring 2023

Global Health and Development Policy

Alexandre Lambert

Washington University in St. Louis

Philosophy-Neuroscience-Psychology

## **Abstract**

As life expectancies increase in many places around the world, the prevalence of aging populations has increased. Consequently, increased numbers of people globally, especially in developing countries, have been diagnosed with conditions associated with old age. Dementia, a group of conditions associated with impaired cognitive functions, is among these. Notwithstanding, many developing countries have done poorly with regards to diagnosing and treating dementia, with some cultures not even having a word to describe the condition. (*ADI* 2022). The lack of a diagnosis and knowledge about dementia for some refugee communities has led to healthcare challenges in their host countries (*Corfield et al.* 2019). From diagnosing dementia, to providing adequate treatment and adapting humanitarian aid response to allow for equal access to healthcare for these populations, humanitarian actors dealing with refugees have a large responsibility to ensure the well-being of this group. My research looks at the way these groups are currently interacting with healthcare systems in order to explore gaps in healthcare access and the potential ways humanitarian actors are dealing with these gaps. I am focusing my research on Lebanon, the country that hosts the highest number of refugees per capita worldwide according to the United Nations High Commissioner for Refugees (UNHCR), and Switzerland, a country that hosts a significant number of refugees from the Middle East and North Africa (MENA) region.

### **Acknowledgements**

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Lastly, I would also like to extend my sincere thanks to my SIT classmates for giving me advice, suggestions, and inspiration, and my family and friends who helped support me and motivate me throughout the time I was conducting my research.

**Table of Contents**

Introduction .....	4
Research Methodology.....	5
Literature Review.....	8
Analysis.....	12
Dementia in the MENA Region.....	12
Barriers to Healthcare Access for People with Dementia.....	14
Lebanon as a Country of Refuge.....	17
Elderly Refugees and Healthcare in Lebanon.....	25
Switzerland and Geneva as Places of Refuge.....	29
Elderly Refugees and Dementia in Switzerland .....	34
Conclusion .....	35
Bibliography .....	37

## **Introduction**

Around the world, as healthcare has advanced, outcomes have improved, and life expectancies are increasing. These increases are especially prevalent in developing countries.

With a growing aging population has come an increased number of people developing dementia (GHE: Life Expectancy and Healthy Life Expectancy, 2020). Dementia is a group of conditions associated with impaired cognitive functions that is most common in older populations.

Alzheimer's disease is the most common type of dementia, accounting for sixty to seventy percent of all dementias followed by vascular dementia which accounts for a remaining ten to twenty percent. In 2020 there were over 55 million people around the world living with dementia with projections saying the number will double every 20 years. The vast majority of this increase will be in developing countries which currently account for around 60% of the world's dementia cases, and is projected to account for 71% by 2050 (*ADI 2022*).

Despite the large proportion of individuals living with dementia, research has shown that a significant percentage of people who have the condition have never received a formal diagnosis. Lack of diagnosis is a problem in all countries, but especially low and middle income countries. One study showed that worldwide, around 75% of people with dementia have never received a diagnosis and thus are not receiving treatment (*ADI 2022*). Early diagnosis and early intervention is essential to deal with dementia, so these statistical differences between low and high income countries have resulted in a sort of treatment gap. This treatment gap is also driven by cultural differences, with some cultures lacking a word for dementia, and many viewing dementia symptoms as a normal part of aging (Hillman & Latimer, 2017).

The rapid number of growing dementia cases in low income countries and the resultant treatment gap has led to a number of issues for those people with dementia receiving humanitarian aid in their home countries, in addition to refugees receiving healthcare in their host countries. This research paper looks at the prevalence of dementia among refugees primarily originating in the MENA region, paying special attention to barriers to humanitarian aid delivery to people with dementia. Additionally, the paper looks at an overview of healthcare for refugees in Switzerland and Lebanon, and the role of humanitarian actors in addressing healthcare barriers.

### **Research Methodology**

In order to learn about the barriers in healthcare access for migrant and refugee populations with dementia, I gathered qualitative data via interviews with individuals serving in a wide variety of professional capacities related to the issue. Badia El Koutit, my first interviewee, is the founder and current executive director of l'Association pour la Promotion des Droits Humains (APDH) which can be translated to "The Association for the Promotion of Human Rights". APDH is a non-governmental organization (NGO) based in Geneva, Switzerland that seeks to provide support in many facets to refugees and migrants regardless of whether they are newly arrived, or have been in Switzerland for long periods of time. Georges Karam is the current President of the Alzheimer's Association of Lebanon (AAL), a network member of HelpAge, a non-governmental organization that advocates for the rights of older people, and Chairman of the Department of Psychiatry and Clinical Psychology at the St. George Hospital University Medical Center in Beirut, Lebanon. My final interviewee, Sarah Al Omari, is

a Social Epidemiologist and Monitoring, Evaluation, Accountability and Learning (MEAL) Specialist who is currently coordinating the research activities of a project on elderly Syrian refugees in Lebanon. The interview with Badia El Koutit took place in person at the APDH headquarters in Geneva, Switzerland, while the interviews with Georges Karam and Sarah Al Omari were both held in a video call format. These interviews allowed me to gather data related to first-hand experiences working with migrants and refugees in a wide variety of locations and circumstances. The expertise of Badia El Koutit with regards to refugee integration in Switzerland allowed me to learn more about refugee healthcare in Switzerland while the expertise of Georges Karam and Sarah Al Omari working with NGOs and medical institutions in Lebanon allowed me to understand more about the status quo of dementia care in the MENA region, and what humanitarian actors are doing to address these issues with regards to refugees.

Qualitative data conducted from interviews was utilized along with quantitative and qualitative data from previous literature in order to build a better understanding about what has been done with regards to dementia healthcare for migrants and refugees, and what remains to be done. Data was sourced from scientific and gray literature collected using a wide variety of academic databases including Google Scholar and PubMed as well as government and NGO reports. Given these data source categories, the analysis section is divided into an overview of the current literature discussing dementia in the MENA region, barriers to health care access for people with dementia, and refugee healthcare in Switzerland. This introductory section is followed by qualitative interview data from Lebanon as well as Switzerland. Finally, the last section summarizes findings about the inequities in the status quo of healthcare access, and finalizes with recommendations.



### **Ethical Considerations**

A Human Subjects Review (HSR) was submitted and approved by a local review body prior to the start of the research process. Vulnerable populations were excluded from the interview pool to avoid ethical concerns. Informed consent was received by all three interview participants in addition to the option to exclude names and identifying information. Participants were asked for consent to having the interview recorded. Following use for the paper, all audio and transcripts obtained from the interviews were deleted from personal devices.

### **Limitations and Challenges**

Throughout my research period, I was faced with a number of limitations and challenges that influenced my research process and outcome. First and foremost, the topic of refugees with dementia is largely understudied as elderly refugees are not as common. Because this population is a minority, this issue is commonly overlooked. Only recently have academic journals and NGOs begun to release reports and adopt guidelines with regards to diagnosing and caring for this vulnerable population. This served as a challenge given the limited pool of prior literature, but also as an opportunity to raise awareness and highlight what still needs to be done. Another limitation faced during the research process was the relatively small number of interviewees. Having one interviewee based in Switzerland and two interviewees based in Lebanon makes it difficult to generalize the situations in those countries to all of Europe or all of the MENA region despite their international expertise. A final limitation was not being able to directly interview refugees and their families as a result of ethical concerns. I was able to learn about numerous

cases related to refugee healthcare experiences from my interviewees which were very useful to illustrate the situation, but not being able to hear directly from those impacted limits the number of perspectives.

### **Literature Review**

Given the relatively small number of elderly refugees as a demographic, in addition to the low levels of dementia diagnoses in the MENA region in general, the topic of healthcare access for migrants and refugees living with dementia is under-researched. Consequently, I worked with a select pool of sources in addition to my interviews. This allowed me to learn more about what NGOs in Lebanon and Switzerland are doing to care for refugees with dementia, and what could be implemented in the future.

The initial sources used were predominantly quantitative demographic data sources about dementia and aging statistics with a focus on the MENA region. These sources allowed me to begin my research with a comprehensive overview of how dementia is currently impacting both people living in and seeking refuge from MENA countries. Moreover, many sources provided projections that allowed me to place my research on this issue in perspective, and show the importance and gravity of the refugee dementia issue in the long term. The sources used included (*Dementia* 2022), (Halsall & Cook, 2017), (Schaer et al., 2022), (Kisa, 2022), (Dummer, Halsall and Cook, 2011, p. 311), (Yount and Sibai, 2009, p. 279).

(*Dementia* 2022) is an article published by the World Health Organization Regional Office for the Eastern Mediterranean which gives estimates on dementia prevalence and trends in low and middle income countries, with a focus on the MENA region. This source provided me

with reliable statistics that allowed me to gather quantitative data about the region of origin of the refugees I sought to focus on. This source also linked the mhGAP Humanitarian Intervention Guide, a guide to diagnoses and care protocols for mental, neurological, and substance use disorders for health-care providers in humanitarian settings where access to specialists is limited. This guide served as another useful source in order to learn about the recommended protocols for dementia diagnosis and care for crisis-affected populations. The mhGAP guide was also created by the World Health Organization, and is thus a highly trustworthy source (mhGAP-HIG, 2015).

(Halsall & Cook, 2017) is another article published by Population Horizons Publications, a journal hosted by the The Oxford Institute of Population Aging of the University of Oxford. This article helped provide me with quantitative data related to projected life expectancy increases and the relationship these projected increases have with dementia projections. The paper focused on the MENA region, which is of interest to my paper, but did not touch on refugee or crisis affected populations.

(Schaer et al., 2022) is an article published in Deutsche Welle (DW) discussing dementia projections in the Middle East, and the current infrastructure available in the region to diagnose and care for people with dementia. DW is an international media company regulated by the Deutsche Welle act, meaning its content is supposed to be independent of government influence, and it is a member of the European Union Broadcasting Union. Nonetheless, the fact that it is a media company that is state-owned, and funded by the German Federal tax budget might cause reliability concerns. All of the statistics taken from the article however, come from the paper (Kisa, 2022) which was published in The Lancet Public Health, a renowned academic journal, and referenced in my paper.

(Dummer, Halsall and Cook, 2011, p. 311) is yet another academic article published in the International Journal of Society Systems Science, a journal which focuses on the barriers between social and natural sciences. This article provided me with more information about demographic trends with regards to life expectancies, but this time also discussing environmental disasters, and the policies required to assist elderly population in these crisis situations. Although dementia is not necessarily the focus, this article was a useful overview of some of the policy recommendations for vulnerable populations in general during crises. Moreover, elderly people are the demographic overwhelmingly impacted by dementia, so the focus on this demographic was a useful way to make connections.

The final source looking at demographic information was (Yount and Sibai, 2009, p. 279) a section of the International Handbook of Population Aging, the first handbook published with a comprehensive overview of population aging issues. This handbook was published by Springer Science+Business Media, a renowned publishing company that manages numerous peer-reviewed science journals. The section of this handbook used for my research, titled *Demography of Aging in Arab Countries* provided me with more quantitative data regarding specific life expectancies and projections for different countries in the Arab world. Once again, this helped me make the link with dementia, given dementia has an exponential relationship with age (Corrada et al., 2010).

After collecting demographic data from this first group of sources, the next group of sources focused more specifically on refugees and crisis affected populations with dementia both in the MENA region and in Switzerland. This group of sources included (*Disability Universal Indicator* 2015), (Schmidt & Julia, 2010) , and (Corfield et al., 2019).

The first source, (*Disability Universal Indicator 2015*) is a resource built on the Washington Group Questionnaire which was established by the United Nations in order to provide a universal uniform disability measurement. This source provided me with an overview of the different types of existent measurement tools used to diagnose disabilities and dementia in crisis settings.

The second source, (Schmidt & Julia, 2010) was a very pertinent article published in the Swiss Medical Weekly journal in 2010. Swiss Medical Weekly is a well-known peer-reviewed open access medical journal. This paper provided me with information about the mental health and healthcare utilization of adult asylum seekers in Switzerland.

The final source, (Corfield et al., 2019) was by far the most comprehensive source I found related to my topic, and was very instrumental in conducting my research and even finding interviewees. This source, titled “Forgotten in a crisis: Addressing dementia in humanitarian response” is a report published by Alzheimer's Disease International and the Global Alzheimers and Dementia Access Alliance. Alzheimer's Disease International is a not-for-profit international federation of Alzheimer and Dementia organizations in official relations with the World Health Organization. Similarly, the Global Alzheimer's and Dementia Access Alliance is a network of dementia civil society organizations from around the world. Both of these are very reputable and reliable organizations of NGOs and the report is the first comprehensive analysis of dementia in humanitarian settings. The fact that the first and only analysis of this type was published in 2019 shows how understudied the issue of crisis affected populations and refugees with dementia is. The report discusses key issues with regards to dementia and emergencies, international standards and frameworks, dementia focused frameworks and tools, recommendations and areas for action, and finally numerous case studies.

While the report is very successful in providing information about the status quo of dementia care in humanitarian settings, there is not as much of a focus on refugees, and no mention of refugees in Europe, or refugees in Lebanon with dementia, despite the large number of elderly Syrian refugees living in Lebanon. My paper seeks to contribute to filling some of these gaps by providing more information about healthcare access for migrants and refugees with dementia in Lebanon and in Switzerland.

## **Analysis**

### **Dementia in the MENA Region**

According to the World Health Organization, in the Middle East and North Africa (MENA) region it is estimated that the number of people living with dementia will change from 1.15 million in 2010 to 6.19 million by 2030 (*Dementia* 2022). Another report, published in the British medical journal *The Lancet*, estimated that while Western Europe will see cases of dementia rise 74% by 2050, there is an expected increase of over 400% for North Africa and the Middle East (Kisa, 2022). There are numerous reasons behind the size of this projected increase in the MENA region, primarily the projections for life expectancy growth. An aging society is generally recognized as one in which at least 7% of the population is 60 years of age or older. It was not until the current century that many countries in the MENA region advanced significantly in terms of social change, healthcare improvements, and introduction of pensions which allowed it to reach that 7% benchmark. Furthermore, projections estimate that if current trends continue,

by 2050, the “Western Asia” part of MENA will reach 18% and the “Northern Africa” part will reach 19%. (Dummer, Halsall and Cook, 2011, p. 311). Another study that looked at the 23 Arab countries projected that three will reach life expectancies of 60 to 69 years, thirteen will reach 70 to 79 years, and seven will reach a life expectancy of 80 years or more (Yount and Sibai, 2009, p. 279). Given the fact that dementia is primarily a condition of age, it is no surprise that growing life expectancies are a large factor behind projected dementia increases (Halsall & Cook, 2017).

Other factors that account for projected rapid increases in dementia in MENA include factors like air pollution, mid-life obesity, low levels of physical activity, smoking, diabetes, and heart disease in addition to low education and illiteracy. Illiteracy is a major risk factor because reading is a way to put certain parts of the brain to work and studies have shown that not being able to read makes one 3 times more likely to eventually develop signs of dementia in their lifetime. Literacy in the Middle East in 1973 was at only 47%, meaning that much of the aging population in the area are likely to have been, or continue to be illiterate, putting them at a greater risk. The rate recorded in 2019 was 79%, which is considerably higher, but still lagging behind the global average literacy rate of 86% for the same year (Schaer et al., 2022).

The rapid increase in dementia cases in this region is also posing a large threat due to the lack of reported statistics, and dementia care facilities. A lack of education on dementia has made it likely for many families to disregard dementia symptoms as a part of normal aging. This underreporting is also due to cultural factors such as the importance of elderly family members living in the same household as their children (Hillman & Latimer, 2017). This cultural practice makes it less likely for diagnoses to happen compared to societies in which a greater proportion of elderly people are in assisted living communities and geriatric care facilities.

The lack of dementia diagnoses in the MENA region combined with projections for future increases in affliction has set a challenging scene for local healthcare systems, but also for humanitarian aid organizations serving the region, and host countries receiving refugees.

### **Barriers to Healthcare Access for People with Dementia**

There are numerous barriers to ensuring proper and equitable access to care for people with dementia. Many of these challenges are made even more difficult for humanitarian organizations responding to humanitarian crises given the time pressures and lack of medical records associated with patients. The number one barrier in all of these cases is the identification of people living with dementia (ADI - World Alzheimer Report Reveals, 2023). In many regions impacted by disaster, health information systems (if existent in the first place) may be impacted, or contain very limited information. More often, communities rely on local knowledge of community health. This reliance can cause issues especially during humanitarian crises because there may be death and displacement within the community, thus making this “local knowledge database” vulnerable. Moreover, poor health literacy in many communities may result in a lack of understanding about what conditions individuals are really facing. In many rural communities, medical conditions may be thought of as a form of witchcraft or possession. This reliance on local community knowledge in combination with poor health literacy creates a situation in which many patients are undiagnosed and thus have not received care even prior to humanitarian crises.

There also exist a number of challenges to diagnosing individuals with dementia during humanitarian response. One recurrent issue is humanitarian health workers mistakenly confusing dementia symptoms for those of post traumatic stress following a humanitarian emergency.



Likewise, health workers may also confuse these symptoms as a part of regular aging. In order to aid in diagnosis, the Global Alzheimer's and Dementia Action Alliance has recommended humanitarian organizations to use the Washington Group Questions, a set of questions designed to identify people with disabilities living in a diversity of cultures and with different socioeconomic statuses. The Washington Group Questions was piloted by the United Nations High Commissioner for Refugees (UNHCR) in registration interviews for the entry of Syrian refugees in Jordan in 2018, and the percentage of people diagnosed as having disabilities increased 25%, from 2.36% to over 27.55% (Corfield et al., 2019). Other recent tools that have been developed to facilitate the use of diagnoses and care of individuals with dementia in humanitarian situations are the Integrated Refugee Health Information System (iRHIS) and the WHO Mental Health Gap Action Program (mhGAP).

The iRHIS was released by the UNHCR and partners in 2018, and is currently being implemented on a country by country basis. This system allows health workers in refugee settings to be able to diagnose and record a wide variety of health issues. Very recently, the iRHIS was updated to include 9 new categories for recording neurological and substance use issues, including a new separate entry for dementia (Corfield et al., 2019). Once recorded, health information in the iRHIS can be used by healthcare practitioners to provide proper care and can be aggregated to provide a more accurate picture of the health needs of different populations. This tool is also key to improving access to healthcare systems in refugee host countries as having existent records facilitates care.

The mhGAP is a guide and training program that was created to help address the gaps in knowledge by healthcare providers in diagnosing and caring for mental, neurological and substance use (MNS) disorders including dementia. This guide was intended for non-specialist

healthcare providers primarily in low and middle income countries where there is a higher burden of undiagnosed dementia cases and limited treatment. Included in the mhGAP is the Dementia Assessment Pathway, a set of questions used to determine if dementia or other MNS disorders are likely (mhGAP-HIG, 2015). The guide and training program has been used with very positive results in seven Sub-Saharan African countries, but the Global Alzheimer's and Dementia Action Alliance agrees that we must further disseminate this tool and make it more readily available for use by humanitarian actors (Corfield et al., 2019).

Some additional barriers that exist with regards to the care of people with dementia in humanitarian emergency situations include numerous social factors. Many times emergencies can result in a major disruption of social networks. These networks can include caretakers, family members, and community ties, which are vital for people with dementia. As dementia progresses, people are made entirely dependent on others to care for themselves, and if this support is cut off, many are left in extremely vulnerable circumstances. Likewise, in the aftermath of the emergency, it can be very difficult for people with dementia to access humanitarian aid, especially if their social network is cut off. Relocation can also cause many issues for people with dementia as it is more difficult for them to adapt to unfamiliar environments. Additional social factors that can lead to barriers in healthcare access include stigma, discrimination, and abuse. A 2015 Humanity and Inclusion investigation looking at disabled people in humanitarian crises found that 59% of respondents that were internally displaced reported some sort of abuse, with those suffering from memory issues being particularly vulnerable (*Disability Universal Indicator 2015*). Stigma can also be a significant issue in some communities where dementia symptoms are associated with supernatural occurrences, and people with dementia are ostracized as a result.

## **Lebanon as a Country of Refuge**

Lebanon is currently the country hosting the largest number of refugees per capita and per square kilometer in the world (UNHCR Lebanon at a Glance, 2022). In order to understand the origins of Lebanon as a country of refuge, we must look at the history of the region. The region that is now Lebanon along with Syria and much of Anatolia was a major center of Christianity during the early spread of the religion in the Roman Empire. Between the late 4th and early 5th centuries, a monk from the region known as Maron founded a religious movement near the mediterranean mountain range known as Mount Lebanon. This religious movement, which upheld monotheism and asceticism, came to be known as the Maronite Church, and is in full communion with the Catholic Church. During the 7th century, the Muslim Arabs conquered Syria and the area of modern day Lebanon. Nonetheless, the relative geographical isolation of the region of Lebanon due to the mountains led the region to become an area of refuge in the Levant during times of religious and political crisis. This led to high levels of religious diversity, with the Druze religion emerging in the region from a branch of Shia Islam. Maronite Christians and Druze minorities from all over the Levant sought refuge and immigrated to the area of Lebanon for many years. Between 1516 and 1918, the area of Mount Lebanon was controlled by the Ottoman Empire. From the mid 16th until the early 19th centuries, this area was known as the Emirate of Mount Lebanon, and had partial autonomy under the Ottomans. In the early 18th century a ruling system known as the “Maronite-Druze dualism” was created, setting the foundation for modern day Lebanon. In 1860, however, thousands of Christian residents were killed by Druze and Muslim militiamen during a civil conflict. This massacre led to a French-led

international intervention to protect the maronites which resulted in the Mount Lebanon Mutasarrifate, an autonomous administrative region of the Ottoman Empire with a Christian district created as a homeland for the Maronites. After the fall of the Ottoman Empire during World War I, France established and ruled over the state of “Greater Lebanon” followed by the Lebanese Republic in 1926 until finally achieving status as an independent country amidst World War II in 1943 (Maksoud et al., 2023).

Only a couple of years after the independence of Lebanon, the 1948 Arab-Israeli war took place and left many refugees. During this war approximately 100,000 Palestinians fled to Lebanon and remained there as Israel did not allow them to return following the ceasefire. A 2017 report from the United Nations Relief and Work Agency (UNRWA) estimated the amount of Palestinian refugees in Lebanon at around 400,000, estimated to be around 10% of the population at the time, with just under half of these living in refugee camps. Barriers to obtaining Lebanese citizenship, owning property, and even some occupations has resulted in many of these refugees living in very poor conditions (Al-Issawi, 2009).

The defeat of the Palestinian Liberation Organization (PLO) in Jordan in 1970 resulted in the relocation of many Palestinian militants to South Lebanon. This relocation caused increasing sectarian tensions, primarily between Palestinians and the Maronites along with other Lebanese factions, which resulted in a civil war known as the Lebanese Civil War in 1975. This civil war, along with subsequent conflicts due to Israeli and Syrian occupations of parts of the country resulted in thousands of internally displaced peoples, and worsened the living conditions of both Lebanese citizens and refugees. The ongoing Syrian Civil War in 2011 has resulted in a vast number of refugees fleeing to Lebanon in the past several years. Reports from the United Nations Human Rights High Commissioner for Refugees (UNHCR) estimated the number of Syrian

refugees in Lebanon to be around 250,000 in early 2013 to 1,000,000 only one year later.

Government sources placed the number of Syrian refugees at over 1.5 million in 2017, which was around 25% of the total population in Lebanon at the time. It is important to note that there has been no official government census in Lebanon since 1932 in order to avoid potential further denominational conflict (Maksoud et al., 2023).

Corruption, political instability, and the piling up of debt for many years following the Lebanese Civil War has led to an ongoing financial crisis in Lebanon, exacerbated by the Syrian Civil War and the recent explosion in the port of Beirut (Emhj, n.d.). The recent financial crisis which has led to the government having defaulted on debt and an inflation rate of 124%, has left over 80% of the population in poverty according to reports by Human Rights Watch. This economic and political crisis has impacted marginalized populations like refugees disproportionately. Healthcare access has been one of the areas most impacted. In 2020, a lack of proper safety measures resulted in the explosion of a large amount of ammonium nitrate stored at the port of Beirut, resulting in 218 deaths, and 7,000 injuries, including 34 dead and 124 refugees injured according to the UNHCR. As a result of this blast, St. George Hospital, one of the largest in the city, was severely damaged, and had to resort to treating patients in the street. The economic crisis has also led to a shortage of medical supplies and the inability of many hospitals to pay their medical staff. Thousands of doctors and nurses have left the country and many people are not able to afford private healthcare, leading private hospitals, which account for 80% of health services in the country, to close some departments (Emhj, n.d.). Additionally, the Lebanese budget for healthcare is shrinking while demand for government support is increasing drastically, leading to a system that is “on the brink of collapse” according to Health Minister Firass Abiad.

### **Dementia Care in Lebanon**

Dementia affects more than 7% of people in Lebanon according to numerous studies, a percentage that is considerably higher than the global average (Phung et al., 2017). Likewise, Lebanon has a very high number of elderly refugees, given its proximity and cultural similarities with countries like Syria, making it a more likely place of refuge for these populations than regions like Europe. Dementia is most common in elderly populations, with statistics from the Alzheimer's Association in the United States showing dementia affects 10.7% of people 65 or older. Consequently, although there are no official statistics it is probable that there is a severe lack of dementia diagnoses for refugee populations in Lebanon, and thus inadequate care (Alzheimer's Disease Facts and Figures, 2023). Given the current healthcare crisis Lebanon is facing, it is no surprise that dementia care even for the Lebanese population is very poor. Studies have shown that, of those diagnosed, access to formal care is very limited, with the vast majority of individuals living with dementia being cared for by relatives (Phung et al., 2017).

Alzheimer's Association Lebanon (AAL) is one of the most important organizations focusing on the issue of dementia in Lebanon. The non-profit organization was founded in 2003 to help raise awareness for dementia and to support people living with dementia, and is a key partner of HelpAge, an international NGO that works to promote the rights and care of older persons. Fortunately, I was able to interview Georges E. Karam, the current president of AAL and Chairman of the Department of Psychiatry and Clinical Psychology at the St. George Hospital University Medical Center in Beirut, in order to learn more about the status quo of dementia care in Lebanon.

### **Elderly Refugees in Lebanon**

According to Dr. Karam, at the start of the Syrian Civil War, primarily women and children fled to Lebanon to escape. Men mostly stayed to fight, and elderly people stayed in their villages for the most part. Consequently, at the beginning there were not very many elderly refugees. Nonetheless, as the war progressed and began to directly affect more and more rural areas, many of the parents of those younger individuals that had moved to Lebanon, moved out of their villages in Syria to join their children. It is important to note that many of these individuals that moved here that were in their 50s are now in their late 60s. As a result of these factors, Dr. Karam says we are now seeing more elderly Syrian refugees in Lebanon, which translates to more dementia.

### **Refugee Healthcare Inequality in Lebanon**

Conflict and economic depression in Lebanon has played a large role in issues related to dementia for both migrant and refugee populations, but also for the domestic population. According to Dr. Karam, the inequality gap with regards to primary care between the domestic population and refugees is not as vast as a result of the large amounts of NGOs with international funding providing care for Syrian populations. Nonetheless, the situation is different when it comes to specialized treatments like dementia care. Most NGOs working on the ground either lack expertise, or don't have the trained staff to provide care for dementia. As a result, refugees living with dementia would have to be referred to tertiary care where they have to pay out of

pocket. The vast majority of refugees can simply not afford to pay out of pocket. Consequently, there is a very large healthcare inequality gap when it comes to specialized healthcare for refugees in Lebanon.

### **Effects of the Economic Collapse on Healthcare**

Dr. Karam says that the recent Lebanese economic collapse has played a monumental role in healthcare as a whole. Both refugee and Lebanese populations have dealt with the consequences of economic collapse, but NGO aid has been directed primarily to Syrian refugee populations, leading to resentment by Lebanese populations. According to Dr. Karam, there are currently a number of clinics funded by NGOs that have been established to treat Syrian refugees. Lebanese people traditionally did not need these types of clinics because they were more wealthy. Nonetheless, the situation in recent years is different. In the last three years statistics have shown around 85% of the Lebanese population in poverty. This has led some local NGOs to place restrictions on international donors saying we will not receive funds for Syrian refugees unless there are also funds for the domestic Lebanese population. The recent increase in levels of resentment risks tensions that could lead to yet another civil war in Dr. Karam's opinion. Because of the economic collapse, medications were nonexistent for two years because they were subsidized by the government. The government did not have enough money to subsidize. However, instead of removing the subsidy, the medications were just not available. NGOs and doctors, including Dr. Karam, were urging the government to remove subsidies to allow the medications back on the market, even if they were more expensive. In Dr. Karam's view, more expensive medications that are available are better than no medications at all. As a



result of these pressures, in the past few months, the government has lifted the subsidies. Now, medications are available but considerably more expensive.

### **Minerva Adult Day Care**

Dr. Karam was the founder of the Minerva Adult Day Care Center in 2018; the first center of its kind anywhere in Lebanon, affiliated with AAL and HelpAge. Similar to community elderly care centers in the US, the Minerva Adult Day Care Center was created as an outpatient center for stimulating and engaging elderly populations with different activities. The day center was created not only to benefit individuals with dementia, but also to benefit families, giving them more free time to work and relax while their family member is in the center. Unfortunately, the Minerva Adult Day Care Center was forced to close because of COVID, and was subsequently destroyed as a result of the Beirut explosion. Dr. Karam had to completely fund the reconstruction with his own funds. As a result of the economic crisis following the reconstruction of the center, funding, which was completely private, became unsustainable and closed down. Nonetheless, Dr. Karam says he is planning to reopen the center by the Fall of this year based on the high demand for the center and the initial success.

### **Damage of St. George Hospital**

The Beirut explosion served as a significant hit to the healthcare of Lebanon as a whole. One of the largest hospitals in the country, St. George hospital, which was located less than a mile from the explosion, was severely impacted, and left non-operational following the blast

according to the hospital's disaster management spokesperson George Saad. Statistics show that 10% of people that died in the explosion died in the St. George Hospital (Mroue, 2021). As one of the hospitals with the most up to date research and technology when it comes to dementia, damage to the St. George hospital has served as yet another obstacle to adequate dementia care in the country.

### **Dementia Diagnoses Tools**

Within Lebanon, the St. George hospital and AAL have the best diagnoses technology according to Dr. Karam. The AAL has provided numerous workshops to healthcare workers in order to distribute these tools throughout the country. The Clinical Dementia Rating (CDR) instrument, which was developed at Washington University in St. Louis, is one of the major tools. This instrument was translated into Arabic by the AAL before being distributed to numerous hospitals. Dr. Karam said that the crisis has made it harder for healthcare workers to use other tools in the last 2-3 years such as PET scans and brain imaging, but most of the time these aren't necessary because rating scales like the CDR have been shown to be very accurate. The issue with this, however, is that even rating scales, which are readily accessible, are rarely used in the humanitarian and low-income settings where refugees live. Through the AAL and HelpAge, Dr. Karam has worked with 2 NGOs in order to train practitioners on how to complete dementia diagnoses in the field in order to make diagnosing elderly refugees more commonplace. Nonetheless, he expressed his uncertainty about how much of the rating scales are actually being put into use on a more structural level in humanitarian settings.

## **Elderly Refugees and Healthcare in Lebanon**

According to a 2022 report by HelpAge and the International Labor Organization (ILO) the number of elderly people in Lebanon as a whole is 11 percent, the highest figure in the Arab world (Older, 2022). This figure along with the information provided by Dr. Karam highlights the large number of elderly refugees living in Lebanon.

In order to better learn about the healthcare needs of elderly refugee populations in Lebanon, I was privileged enough to interview Sarah Al Omari, a social epidemiologist working on research concerning the needs of elderly Syrian refugees in Lebanon, and the role that humanitarian actors are playing in fulfilling them.

## **Overview of Refugee Status in Lebanon**

When considering the healthcare access of refugees in Lebanon, it is important to note that the country did not sign the 1951 Refugee Convention (Janmyr, 2017). The convention, signed by the vast majority of countries, defined the term “refugee”, outlining their rights and the legal obligations that countries have to protect them. Because Lebanon did not ratify this convention, there is currently no statute in Lebanese law that establishes a refugee status. Refugees are officially referred to as migrants in legal terms by the Lebanese government according to Al Omari. Consequently, there is no law requiring the Lebanese government to provide refugees with shelter. Other barriers include necessitating a residency permit to access any job, and prohibiting refugees from accessing higher paying jobs. Many refugees are residing without a permit according to Al Omari, and thus finding employment becomes an enormous

challenge. Public institutions in Lebanon are also not functioning well in general, trapping many refugees in a poverty bubble without proper access to healthcare. As a result of Lebanon's weak public institutions, all NGO efforts are led by sectors, with the government having virtually no role. According to Al Omari, however, there is still much to be done to address coordination and organization by humanitarian actors. The lack of an official refugee status makes this coordination more difficult.

### **Need Assessment of Refugees in Lebanon**

In recent years, Sarah Al Omari has been working on a research project titled "Older People tend to be invisible": a qualitative study exploring the needs and inclusion of older Syrian refugees in the context of compounding crises in host country, Lebanon". This project, published in November 2022, sought to outline a comprehensive need assessment for elderly refugees both in tented settlements and hosted settlements. Al Omari expressed how logistically, the research was very difficult because there is little to no government data on refugees, meaning researchers needed to find focal points for sampling frames themselves. In this research, an assessment was carried out across the following sectors: health, nutrition, food insecurity and domestic abuse. The two settings in which this research was carried out differ primarily in location. Hosted settlements are classified as Syrian refugees living in regular apartment complexes amongst Lebanese families, whereas tented settlements are groups of only Syrian refugees living in communities with tents. People in the tented settlements come from the same village in Syria, because they moved in bulk to the same place when the camp was created. Therefore, culture is similar, and there is not very much tension, but there is also not as much warmth in relationships

as you would expect as a result of the financial situation. When it comes to individuals living in hosted settlements, there is not the same dynamic as having a lot of Syrians living nearby. It is very random as to where refugees are placed, with some villages being very xenophobic, as evidenced by one of the research interviews in which a refugee experienced physical aggression as someone told him “go back to your country”. During her research, Al Omari described how she found enormous disparities in settlement quality, with some settlements with sanitation 300-400 meters from other settlements with no access to sanitation or toilets. In general, according to Al Omari, refugees in Lebanon face worse living conditions than those in Turkey and Jordan. During her research, Al Omari and her team used a battery of questions in order to identify individuals with mental health issues and exclude these individuals from interviews. Out of the 15 interview participants, no one was excluded for this problem. Notwithstanding, there were many elderly individuals that reported some sort of disability.

### **Inequality Gaps for Refugee Healthcare in Lebanon**

After carrying out the qualitative interviews and analyzing their contents, Al Omari and her team found the main barriers to healthcare access for refugees in Lebanon to be cost and availability of medications. The cost barrier is related to both the cost of care and the cost of transportation to healthcare centers. Lebanese healthcare is predominantly private, there are very few public hospitals with poor quality of care, and some services are not even present in some governorates outside of Beirut. The UNHCR currently has an agreement with hospitals in Lebanon that covers 70-100% of costs of surgeries for refugees depending on the type of surgery (UNHCR UK, 2023). This service is accessed via a hotline. Through her interviews, Al Omari

found that sometimes, even that small percentage of the cost they have to pay, they don't have access to. Consequently, Al Omari emphasized that the issue with regards to refugees in Lebanon is fundamentally poverty. Once you add in other factors including the lack of safety and the financial crisis and economic collapse, the problem of poverty and its effects on healthcare access are compounded. When it comes to the issue of dementia, Al Omari said that despite working in the humanitarian sector for three years, she has heard of very little with regards to the disorder. A lot of dementia services are not even available for the Lebanese domestic population, making access for refugees virtually nonexistent. Even in her research, Al Omari expressed how the interviews yielded little to no mention of dementia in the elderly refugee populations. There were many potential reasons that could account for this that are discussed later in this paper. These potential reasons include a cutoff definition for older age (50 years) that was lower than internationally defined cutoff, given the observation that a lot of refugees age quicker than the general populace given trauma and poverty concerns.

### **Diagnosis Process for Incoming Refugees**

There is currently no standard system for medically assessing incoming refugees in Lebanon as the immigration process is very uncoordinated. In order to implement a medical assessment system, according to Al Omari you would need coordination and the capacity of the government, not only NGOs, because it has to do with security and triage. Funding would also be an issue because funds from international NGOs in Lebanon are overwhelmingly used for very short term projects, not even taking into consideration maintenance. Another issue would be that of logistics and enlistment. If you don't have proper mapping about where refugees are

living, projects are logistically very difficult. This is especially the case for those living in hosted settlements. A final issue with this system currently is that disability in terms of cognitive functions and dementia is not very well understood by humanitarian actors. The focus is primarily on physical disabilities while cognitive disabilities are mentioned, but not addressed very well. In the case of Al Omari's research, one of the main reasons behind the lack of mention of dementia could be that the interviewers and interviewees needed to be sensitized about dementia as a disorder. It could be the case that many of the individuals interviewed were not familiar with dementia issues as a medical problem and thus it was underrepresented in research results. It is therefore very evident that humanitarian actors in Lebanon have a lot of room for improvement when it comes to addressing dementia care for refugees.

Another target for many refugees from the MENA region is Europe. So, how is Europe addressing dementia diagnoses and care for incoming refugees? Given the history of Geneva as a place of refuge, and the localization of so many healthcare and refugee oriented NGOs and organizations including the UNHCR and the WHO, I sought to focus on Switzerland, and more specifically Geneva to learn about how this issue is dealt with.

### **Switzerland and Geneva as Places of Refuge**

Switzerland has had changing attitudes to immigration throughout its history, with the Bartholomew Massacre of Protestants in France, following the reformation, triggering a mass migration of French Protestant refugees to Geneva. The city of Geneva became known as a city of refuge among Protestants, but the door was closed to many outside of this category. More than one hundred years after the Bartholomew Massacre, Geneva received a second wave of

Protestant refugees as a result of the revocation of the Edict of Nantes and the declaration of Protestantism as illegal in France. For many years following, Switzerland served as a welcoming country for Protestant refugees (*City of Refuge*, 2020). The ability for these individuals to be able to freely practice their Protestant religion in Switzerland, was their source of refuge.

During the 19th century Switzerland established itself as a country of emigration as many left the country due to poverty. At the end of the 19th century, however, Switzerland changed from a country of emigration to one of immigration. The end of the Second World War especially saw a large increase in asylum seekers from several countries in Europe (*Sfa*, 2019). More recently, asylum seekers from a wide variety of countries in the MENA region including Afghanistan, Syria, and Iraq have come to Switzerland, adding to the religious and cultural diversity of the country.

### **Overview of Refugee Healthcare in Switzerland**

According to Swiss National Law, asylum seekers must be guaranteed access to healthcare during the entire asylum seeking process while they are in a federal center. This access is guaranteed under the Federal Act of March 18, 1994 on health which provides a general health insurance affiliation for all asylum seekers. An ordinance enacted in August 1, 2011 also upheld the mandate that rejected and dismissed asylum seekers with a right to emergency aid are entitled healthcare insurance (Federal Office of Public Health FOPH, 2023). Upon arrival at federal asylum centers, all asylum seekers are required to attend a compulsory medical briefing with the goal of detection, prevention, and treatment of infectious diseases. Furthermore, a sort of “triage” system is implemented in which medical staff or the asylum seekers themselves can request a consultation with a healthcare specialist. Currently, an early identification of



psychiatric issues is recommended, but the identification of psychological problems and psychiatric disease remains challenging. Translation services on the phone are also available for medical staff, but unfortunately few make use of it according to the head of APDH Badia El Koutit. Following their stay in federal asylum centers, accepted refugees are obligated to have healthcare insurance. Individuals under a certain income threshold are able to apply for welfare to help cover expenses for their insurance (Federal Office of Public Health FOPH, 2023).

A 2010 study by Schmidt et al. looked at mental health and the utilization of healthcare by refugees after having lived in Switzerland for one year. More specifically, Schmidt et al. studied a sample of 78 adult asylum seekers, assessing their mental health through diagnostic interviews and their use of healthcare services over a 12 month period via health insurance records. The study found that 41% of participants had at least one psychiatric disorder. Furthermore, refugees sought healthcare more than twice as often as local residents, but received little specific treatment for their psychiatric disorders (Schmidt & Julia, 2010). Consequently, the study concluded that refugees impacted by mental health issues are underdiagnosed and often inadequately treated.

### **APDH and Elderly Refugees in Geneva**

Association pour la Promotion des Droits Humains (APDH) is one of the organizations that was founded in order to help fill in these inequality gaps by assisting migrants in adapting to their new life in Switzerland, and understanding their rights. Badia El Koutit, whom I was privileged enough to interview, is the founder and executive director of APDH. An expert in

intercultural mediation in relation to populations from the Middle East and North Africa, and previously a consultant for numerous organizations, from the International Committee of the Red Cross (ICRC) in many countries in the Middle East, to the Association for the Prevention of Torture (APT), Badia founded APDH in 2002. Through my interview with her, I was able to learn more about the way that migrants and refugees access healthcare in Switzerland, and the presence of elderly refugees and dementia in Geneva. It is important to understand the healthcare barriers that refugees in general may face in Switzerland, in order to understand how these barriers are made even worse for refugees living with dementia.

### **Obstacles to Healthcare for Refugees in Switzerland**

Amongst all of the healthcare obstacles for refugees in Switzerland, language poses the biggest difficulty according to Badia. Given the diversity of countries of origin when it comes to refugees in Switzerland, combined with the multilingual nature of Swiss society, it is no surprise that language is a large obstacle. Switzerland has four official languages (German, French, Italian, and Romansch) and is divided into larger regions of predominantly French, German, and Italian speakers. Most refugees who arrive in Switzerland come from countries where none of these languages are spoken, barring them from properly assessing a number of both public and private sector services, including healthcare. In the case of the refugees that Badia works with, the native language is predominantly Arabic. After language, Badia considers technological barriers to be the next largest obstacle. Differences in technological development and use differ significantly by country, especially when comparing the economically developing countries that most refugees originate from, with the more economically developed countries that many of

them immigrate to, like Switzerland. Much of the Swiss healthcare system uses technology, from online information about clinic sites and payment policies, to online appointment booking and payment platforms, technology has been used to facilitate access, but it is important to note that many people either don't have access to the internet in a reliable manner in the first place, and for some of those who do, they are not used to the technological systems that have been implemented to access healthcare. Refugees make up a large percentage of this population. The third largest obstacle to refugee healthcare according to Badia is cultural differences. Differences in the way healthcare is manifested culturally poses numerous issues when it comes to refugees determining when and how healthcare is accessed. Some cultures rely more on traditional manifestations of healthcare such as local herbs and ritual healers, and thus they are left in a big shock when experiencing a completely new healthcare system like that of Switzerland. The final large barrier that is faced, that is especially relevant in the case of women, is the issue of domestic abuse. Domestic abuse is a significant issue according to Badia in some refugee communities as refugees are less aware of their rights and how to access support. In addition to all of the aforementioned obstacles, economic barriers, especially when it comes to more specialized care, make it harder for refugees and immigrants without documentation to access care. While there are social support systems in place, Badia argues that there are still many gaps that she seeks to help fill through APDH.

### **How APDH Helps Address These Obstacles**

When accessing healthcare in Switzerland, migrants and refugees that are unable to afford services are assigned a social service assistant. Social service assistants are provided by

the government and tasked with helping the patient navigate and access healthcare regardless of their financial situation. The issue with the social service program according to Badia is that assistants are random, and she has heard of cases of xenophobia and racism as well as misogyny on the part of the assistants. APDH provides legal assistance in such cases. In the case of language barriers, many refugee populations struggle with accessing healthcare service directories in their native languages, and finding translators once they are seeking care. APDH helps to translate and distribute healthcare service directories in addition to assisting individuals seeking translators in emergency care through healthcare campaigns to inform them about the quality of care that they are entitled to. These campaigns also inform patients about how to access financial aid for translation services. Hospitals in Switzerland pay translators according to Badia, but some services aren't covered and ask families to pay out of pocket, or rely on children or other family members for translation. On the cultural differences front, APDH helps refugees to learn about Swiss cultural norms while also providing coping and relaxation techniques to help with the stress that comes with relocating to another country. These techniques are taught through a series of workshops that help ease populations into understanding certain aspects of life in Geneva.

### **Elderly Refugees and Dementia in Switzerland**

Similar to many other European countries, the refugee population immigrating to Switzerland consists predominantly of younger people. Elderly populations are less likely to take the risk and move to a completely different country with a different culture even in times of crisis. As a result of this, Badia emphasized the lack of support by many NGOs when it comes to

serving the specific needs of elderly refugees, especially when it comes to disabilities and conditions like dementia. It is only until recently that some NGOs have begun to look more into the elderly population, but there is still a significant gap with regards to this demographic according to Badia. The UNHCR is the main entity that sponsors older refugees, and APDH is one of the NGOs that helps serve elderly migrant and refugee populations in Switzerland. According to Badia, one of the main issues she has found that elderly populations in Switzerland face is not knowing their rights. APDH helps address this issue by preparing workshops to inform elderly refugees and migrants about the services they have the right to access, including healthcare services. A key component of these workshops is that APDH brings workshop participants physically to the places where they need to go to receive the services in order for them to familiarize themselves with the area. This is particularly helpful for people living with dementia and their families, as one of the things that they struggle with the most is remembering and navigating directions. All of the issues mentioned that refugees generally face when attempting to access healthcare in Switzerland are only compounded for people living with dementia given that this population requires specialized care, but at the same time faces even more difficulties adapting to a new culture. More NGOs catering to these populations and raising the problems of lack of diagnoses and barriers in access to healthcare are needed to provide basic dignifying healthcare to refugees living with dementia in Switzerland.

## **Conclusion**

While dementia cases are increasing throughout the world, especially in the Middle East and North Africa, numerous barriers continue to inhibit the proper diagnoses and treatment of

these populations. Very high levels of underdiagnosed people also pose challenges to humanitarian workers attending to healthcare workers in these countries, in addition to the healthcare systems of host countries receiving refugees. In Lebanon we see how the economic crisis compounded the issue of healthcare access for refugees, putting elderly refugees living with dementia at an even greater risk. Nonetheless, the numerous cultural barriers to dementia care access for elderly refugees in Switzerland that were discussed demonstrate that inequality in dementia care for refugees is not purely an economic issue. Lack of awareness regarding dementia diagnoses and lack of attention placed on people with dementia in humanitarian settings is an issue even in countries that are considered high-income. These barriers underscore the importance of expanding the availability of health records for these populations, expanding health literacy, and training local primary care doctors to care for neurological conditions like dementia using existent tools like the mhGAP, the Washington Group Questionnaire, and the CDR. Humanitarian actors must do more to help enact these changes, but also to push for increased diagnoses and specific treatment for refugees once in their host countries.

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