

**Perceptions of Dementia
among Young Arab Adults in Ontario**

by

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Author's Declaration

I hereby declare that I am the sole author of this thesis. This is a true copy of the thesis, including any required final revisions, as accepted by my examiners.

I understand that my thesis may be made electronically available to the public.

Abstract

Introduction

As dementia rates are projected to rise among ethnic communities in Canada, understanding how these communities perceive the condition is increasingly important (Alzheimer Society of Canada, 2024). This study focuses on young Arab adults due to the Arab population's rapid growth and relatively young age profile in Canada (Statistics Canada, 2022; Canadian Arab Institute, 2019). Given cultural expectations around caregiving, many of these individuals may assume caregiving roles for relatives with dementia in the future. Their perceptions are therefore critical, as they can influence caregiving approaches and help-seeking behaviors. While international studies suggest that Arab communities may hold negative views of dementia (Brijnath et al., 2021; Kane et al., 2021; Abojabel & Werner, 2019), there is limited research exploring these perceptions within the Canadian context.

Objective

The objective of this qualitative study is to explore the perceptions of dementia among young adults between the ages of 18 and 30 who are members of Arab communities in Ontario. The research question is ‘how do young Arab adults perceive dementia?’.

Methods

This study recruited 10 young Arab adults and conducted in-depth, semi-structured interviews with each participant. Although the participants were provided with the choice of having an Arabic or English interview, all the participants opted for an English interview. Two interviews were conducted in-person and eight were conducted online. The study used reflexive thematic analysis to analyze the data using a software called MAXQDA.

Findings

Three themes were generated from the reflexive thematic analysis. The themes provided an idea on how the participants and their communities perceive dementia. The three themes were: *Describing dementia*, *Understanding the causes of dementia*, and *Living with dementia*. The themes shared a range of different perceptions, which may be a reflection of

the differences between the participants and their communities. The participants highlight many perceptions that were rooted in religious or spiritual beliefs – highlighting the importance of religion to the community. Overall, many perceptions reflect some stigma in how participants and their community view dementia, such as the hesitancy to use the word dementia or the negative language used to talk about dementia.

Implications

This study shows the value of developing dementia resources that are both culturally and spiritually sensitive for Arab communities. Involving community members in co-creating educational tools, working with places of worship, and acknowledging the role of cultural beliefs in shaping care can help make public health efforts more effective. As for future researchers, there is a pivotal need to include Arabs living with dementia in Canadian research.

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Land Acknowledgement

I would like to acknowledge that I am an Arab student who completed her graduate studies on occupied land that was promised to the Neutral, Anishinaabeg, and Haudenosaunee Peoples. The University of Waterloo is located on the Haldimand Tract, a territory granted to the Six Nations that encompasses six miles on each side of the Grand River. As such, I am someone who unintentionally benefits from the colonization of Peoples who were meant to be the stewards of this land.

Although I cannot change the past or present, I intend to do what is within my power and capacity to support Indigenous communities in the future as meaningfully as I can. This includes building respectful relationships with Indigenous groups and supporting local Indigenous businesses and organizations. While I recognize that my individual impact may be limited, I am committed to continuously reflecting on how I can do more.

I acknowledge that none of my efforts can undo the harm that has been done to Indigenous Peoples on this land. Still, I pray that the collective efforts of those who care may provide indigenous communities with the space they need to heal. These efforts may involve actively removing barriers, creating space for healing, or offering support in ways that Indigenous communities themselves define as necessary, recognizing that these needs may differ across communities.

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Chapter 1

Literature Review

1.1 Introduction

Dementia is a term used to describe a collection of conditions that have a shared set of symptoms that impact cognitive functions (US Preventive Services Task Force et al., 2020). Dementia is projected to increase in Canada among ethnic minority communities (Alzheimer Society of Canada, 2024). This thesis focuses on young Arab adults as Arabs are one of the fastest-growing ethnic group in Canada (Statistics Canada, 2022). Based on what we know from studies conducted in the Middle East, Australia, and the United States, there may be unique perceptions of dementia held by Arab communities that contribute to how they seek support and resources (Abojabel & Werner, 2019; Brijnath et al., 2021; Dallo and Kindratt, 2019; Kane et al., 2021; Karam & Itani, 2013). By exploring how Arabs in Canada perceive dementia it can create a stepping-stone for future researchers to understand perceptions of dementia (Brijnath et al., 2021; Kane et al., 2021; Karam & Itani, 2013).

1.2 Who are Arabs?

Arabs are a diverse ethnic group of people who may differ in terms of nationality, physical traits, dialects, foods, and cultural norms shaped by religion, politics, nationalism, and colonization (amongst other elements) (Kayyali, 2013). The Arab ethnicity identity evolved to become bound by a shared sense of identity. Race, however, differs from ethnicity because race refers to a classification based on their physical traits. Ethnic classifications allow Arabs to be defined as a group of diverse people who are intertwined and bound by history, heritage, and language (Bulatao et al., 2004). As Arabs have diverse physical traits (such as skin colour, hair texture and facial features), Arabs cannot fit into a racial classification based on common physical traits (Bulatao et al., 2004). For example, if a racial classification is used to classify races by skin colour, Arabs would be separated into many races. Arabs have many skin tones ranging from White to Olive to Black (Bulatao et al., 2004). As Arabs are a large ethnic group there could be cultural differences between Arabs from different geographic regions. For example, within the Arab ethnicity, there are diverse

differences in dialects, foods, and cultural norms shaped by religion, politics, nationalism, and colonization (Kayyali., 2013). The differences between Arabs may influence how Arabs from different regions or nationalities perceive health and health conditions such as dementia.

This study includes individuals who identify as Arabs rather than Arabs of a particular culture, nationality, or geographic region. Arabs have a sense of unity associated with their ethnicity. Although Arabs have a shared identity, Sayed and Deardorff (2003, 2009) argue that Arabs have many cultures. Moreover, Arabs have a shared sense of unity associated with belonging to the same ethnic identity despite the cultural diversity of different regions (Rahal et al., 2022). Ethnic classifications allow Arabs to be considered as one group and support their sense of identity, despite ethnic classifications being criticized for being too broad and not fitting into the racial classifications (Braveman & Parker Dominguez, 2021; Bulatao et al., 2004).

1.3 The Significance of the Arab Communities and Young Arab Adults in Canada

The Arab ethnic group is one of the fastest-growing ethnic groups in Canada (Statistics Canada, 2022), with an average annual growth rate expected to range between 3.7% and 5.1% from 2016 to 2041 (Statistics Canada, 2022). This is a high growth rate when compared to the growth rate of the Canadian population, which ranges between 0.7% and 1.5% during the same time period (Statistics Canada, 2022). The steep growth of the Arab population in Canada can be explained by the Arab Spring, which occurred in 2010 and resulted in political instability and war in numerous Arab countries, resulting in increased migration of Arabs from the MENA (Middle East and North Africa) region to Canada (El-Haddad, 2020). Canada accepted 25,000 Syrian refugees between November 2015 to February 2016 (Government of Canada, 2025) and accepted an additional 12,000 Syrians in early 2017 in

response to private refugee applications (Government of Canada, 2025). Similar to Syria, other Arab countries were facing their own civil wars and revolutions, which led to an increase in immigration from these countries (Fraihat & Yaseen, 2020).

In addition, the Arab population in Canada is relatively young (Canadian Arab Institute, 2019). The Canadian Arab Institute (CAI) report is the most recently published source on the age distribution of Arabs in Canada. The report by the CAI (2019) is based on census data from 2016 and indicates that 30% of the Arab population is younger than 15 years of age.

1.4 Why Include Arabs in Dementia Research?

Dementia is projected to increase in Canada – particularly amongst ethnic communities (Alzheimer Society of Canada, 2022). Dementia is a general term used for conditions that impact memory, thinking, and daily activities (US Preventive Services Task Force et al., 2020). There were approximately 597,300 people living with dementia in Canada in 2020, and this number is projected to increase to 955,900 by 2030 (Alzheimer Society of Canada, 2022). Subsequently, the Alzheimer Society of Canada (2022) predicts that there will be more than 1,000,000 care partners for people living with dementia by 2050. According to Alzheimer Society of Canada's (2024) Landmark study, the prevalence of dementia is projected to increase, particularly in ethnic communities.

The Landmark study sought to fill the gaps in dementia data by undertaking a microsimulation study to estimate changes in the number of people living with dementia over the next several decades (Alzheimer Society of Canada, 2022). The second report of the Landmark study highlights that according to the microsimulation involving people living with dementia from different ethnic origins, there is a projected growth in the percentage of people living with dementia among ethnic origins, with the most growth among people living with dementia who are of Asian (including East and South Asian) descent (Alzheimer Society of Canada, 2024). A limitation of these projections is that it considers Asia as one origin and Africa as another origin, and both of these groups include Arabs along with other groups. Other than these projections shared by the Alzheimer's Society of Canada, there is limited information on the prevalence of dementia among Arab communities in Canada (Alzheimer Society of Canada, 2024).

Therefore, statistics from a study conducted in the United States that focuses on Arabs may be a valuable point of reference. A study by Dallo and Kindratt (2019) stated that the prevalence of dementia among foreign-born Arab-Americans, aged 65 or older, was determined to be 10.3%, exhibiting a notable difference in comparison to the observed prevalence of 7.5% among White Americans. This suggests that dementia may be more prevalent among Arab-Americans when compared to White Americans. This aligns with the Landmark study's second report, as both highlight that dementia is projected to have a higher prevalence among ethnic communities (Alzheimer Society of Canada, 2024). Therefore, the disproportional projected increase of dementia among ethnic communities suggests a clear need to understand the perceptions of dementia among Arab communities.

1.5 Perceptions of Dementia

Research on dementia care partners in Arab communities in Canada is scarce. However, research that includes Arab family care partners has been conducted in the Middle East and Australia. The following provides a summary on global dementia research that has included Arabs.

Care partners are the family members and/or friends providing care for a person with a condition that impacts their activities of daily living (Xiong et al., 2018). Many, but not all, people living with dementia are supported by care partners (Xiong et al., 2018; Szabo et al., 2019). The cultural sense of responsibility to care for parents and elders is referred to as filial piety (Dilmaghani & Akbari, 2022). An Australian study revealed that Arab families shared caring roles and responsibilities, where each relative was given a chance to receive a break from their caring roles (Gilbert et al., 2021). The shared sense of responsibility to care for the elders within the family may be explained by filial piety. A possible outcome of filial piety suggested by Gilbert et al. (2021) is that families are less dependent on formal care. For example, Abojabel & Werner (2019) noted in their study that Arabs were less likely to depend on formal care services due to the cultural values held by the families. The collectivist nature of the Arab culture expresses a sense of filial piety, which could be the

reason why family members are less likely to seek services (Gilbert et al., 2021; Khalaila, 2022; Vila-Castelar et al., 2022).

Similarly, one's understanding of dementia can also influence how Arab care partners of people living with dementia seek services. A review conducted in the Middle East suggests that stigma and a limited understanding of dementia are associated with a delayed diagnosis – resulting in a missed opportunity for early mitigation (Karam & Itani, 2013). Dementia-related stigma is a form of negative social perception of dementia, and it can shape the behaviour of Arabs living with dementia (Abojabel & Werner, 2019). Stigma may influence the behaviour of people living with dementia, such as seeking support (Blinka et al., 2023), care partners concealing the dementia diagnosis, undergoing self-isolation, avoidance, and ultimately creating hesitations in seeking help (Abojabel & Werner, 2019). This may be harmful as early mitigation can help people living with dementia to benefit more from treatments, access resources, and making informed and empowered personal, legal, and medical decisions early (Abojabel & Werner, 2019). Abojabel & Werner (2019) studied family stigma of dementia among Arabs in Israel. The participants, who were Arab care partners, believed that the public perceived them as being 'insane' and 'filthy' due to their association with the person living with dementia. Additionally, Arab care partners believed that the public was socially distancing themselves from the people living with dementia and their families due to perceptions of disgust. The stereotypes perceived by the Arab care partners may lead the care partner and other family members to internalize negative emotions towards themselves and the person with dementia. An example of the negative emotions associated with internalized stigma is a sense of shame associated with how others view the care partner's role of caring for the person living with dementia (Abojabel & Werner, 2019). The aforementioned stigmas are associated with negative coping behaviours (Abojabel & Werner, 2019).

Culture may influence how Arab communities may perceive dementia (Brijnath et al., 2021; Kane et al., 2021). An Australian study suggests that the delayed diagnosis in Arab communities may be due to a lack of symptom recognition, the cultural perceptions that

memory loss is a part of ageing, and the cultural perceptions that neuropsychiatric symptoms are an indication of insanity (Brijnath et al., 2021). This may indicate that cultural perceptions influence how Arabs view dementia and its symptoms (Brijnath et al., 2021). It is important to recognize that identifying symptoms can be challenging for care partners as they are continuously in the process of making sense of the symptoms of dementia (Brijnath et al., 2021). Therefore, a limited understanding of dementia amongst Arab communities, in addition to the cultural perceptions that memory loss is a normal part of ageing, can make it hard for individuals in Arab communities to recognize changes in the person and, as a result, seek help (Karam & Itani, 2013; Brijnath et al., 2021; Kane et al., 2021).

Javaid and Elbejjani et al. (2021; 2021) reported that Arab cultures have a deterministic view of illness, which is a belief that fate determines whether people get ill. In other words, people cannot avoid getting ill as fate has already made that decision (Javaid, 2021; Elbejjani et al., 2021). This determinist view of illness can be a cultural barrier by negatively influencing their decision to access health services (Williams et al., 2022).

1.6 Barriers for Ethnic Minorities Accessing Healthcare Systems

Ethnic minorities face barriers when trying to navigate the healthcare system (Brijnath, 2022; Mahabir et al., 2021; George & Bassani, 2018). This includes navigating barriers associated with communication, culture, and racism, which may impact how Arab communities seek services (Salma et al., 2018; Tsai & Ghahari, 2023; Kieseppä et al., 2020; Williams et al., 2019). As there are limited studies that focus on dementia care barriers experienced by ethnic minorities, including Arabs, most of the discussed studies will focus on barriers experienced while navigating the broader healthcare services rather than dementia care specifically.

When ethnic minorities access healthcare services, they may face communication and cultural barriers (Salma et al., 2018; Tsai & Ghahari, 2023). A Canadian study found that Muslim Arab women who were able to speak English were better able to navigate the system and access resources relative to those who did not (Salma et al., 2018). Similarly, a scoping

review highlighted that the possible barriers faced by immigrants in Canada, including Arab immigrants, are likely linguistic and cultural (Tsai & Ghahari, 2023). First, communication barriers may primarily be due to language differences (Tsai & Ghahari, 2023). A Norwegian study by Alkhaled et al. (2022) suggests that Arab immigrants with a language barrier had trouble being understood by healthcare providers. Additionally, Alkhaled et al. (2022) found that there is an association between communication barriers and the negative perceptions of illness and anxieties surrounding the illness. To elaborate, higher feelings of disease dissatisfaction were linked to a gap in communication between the patient and care provider (Alkhaled et al., 2022). In addition, an Australian study suggests that the language barrier made it difficult for people living with dementia and their care partners to communicate with providers and understand information (Chejor et al., 2022). As many immigrant care partners struggle to learn the local language, they may face communication barriers (Chejor et al., 2022).

Second, cultural barriers stem from differences in cultural beliefs (Tsai & Ghahari, 2023). An Australian meta-analysis found that cultural barriers may make it hard for care partners and people living with dementia to access dementia services (Chejor et al., 2022). Therefore, cultural and communication barriers may result in hesitations and challenges in accessing care amongst ethnic minorities (Williams et al., 2019; George & Bassani, 2018).

Many ethnic minorities, including Arab communities, may hesitate to seek health services due to barriers such as racism (Greenaway et al., 2020; Mahabir et al., 2021). Structural racism refers to the racism expressed by rules, policies, traditions, and everyday practices that are used to uphold a larger system (Braveman et al., 2022). Structural racism may be associated with unequal access to healthcare and resources, making systemic racism a barrier to accessing the healthcare system for many ethnic minorities (Brijnath, 2022; Mahabir et al., 2021; George & Bassani, 2018). Structural racism is when systems are designed and implemented in a manner that supports privileged members of society and places barriers on other members of society who may be ethnic minorities (Williams et al., 2019; George & Bassani, 2018).

There is limited research on the experiences of systemic racism among Arab communities when accessing care. However, there are studies that look at the experiences of immigrant groups overall, which include the experiences of Arab communities (e.g., Mahabir et al., 2021). In the study by Mahabir et al. (2021), conducted in Toronto, Canada, concept mapping was used to group responses from ethnic minority health care users, non-minority care users, and health care providers into 5 categories. The responses were to the following prompt: “One way in which patients feel disrespected or feel mistreated when seeking good quality health care (service) is...?” The categories formed from the responses were: (1) racism and classism, (2) dehumanizing the patient, (3) negligent communication, (4) professional misconduct, and (5) unequal access to health services. The participants then rated each statement in 2 ways. One, they rated the importance of each statement in terms of creating challenges or barriers when receiving care for ethnic minorities. Two, they rated the importance each statement based on ethnic discrimination as the underlying cause for the challenge or barrier in receiving health care. Mahabir et al.’s (2021) Greater Toronto Area concept mapping study generated two main concepts. One, ethnic minorities, including individuals from Arab communities, are ‘Viewed as inferior’; and two, ethnic minorities have ‘Unequal access to medical care’ (Mahabir et al., 2021). The ‘viewed as inferior’ concept is generated from the racism and classism, and dehumanizing the patient categories (Mahabir et al., 2021). Additionally, participants reported unequal access to medical care and health services due to negligent communication and professional misconduct (Mahabir et al., 2021). Examples of negligent communication include willfully misunderstanding, ignoring a person’s concerns, or not taking them seriously (Mahabir et al., 2021). Examples of professional misconduct include not treating a patient’s pain, not providing a proper assessment, and not providing a patient referral when required (Mahabir et al., 2021). Ethnic patients have described a need to take action and create equal access to medical services (Mahabir et al., 2021).

1.7 Immigration and the Healthy Immigrant Effect

The health of many Arab Immigrants in Canada may have been impacted by immigration (Lu & Ng, 2019). Many immigrants have better health upon arriving in Canada than the Canadian-born population (Lu & Ng, 2019). After their arrival, some immigrants' health gradually declines until it becomes worse than the health of the Canadian-born population (Lu & Ng, 2019). The decline in the health status of some immigrants after arrival to Canada is referred to as the Healthy Immigrant Effect (Lu & Ng, 2019). The healthy immigrant effect could be attributed to challenges adjusting to the environment, stress, or the adoption of risky health behaviours after moving to Canada (Lu & Ng, 2019). The selection criteria to enter Canada may explain why many immigrants' health status is higher upon arrival to Canada. The Canadian Immigration system selects immigrants with high levels of education and language skills, which could be indicative of higher socioeconomic status and better health relative to others on their countries (Lu & Ng, 2019). The immigration system also requires medical screening tests to ensure that the immigrants entering the country are healthy (Lu & Ng, 2019). In other words, the selection criteria may play a role in selecting healthy immigrants to enter Canada (Lu & Ng, 2019).

1.8 Summary and Rationale

As dementia is projected to increase among ethnic communities, it is important to understand how ethnic communities perceive dementia (Alzheimer Society of Canada, 2024). The perceptions of young Arab adults are of interest because Arabs are a rapidly growing ethnic group in Canada (Statistics Canada, 2022), and the Arab population in Canada is relatively young (Canadian Arab Institute, 2019). Further, some of these young adults may end up taking on caring roles for their relatives who may develop dementia in the future as a form of cultural obligation or duty. Therefore, understanding their perceptions of dementia is essential, as these beliefs may shape how they approach caregiving and seek support. Existing research on Arabs conducted outside of Canada suggests that Arab communities may hold negative perceptions towards dementia (Brijnath et al., 2021; Kane et al., 2021;

Abojabel & Werner, 2019). However, there is limited research in Canada on this topic. Therefore, this research focuses on how young Arab adults in Canada perceive dementia.

1.9 Objective and Research Question

The objective of this qualitative study is to explore the perceptions of dementia among young adults between the ages of 18 and 30 who are members of Arab communities in Ontario. The research question is ‘How do young Arab adults perceive dementia?’.

Chapter 2:

Methods

2.1 Sample and Recruitment

Young adults who are members of Arab communities were recruited to participate in the study.

2.1.1 Inclusion Criteria

Participants were required to meet the following inclusion criteria. First, participants were required to identify as Arabs who originate from the MENA region. For purposes of this thesis, the MENA region included Sudan and Djibouti because of the cultural similarities found between the many Sudanese and Djibouti Arabs and MENA region Arabs (Kostelyanets, 2022). Appendix A contains a map of the MENA region for reference. Second, participants were required to live in Ontario and be 18 to 30 years of age. Statistics Canada's Data Report has classified youth as individuals between the ages of 18 and 30 (Garriguet, 2021). This classification was used in this thesis. Finally, participants did not require any previous knowledge of, or experience with, dementia.

2.1.2 Recruitment Strategy

The recruitment strategy employed criterion sampling, a form of non-random sampling, which restricts the sample population to a specific population of interest who meet specific inclusion criteria (Sandelowski, 2000). To reiterate the inclusion criteria, participants were required to identify as Arab, reside in Ontario, and be between the ages of 18 and 30 years.

The student researcher implemented this sampling strategy using two avenues. First, the student researcher engaged Arab community organizations who know community members who qualify for this study. For example, the student researcher was able to connect with the Director of Research and Policy of one of the organizations – who offered to connect the student researcher with eligible community members. Second, the student researcher reached out to members of their personal network who qualified for the study.

The student researcher engaged these organizations by attending community events, sharing information about their research interests, and building rapport with organizations and community members. These efforts also helped the student researcher facilitate their entry into the local Arab community's WhatsApp group chat, which was used to stay up-to-date on community events. Consequently, forming this network in advance helped facilitate the recruitment process because the student researcher was well connected to the community.

Once a participant expressed interest in the study, the letter of information and consent form were shared with them through email. The participants were provided an opportunity to inquire about the study before scheduling an interview. After scheduling the interview, the interview guide was shared with the participants before the interview date, and consent was obtained before the interview.

2.2 Interview Guide

The interview guide was developed by the student investigator in consultation with the thesis committee, informed by the research literature. The questions in the interview guide were open-ended, which means the questions were worded to be broad (Bergen & Labonté, 2020). In other words, open-ended questions enabled participants to provide a free-form response.

An unintended consequence of open-ended questions is the risk of the participants' feeling lost or feeling as though they "do not know where to begin" (DeJonckheere & Vaughn, 2019). Prompts followed each open-ended question to prevent participants from feeling lost (DeJonckheere & Vaughn, 2019). The prompts linked broad domains to the subject of the question, which cued the participant to respond to the question (DeJonckheere & Vaughn, 2019).

Social desirability bias is a bias expressed by a participant in response to their perception of what the interviewee wants (Bergen & Labonté, 2020). Participants were provided reassurance and encouragement to speak freely to limit social desirability bias (Bergen & Labonté, 2020).

The interview guide included questions that explored how participants and their communities perceive dementia. For example, one of the questions in the interview guide was “From your experience, how is dementia talked about in the Arab community?”. The interview guide is included in Appendix B.

Additionally, demographic information was gathered to be able to describe the sample. The variables that were asked about in the demographic questions are:

1. Gender
2. Age
3. Education
4. Classification of generation status
5. Country of Origin
6. Religion
7. Culture
8. Whether they live alone or with others

2.3 Data Collection

Individual, in-depth, semi-structured interviews were conducted with 10 participants. Two interviews were conducted in-person and eight were conducted online. Although participants were provided with the option of having the interviews in either Arabic or English, all the participants requested to have their interviews in English. The interview guide, which included the demographic questions and interview questions, was shared with participants prior to the interview to provide them with an opportunity to reflect on what they would like to share.

The interviews were recorded for accurate transcription. Each interview was between 24 and 52 minutes in length, with an average duration of approximately 38 minutes. The interview recordings were transcribed, then checked and anonymized. The software used for transcription and coding was MAXQDA.

2.4 Participants

The characteristics of each participant are highlighted in Table 1. Participants ranged in age from 22-30 years. Most were women, and almost all participants were Muslim except for one who was a Coptic Orthodox Christian. Other than one participant who was a second-generation immigrant, all participants were first-generation immigrants. In terms of education, five had an undergraduate degree, two were pursuing graduate degrees, and three were working on their Bachelor's degree.

Table 1: Overview of the Participants' Demographic Information

Participant ID – Pseudonym	Gender	Age	Education	Classification of generation status	Country of origin	Religion	Culture
1- Rafqa	Woman	20	High School Diploma (Completing Bachelor's degree)	First generation immigrant	Egypt	Coptic Orthodox	Coptic Egyptian
2- May	Woman	24	Bachelor's degree	First generation immigrant	Egypt	Islam	Egyptian and Canadian
3- Sarah	Woman	23	Bachelor's degree (completing Master's)	First generation immigrant	Jordan	Islam	Arab culture
4 – Noura	Woman	24	Bachelor's degree	First generation immigrant	Egypt and India	Islam	Egyptian and Indian
5 – Yazan	Man	22	High School Diploma (Completing Bachelor's degree)	Second generation immigrant	Iraq	Islam	Arab
6 - Razan	Woman	23	Bachelor's degree	First generation immigrant	Iraq	Islam	Arab, Iraqi
7 – Jehan	Woman	23	Bachelor's degree	First generation immigrant	Palestini an	Islam	Arab, Iraqi

					Jordania n		
8 - Ghayda	Woman	30	Master's (completing her PhD)	First generation immigrant	Jordan	Islam	Jordania n, Arab
9 - Rund	Woman	24	High School Diploma (Completing Bachelor's degree)	First generation immigrant	Syria	Islam	Arab
10 - Zeyad	Man	23	Bachelor's degree (Completing Master's degree)	First generation immigrant	Palestini an	Islam	Middle Eastern

2.5 Reflexive Thematic Analysis

Reflexive thematic analysis was used to analyse the data (Braun and Clarke, 2019). Thematic analysis is an analysis method that finds patterns of meaning within a qualitative data set (Braun and Clarke, 2019). Reflexive thematic analysis differs from the other types of thematic analysis because it leverages the researcher's positionality and subjectivity to make meaning out of the data and tell a story (Braun and Clarke, 2019). Consequently, reflexive thematic analysis results in the co-creation of knowledge between the participant and the researcher (Braun and Clarke, 2019). Reflexive thematic analysis is creative in nature and utilizes a big Q approach (Braun and Clarke, 2019). Big Q is a philosophical, qualitative paradigm to make sense of the data and steers away from the positivist approach presented by methods that use a small q approach (Braun and Clarke, 2019). The small q approach is focused on discovering the truth rather than generating knowledge by using sense-making (Braun and Clarke, 2019).

There are a few orientations reflexive thematic analysis researchers must consider. First, this analysis utilized an inductive orientation to the data rather than a deductive orientation (Braun and Clarke, 2019). An inductive orientation is "grounded" in the data, while a deductive orientation utilizes pre-existing theories as a lens to interpret the data

(Braun and Clarke, 2019). As this study did not utilize pre-existing theories to analyse the data, the study was inductive in nature and the themes identified were drawn from the data (Braun and Clarke, 2019). An inductive orientation was selected to produce a broad overview of the data collected (Braun and Clarke, 2019).

Second, this analysis utilized semantic coding rather than latent coding (Braun and Clarke, 2019). Semantic coding was selected because it focuses on the direct, descriptive meaning of the language used by the participants (Braun and Clarke, 2019). Given the exploratory nature of this study, semantic coding is a useful initial approach to understanding participants' perceptions of dementia by focusing on the explicit content they shared, rather than interpreting underlying meanings or assumptions. (Braun and Clarke, 2019).

2.6 Data Analysis using Reflexive Thematic Analysis

There are 6 phases used to conducting a reflexive thematic analysis. The first phase is concerned with the researcher familiarizing themselves to the data (Braun & Clarke, 2006). This included writing familiarization notes to support the researcher in identifying their response to the data and ideas that intrigued them (Braun & Clarke, 2006). The researcher read the data actively and intended to be purposeful, analytical, and critical; while attempting to separate their biases revealed by their initial response from data (Braun & Clarke, 2006). The second stage is concerned with semantic coding. The third stage organized the initial codes to form potential themes (Braun & Clarke, 2006). Stage four and five required further revision and refining of the developed themes, as highlighted in the list below (Braun & Clarke, 2006).

1. Familiarization with the data.
2. Coding the data.
3. Generating initial themes.
4. Reviewing and developing themes.
5. Refining, defining and naming themes.
6. Producing the Findings.

2.7 Positionality and Rigour

Using reflexive thematic analysis, I drew on my positionality as a researcher with lived experience in the culture of both the Middle East and Canada. This bicultural lens helped me interpret cultural nuances in participants' narratives. At the same time, it required ongoing reflection to avoid bias, while contributing to methodological rigour. I did this by trying to be as critically reflexive as possible by maintaining a journal, documenting assumptions, and questioning interpretations. This was especially important when my familiarity with Arab culture risked influencing the analysis.

To enhance rigour, I also engaged in regular dialogue with my supervisor as well as receiving feedback on written work from my supervisor. Their targeted feedback prompted deeper reflection on my assumptions and analytical decisions. These strategies, including reflexive journaling, supervisory feedback, and self-questioning, helped ensure that my positionality enriched the research while maintaining analytical integrity.

2.8 Ethical Considerations

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Board (REB # 46219). This research followed the Office of Research Ethics, Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2) principles and training. Participants were informed of their right to withdraw, the confidentiality of their identity, and the anonymity of the data using pseudonyms before the interview.

Chapter 3:

Findings

3.1 Overview

Three themes were identified from the reflexive thematic analysis. The first theme focuses on the terminology used to talk about dementia and how some may avoid using the term ‘dementia’. The second theme focuses on the perceptions of what causes dementia. Participants understood dementia to relate to disease, aging, or religious and spiritual causes. Theme three highlights what it means to live with dementia. Participants described dementia as being progressive, that living with dementia can mean being dependent, that dementia impacts a person as a whole, and that dementia is “the end” for the person living with dementia. During the interview, some questions asked participants about their personal perceptions, while other questions asked the participants to reflect on perceptions in their community. Therefore, within each of these themes, participants at times discuss their own perceptions of dementia and at other times they discuss their understanding of how their communities perceive dementia. The presentation of themes below indicates when participants are referring to each of these aspects (personal or community perception).

3.2 Theme 1: Describing Dementia

This theme describes the terms used by participants and their communities when discussing dementia. After analyzing the data, I found that ‘dementia’ is a term that is not used by some of the participants’ communities because dementia is a “hush-hush” topic. Some may avoid using the term ‘dementia’ and used symptom-oriented language instead. Other participants used negative terms to talk about dementia, such as Kharaf, or portrayed dementia as something scary, such as a nightmare. Finally, there was some indication that more people were becoming open to talking about dementia despite dementia being stigmatized for a long time.

Many participants explained that dementia is a “hush-hush” topic that is often not discussed within the Arab community. For instance, one participant indicated that members

of their community may avoid naming dementia and referring to it as the ‘You know what disease’ or ‘The bad illness’ because dementia is a taboo topic. This view is also applicable to other diseases that may be hush-hush, such as cancer.

Dementia or diseases in general in the Arab home is a taboo thing. The word itself is not said. Same thing with cancer stuff. They’re just mentioned as ‘You know what’, which I’ve seen into dementia as well, where they say like ‘The bad illness’.-Rafqa

There was a general hesitancy towards using medical terms when discussing dementia. Rund suggested that community members avoid saying ‘dementia’.

Rather than using the medical term..... It’s like they won’t say the word right away. They will just try to say anything other than [dementia]- avoiding saying the word. - Rund

Another participant shared their community’s use of symptom-oriented language as a substitute for the term dementia. Ghayda, who is a Jordanian woman, highlighted that the community avoided using the word ‘dementia’ and used symptom-orientated language instead.

Let’s assume that grandmother- someone’s grandmother are having dementia, so they just might disclose that ‘she’s just start to forget some stuff in the last period of time. But she’s gonna getting better.’ ‘I believe that she’s going to get better.’ or ‘She’s going to recover.’. So they try to hide it by making funny excuses that this status is just temporary.-Ghayda

Within this quote, Ghayda indicated that community members may describe the grandmother living with dementia as recovering, getting better, and that the condition is merely temporary. By describing dementia in this way, Ghayda indicated that community members are concealing that the grandmother has dementia from other members of the community.

Interestingly, a few participants drew parallels between dementia and mental health—particularly surrounding how the Arab community does not want to talk about dementia and

mental health. One participant highlighted that Arab parents would not know what to do with that information since the topic is foreign to them – possibly indicating some hesitancy related to discussing dementia.

Mental health and dementia. It's quite brand new, especially for first-generation Arab parents. A lot of this is brand new to them. So, they will be like, 'I don't know what to do with this information'.”-Yazan

The hesitancy to talk about dementia was depicted in how a couple of participants were not aware of the word for dementia in Arabic. For example, May shared that they do not know the word for dementia in Arabic.

No, it's [the word dementia in Arabic is] not used because I don't actually know what it's called in Arabic. And in my experience, when people have talked about it, it literally is just forgetfulness.- May

Other participants who knew the word for dementia in Arabic used the word الخرف [Al-Kharaf], which has a negative connotation. A few participants shared that relatives or community members use the word Al-Kharaf to mean dementia. One participant described Kharaf as an insult and indicated that her relatives prefer to use symptom-oriented language or ‘Alzheimer’s’ to mean dementia which, interestingly, seem to have a more positive connotation.

In my family, it [dementia] is الخرف [Al-Kharaf]. And then if you say someone مخرف [M'kharfin], which means losing their memory. It's an insult. It's not really a diagnosis. So nobody says it. If someone is losing their memory, for example, my great-grandma, she has lost most of her memory, we just say 'She has Alzheimer's' or 'She's just old'.-Sarah

The use of ‘negative connotation’ was also highlighted in how dementia is described as a scary condition. One participant shared that if one of his parents developed dementia, that would be his worst nightmare because it would be hard to explain to his parents that he is their son. The participant’s words:

It's my worst nightmare. I'd say something that I would never want to see happen between me and my parents is having to explain 'I'm your son' and having to go through all those memories.-Yazan

While most participants described dementia negatively, there may be a shift in how dementia is being discussed. To elaborate, Rund believed that people were more willing to have conversations surrounding dementia. This suggests that dementia is starting to gain some acceptance in the community.

It's been stigmatized for so long that it's just that's just the way it is. I think it's less so now than it was before. I think people are more open to speaking about things, which is good, but that's just the way it's always been in my community.-Rund

This theme described the considerable stigma reflected in the hesitancy to use the term 'dementia' or speak about it openly. When dementia was discussed, participants often preferred symptom-oriented language or the term 'Alzheimer's'. That said, there was also some negative language used to describe dementia overall, such as describing it as "degrading [someone] as a whole." Despite the stigma, some participants expressed that dementia may be gaining more acceptance in the community.

3.3 Theme 2: Understanding the Causes of Dementia

This theme describes participants' perceptions of what causes dementia. Some participants perceived dementia to be a disease while others shared that they or their communities perceived dementia to be caused by the natural process of aging or by religious or spiritual causes. These religious or spiritual causes can be related to God or a person's envy. Interestingly, some participants also shared a shift in their perception of what causes dementia as a result of their education.

Some participants understood that dementia has a biological basis, describing it as a "condition" or as a "disease that can happen to anyone". For example, Raqfa stated that

“Since we’re modern and evolving and all that jazz, we know dementia as something, which is a disease, and it affects the brain.”

Other participants shared the belief that they or people in their community understand dementia as being attributed to age or part of the natural process of aging. For example, Jehan shared that she thought dementia was something that naturally occurs with aging and did not think of it as a medical condition that impacts cognition.

They [people living with dementia] lose their memory. They lose their cognition. And I didn’t necessarily know if there was- I didn’t think of it as a medical condition or a disease. It was just something that happens naturally with aging.- Jehan

In addition, a few participants connected the perception of dementia being a normal part of aging to older generations. For example, Ghayda explained that the older generation may define dementia as forgetfulness or loss of mind that occurs with age. Therefore, there may be in how different generations perceive the causes of dementia.

The old generation defined dementia as I mentioned, a loss of memory or mind or forgetfulness, and they look at it from a more traditional lens, I could say. And it’s always associated with aging....so for those having dementia while the older generation, they just oversimplify this. They view it as a thing that happened to almost all seniors. And the main cause of it is aging, and it’s something normal.-Ghayda

For others, divine intervention was also seen as a cause of dementia. However, the specific role that God played varied among participants. Some participants indicated that dementia was a punishment or decree from God. One participant, Rafqa, is a Coptic Orthodox Christian who explained that they think their community perceives God as the cause for why a person has dementia.

For dementia, people- they always find the tiniest thing that this man or this woman did, and they’re like, ‘No, you see, he got that because he did this’. And then it’s sort of a punishment or even if it’s not a punishment, they mention it as, ‘No, God has –God is wise, and he’s he has some sort of orders to do that’.-Rafqa

In addition to the perception of dementia being punishment or a decree from God, a participant shared that God's decree should be accepted because it is beyond one's control. Zeyad, a Muslim man, stated:

From my perspective, if you accept this is God's decree, there's nothing I can do about it. And then we deal with it... So, it doesn't make sense for you to psychoanalyze and whatnot. You just accept it for what it is and be like, 'There's good in it somehow. So, I'm going to make do with what I have.' - Zeyad

Zeyad also explained that “whatever God's decree is, there's fair in it. There's good in it, whether you can see it or not.”. Zeyad explanation suggested that the good in God's decree is divine and beyond what we can see as humans.

And it's beyond our own- beyond our brain's capabilities to completely understand why or where this is good. Because if you believe in a supernatural or the divine, then you believe in something that's already beyond your human capabilities. - Zeyad

Another spiritual cause of dementia highlighted by participants is Al-hasad [الحسد], which can be referred to as the evil eye. Al-hasad is the belief that someone's envy can harm the person who they are envious of. May, a participant who is a Muslim Egyptian woman, shared that her family believes in Al-hasad. May explained that she can imagine a situation where their grandmother attributes her forgetfulness to the neighbour's Al-hasad – indicating that dementia may be perceived as an outcome of other people's envy.

The envy, الحسد [Al-hasad], my side of the family is very much invested in it. And I think there is a lot of- They like to blame that for a lot of problems...and I can 100% see the situation of my grandma ... being [in] a worse condition and her being like, 'It is those pesky neighbours, these jewelleries that my sons were getting me, and that is why I am forgetting things more'. I see that kind of playing into the whole thing. - May

In addition to describing different perceptions of what causes dementia, a couple of participants also discussed their belief that education influenced understanding of dementia. Razan, who has completed a Bachelor's degree in Kinesiology, explained that she previously perceived dementia as a natural process of aging where people lose their minds. However,

the participant's understanding changed as a result of his education. She now understands that dementia is a disease with underlying biological processes. Razan highlighted that her community may be unaware that dementia is a disease.

Before studying kinesiology and learning about dementia and what it actually is...I saw it as just something that happens with aging and it's not explained... It's sad to say, but they lose their mind [and there is not] an actual underlying disease and biological processes that happen that lead to it. I feel like people are just not aware of that.-Razan

Education may also have shifted one's understanding of dementia. Ghayda, who completed a Master's degree and is in the process of obtaining her PhD, explained that she had a stigmatized view of dementia. However, her view shifted to perceiving dementia as a disease that can impact anyone due to her exposure to information about dementia. Ghayda's experience suggests that education helped her alleviate some of the stigma she had towards dementia.

I was view it as a stigmatized. I was very saddened and concerned. If I hear someone having Alzheimer's or those and- I also didn't feel that this is something can touch my family. But now when especially when I started to teach that kind of courses about the health care system in Canada, and I start to see how the prevalence and the incidence of dementia cases in Canada and how the Canadian health system are supporting them, I start to feel it's challenging, but I am seeing it as a disease like any other disease that we should care about.-Ghayda

This theme described the considerable stigma reflected in the hesitancy to use the term 'dementia' or speak about it openly. When dementia was discussed, participants often preferred symptom-oriented language or the term 'Alzheimer's'. That said, there was also some negative language used to describe dementia overall, such as describing it as "degrading [someone] as a whole." Despite the stigma, some participants expressed that dementia may be gaining more acceptance in the community.

As described in this theme, spirituality and religious beliefs play a significant role in the perceptions of the causes of dementia. The participants shared a range of beliefs: some viewed dementia as a decree from God, some viewed dementia as a punishment from God, and others viewed dementia as an outcome of envy. In addition to the religious and spiritual causes of dementia, some participants also perceived dementia as a medical condition, others perceived dementia as a natural process of aging. A few participants noted that their perception of dementia has been influenced by their education.

3.4 Theme 3: What It Means to Live with Dementia

Theme 3 describes how participants view what it means to live with dementia. Specifically, dementia was described as a progressive condition, as something that led to dependence, as a condition that impacts all aspects of a person's life, and as "the end" for the person living with dementia. In these descriptions, some participants used very strong language to convey how they viewed dementia and its impact on individuals.

Some participants highlighted their understanding of dementia as something that was progressive. For example, some participants described dementia as being a progressive condition that gradually develops and impacts day-to-day activities. As one participant explained:

It's not just a static state where you have dementia and that's it, but there's levels to it where you start forgetting more and more. And it just affects- Overtime will affect how you perform your most normal and basic day-to-day activities.-Yazan

Another participant, May, described dementia as progressing backwards and "taking over" – suggesting that the progression of dementia impacts a person as a whole . May painted an image of an adult going back to needing help in the same way a baby would need help.

You age back down to a baby, where you have your independence in the middle of your life, but then as you get older, this dementia takes over. You can't remember where you put your food. Someone has to feed you. Someone has to take you to the

bathroom. Someone has to be there full-time to make sure you don't trip and fall the way babies trip and fall. And it does kind of take over. -May

A few participants shared a perception that people living with dementia are dependent because they would have challenges with daily activities. For example, one participant said, “[dementia] degrades you as a whole”. Noura explained the impact that dementia can have on a person's daily life:

For example, you might not be able to drive anymore. You might not be able to do those daily activities. So, you're depending on someone else. - Noura

Ghayda echoed Noura and explained their perception of how impaired cognitive function can create challenges in multiple areas. Ghayda highlighted the belief that a person living with dementia would become dependent and need help.

It's impairment or declination in a cognitive function, including memory loss, including some difficulties in doing the daily tasks, and communications, and decision-making. And I think it can affect maybe the independence of someone's life because they become dependent on someone else. .- Ghayda

This loss of independence was identified as being particularly impactful for the Arab community. Sarah shared that it is a part of their culture to want to be independent— making it challenging for members of the community to seek help. Although members of her community found it hard to ask for help, Sarah also mentioned that members of the community still cared for one another because of the collectivist nature of their community.

In my community, even if you are sick or you're not feeling the best, it's kind of hard to ask for help since people want to be independent so badly. So that's something I've noticed in my culture. In that same sense though, the Arab community has much more – It's more collectivist than the community here, like in the West... it's interesting because people will still take care of each other in my community more than in other communities. -Sarah

Finally, some participants saw dementia as an indication of the end of life. As Rafqa describes, the idea that dementia represents “the end” has been portrayed in an Arabic movie called *Alzheimer’s*, suggesting that this perception is common in Arab cultures.

It’s even portrayed in the movies and stuff. It’s like the end. Let’s say now some character on a movie or a TV show that’s Arabic. And then that guy got dementia, or he’s prone to dementia ... Now, when you hear that, the story is ending, this is how you know, this is the last season or the last episode of that show.-Rafqa

Although most participants shared information about their perception of dementia, one participant knew very little about dementia and did not have much to say. Rund expressed that “[she] just know[s] the overall. It’s a cognitive function and memory disorder. Cognitive function and memory.” Therefore, Rund does not know much about dementia beyond it being a memory disorder that impacts memory and cognition. She further explained that if her relative had dementia, she would need to ask a doctor how to manage dementia.

I feel like the experience would be to ask the doctor more about how to deal with this kind of situation. So, you would know how to deal with it because not knowing about it and not knowing how to deal with it. It would be a huge- It’s going to affect you either way. -Rund

In this theme, participants described living with dementia in a profound manner. Their perceptions focused on dementia as a progressive, life-altering condition that impacts various aspects of a person’s life, increases dependence on care partners, and that living with dementia means ‘the end’.

Chapter 4

Discussion

This study aimed to explore the perceptions of dementia among young Arab adults between the ages of 18 and 30 in Ontario, Canada. The findings of this study provide suggestions on areas of research that may be helpful to study and has implications for health providers and public health practice. Three themes were identified in the study: *Describing dementia*, *Understanding the causes of dementia*, and *Living with dementia*. This chapter begins by discussing the variability of perceptions found within the themes and then interprets and contextualizes the findings within existing literature. Then the chapter will discuss stigma as an overarching theme that appeared within each theme. Following this, the chapter discusses of implications, strengths, and limitations of the findings. Finally, the chapter ends with a brief reflection.

Overall, this study identified variability in participants' perceptions of dementia. These varied perceptions may be explained by the different exposures to people living with dementia, socioeconomic differences, different educational levels, and/or other factors. Arabs are a diverse ethnic group with different nationalities, religions, and cultures, and therefore, there may be different perceptions of dementia between and within Arab communities. This variation in perceptions of dementia within a diverse ethnic group aligns with the variability shared with other scholars who focused on Latinos, who are also a diverse ethnic group (Farina et al., 2021; Light et al., 2024). Scholars who studied the perceptions of dementia among Latinos also found variability of the perceptions across participants, likely due to the diversity of participants (Farina et al., 2021; Light et al., 2024). As scholars explore how dementia is perceived, there may be a need to focus on a particular Arab community, such as nationality or ethno-religious community. By focusing on a distinct community, future researchers can gain a deeper understanding of how dementia is perceived in that community and whether there are differences between Arab communities.

The Describing Dementia theme reveals that some members of the Arab community may be avoiding the use of the word ‘dementia’ by using symptom-oriented language. The term symptom-oriented language refers to terms that are used instead of saying the word ‘dementia’. These terms refer to symptoms of dementia such as ‘forgetfulness’. Although the phrase *symptom-oriented language* is not commonly used, similar descriptions have appeared in the literature. For example, Nguyen et al. (2023) explicitly referred to the use of “descriptive language of symptom” when discussing terms such as ‘forgetfulness’.

According to the participants, symptom-oriented language is commonly used among their communities to talk about dementia. One example is the use of the term ‘forgetfulness’. There could be several reasons for the use of symptom-oriented language and the avoidance of the term ‘dementia’. One plausible explanation for this may be the negative connotation associated with the term used for dementia in Arabic, *Kharaf*, which questions the sanity of the person living with dementia. When the word ‘Kharaf’ is used to refer to dementia, it depicts people living with dementia as ‘losing their minds’. In turn, participants may avoid using the term ‘dementia’ to avoid insulting the person living with dementia. The term ‘Kharaf’ is a colloquial Arabic word that originates from the root خرافه [*khorafah*] to mean fictional or imaginary (Ali et al., 2024; Cipriani & Borin, 2015; Taiebine, 2024; Yaghmour et al., 2019) and has also been described as an insult by a participant of this study.

Although other dementia scholars have also noted hesitancy to speak about dementia across various ethnic communities, it is important to avoid homogenizing ethnic communities and oversimplifying their perceptions of dementia (Jordão et al., 2025; Wilkinson, 2011). These scholars reported the hesitancy to speak about dementia and avoidance of the term ‘dementia’ amongst various ethnic communities, such as South Asian, East Asian, African American, and Latino communities (Kiadarbandsari et al., 2024; Mahoney et al., 2005; Mukadam et al., 2015; Nguyen et al., 2023; Suzuki et al., 2015; Zhai et al., 2022). Some of these scholars noted the use of symptom-oriented language by various communities, such as the term forgetfulness, which is used by African Americans, Latinos, and Chinese caregivers and Vietnamese communities to mean dementia (Kiadarbandsari et al., 2024; Mahoney et al.,

2005; Nguyen et al., 2023). Other examples of symptom-oriented language include terms such as absentmindedness by the Māori, who are an ethnic group in New Zealand or Samoans' use of the term 'Lemautonu' to mean uncertainty about anything (Kiadarbandsari et al., 2024). Therefore, future dementia researchers should try to understand how perceptions of dementia may influence behaviour, such as concealing symptoms and seeking care, among the Arab communities, in particular.

Another notable finding from *The Describing Dementia* theme is the preferred use of the term 'Alzheimer's' compared to dementia, which has been highlighted by a couple of participants. A review by Yaghmour et al. (2019) also noted that physicians in Arab countries may prefer using the 'Alzheimer's' when diagnosing patients as it is considered more acceptable. However, it is unclear why the term 'Alzheimer's' is seen as more acceptable. One plausible explanation may be that participants are more familiar with the term Alzheimer's. Another explanation may relate to the previously discussed stigma associated with the word "Kharaf", which is used to refer to dementia in Arabic (Ali et al., 2024; Cipriani & Borin, 2015; Taiebine, 2024; Yaghmour et al., 2019).

In the *Understanding the Causes of Dementia* theme, participants described many spiritual and religious causes of dementia, including dementia being a punishment from God, dementia being a decree from God, and the evil eye or Al-Hasad. The causes of mental illness have also been described in these ways in other studies conducted with Arab communities. (Bridi et al., 2023a; Bridi et al., 2023b; Daher-Nashif et al., 2021; Fakhr El-Islam, 2008; Hammad et al., 2024; Javaid et al., 2021). Arab communities may understand dementia as a condition that impacts many or all aspects of one's life. In particular, there seems to be an impact of spiritual wellbeing on health (Daher-Nashif et al., 2021; Hammad et al., 2024; Khoury et al., 2024). For example, some Arab communities believe that prayer is a healing technique –depicting an interconnection between spirituality and wellbeing (Daher-Nashif et al., 2021; Hammad et al., 2024; Khoury et al., 2024). Some other cultures also discuss religious causes of dementia. For example, dementia was viewed as a punishment by God amongst some first-generation Black African immigrants in the United Kingdom

(Mokwenye, 2025) and Latino caregivers in the United States (Gonyea & O'Donnell, 2021). Overall, it seems that religious causes of dementia are discussed across various ethnic groups.

While only mentioned by one participant, there was a comment in this study that religion may be used to cope with dementia. Other studies have also identified this idea. For example, Hammad et al. (2024) highlighted that religion was used as a positive coping mechanism for Arab care partners, with some Muslim care partners seeing their role as an opportunity to fulfill a religious duty, and others considered it a blessing (barakah). Muslims believe that there may be ultimate good in misfortune and God may be testing them when themselves or a relative develops an illness, which extends to dementia (Hammad et al., 2024; Seybold and Hill, 2001). Unfortunately, limited studies focus on Arabs of other religious communities and their perceptions of dementia and how religion may be used to cope – indicating a need for research that includes Arabs of various religions (Bridi et al., 2023b; Hammad et al., 2024; Javaid et al., 2021). Within the study described in this thesis, a Coptic orthodox participant and Muslim participants shared very similar community perceptions of spiritual causes of dementia. Therefore, there may be similarities in the spiritual perceptions of the causes of dementia between different religious communities. However, further research is needed to understand what role religion may play in the perception of dementia between Arab communities of different religions.

Arab communities' perceptions of what causes dementia are important to understand because these perceptions might impact whether or not they seek care. According to Kane et al. (2021) and Yaghmour et al. (2019), it is possible that if Arab community members view dementia as having spiritual causes, they may not seek medical services because the cause is not believed to be pathological. Another perception of the cause of dementia that has been highlighted in the literature and findings of this study is that dementia is a normal part of aging amongst Arab communities, which may also influence how members of Arab communities seek care (Algahtani et al., 2020). According to Algahtani et al.'s (2020) survey, which included Saudi civilians, around 45% of the participants perceived dementia as

a normal part of aging rather than a neurodegenerative disease. This study included a wide age range with 20% of the participants being between 18 and 20 years of age. Additionally, the sample was highly educated with 48% attaining post-secondary education. With that said, there are limited studies on how perception can influence how Arabs living with dementia seek support in Ontario, Canada. Therefore, it is important for future research to examine how perceptions of dementia influence the help-seeking behaviour of Arabs living with dementia and their care partners in Ontario and Canada.

This theme also suggests that there may be differences between different generations in how they perceive dementia. As highlighted by some participants, the discrepancy between their own views and those of their communities may be attributed to these generational differences. For example, some participants described dementia as a progressive disease when sharing their personal understanding. However, when describing their perception of their communities' views, the same participants shared different perceptions—such as viewing dementia as a normal part of aging. A few participants explicitly stated that these differences may stem from a lack of access to information. Others emphasized that education played a role in shifting their perceptions, suggesting that education influences understanding in multiple ways (Allam et al., 2023; Hammad et al., 2024; Yaghmour et al., 2019).

The perception that dementia is a normal part of aging is interesting when compared to the negative perceptions of dementia because it normalizes dementia by dismissing it as aging rather than defining it as an 'abnormal process'. However, a participant explained that this perception may stem from the hesitancy to talk about dementia. Similarly, other scholars have noted the same perception in other cultures and shared that viewing dementia as a normal part of aging to avoid sharing or accepting symptoms of cognitive decline (National Research Council, 2004).

The *What It Means to Living with Dementia* theme described the significant impact of dementia on people living with dementia. The main perceptions of this theme are that dementia is progressive, dementia impacts a person as a whole, living with dementia can mean being dependent, and dementia is “the end” for the person living with dementia. These

findings are somewhat interrelated. For example, people living with dementia are perceived to be dependent on a care partner for day-to-day activities. Additionally, these descriptions depicted dementia as having an overall negative effect on the person living with dementia and depicted dementia as ‘the end’. The shared descriptions of what it means to live with dementia are not be accurate to what it truly means to live with dementia because most participants have limited exposure to people living with dementia.

Collectivism encouraging individuals to support the larger collective over the needs of the individual. This may unintentionally result in hesitancy in asking for help. During the interviews, participants also expressed the cultural value of independence and shared that members of the community do not want to trouble others by asking for help. In turn, the collectivist nature of Arab communities may make it challenging for members of the community to ask for help because they worry about burdening others in their community (Allam et al., 2023; Hammad et al., 2024). In other words, there is a desire to contribute to the collective rather than being dependent on others. In turn, it is the responsibility of the younger relative (or multiple relatives) to offer support rather than waiting for older adults to ask for help. This is traditionally done in intergenerational households where support is provided to older adults in the family (Hammad et al., 2024). With that said, it is unclear what that means for Arab older adults to age independently or age well in Canada. However, it seems like culture and family structure may be important when considering views and attitude towards aging (Ibrahim & Bayen, 2019). Therefore, future researchers should consider what it means for Arabs living with dementia to age well.

Stigma and Related Interventions

Stigma was an overarching theme that was reflected in each of the themes. Stigma was most evident in the *Describing Dementia* theme, followed by the *Understanding the Causes of Dementia* theme, followed by the *What It Means to Live with Dementia* theme. First, stigma was present in the strong and negative language used to describe dementia in the *Describing Dementia* theme. Examples of strong language were the use of words like ‘nightmare’ and ‘scary’ to describe dementia. The strong language may reflect the strong

negative feelings associated with dementia. Another striking example was the use of the term Kharaf, which has a negative connotation. Other dementia scholars who included Arab participants in their research have also noted the term ‘Kharaf’ and believed that this term depicted the stigmatized view about dementia that may exist in some Arab communities (Ali et al., 2024; Cipriani & Borin, 2015; Taiebine, 2024; Yaghmour et al., 2019). Allam et al. (2023) further explained the connection between dementia and stigma by arguing that some Arab communities may conflate dementia and mental illness, as demonstrated in the meaning of the word Kharaf. Allam et al. (2023) explained that Arabs living with dementia and their care partners may go beyond avoiding the term ‘dementia’ by concealing that they have dementia or may mask their symptoms – indicating how stigma may shape the behaviour of Arabs living with dementia and their care partners.

Second, stigma was reflected in the *Understanding the Causes of Dementia* theme in some of the perceptions that depicted dementia as negative outcome of a spiritual or religious cause, such as viewing dementia as a punishment from God and an outcome of the evil eye. These negative spiritual and religious perceptions were also highlighted by Bridi et al. and Daher-Nashif et al. (2023a; 2021) who focused on the perception of mental illness among Arab participants. These scholars also noted that these negative spiritual and religious perceptions may be indicative of stigma (Bridi et al., 2023a; Daher-Nashif et al., 2021).

Third, the perception that dementia is the ‘end’ highlighted in the *What It Means to Live with Dementia* theme also reflects stigma. Although dementia is a progressive terminal disease, perceiving dementia as being the ‘end’ may be associated with stigma because people can live well with dementia (Quinn et al., 2022). Globally, there have been efforts to steer away from fatalistic perspectives and consider what it means to age well with dementia (Quinn et al., 2022). This shift in perspective prioritized the quality of life of the people living with dementia (Quinn et al., 2022). Overall, it is unclear why participants perceive dementia as being the ‘end’. However, Allam et al. (2023) believe that the feeling of helplessness may be associated with stigma, which may explain why dementia may be perceived as ‘the end’. Beyond Allam et al. (2023), limited scholars who included Arab

participants discussed the feeling of helplessness surrounding dementia or the perception of dementia being ‘the end’. In other words, we do not know if such perceptions are widespread across many Arab communities or localized amongst a particular Arab community.

Overall, stigma played a role in the perceptions of dementia amongst young Arab adults. As discussed, stigma can impact the perceptions and behaviours of Arabs living with dementia; in turn, this may result in delayed diagnoses or hesitancy to accept the diagnosis (Allam et al., 2023; Kane et al., 2021; Hammad et al., 2024; Yaghmour et al., 2019). Many studies involving different communities aimed to reduce dementia-related stigma or negative cultural beliefs towards dementia by improving knowledge and educational resources that are designed with the support of the community (Cahill et al., 2015; Herrmann et al., 2018; Matsumoto et al., 2023; O’Connor et al., 2020). Many of these resources were shared with the general public through educational institutions, community centers, online, or workplaces (Cahill et al., 2015; Herrmann et al., 2018; Matsumoto et al., 2023). It would be important for future researchers to consider how to make such resources and interventions inclusive to Arab communities in a manner that considers the communities’ spiritual beliefs and cultural values (Brijnath et al., 2019; Patel et al., 2022; Siette et al., 2023).

Other research that focuses on youth’s perceptions of dementia also found that stigma may play a role in the youth’s perception of dementia. However, there are limited studies that focus on young adults (aged 18 to 30). Most studies examined perceptions of dementia among adolescents between the ages of 13 and 18 (Farina et al., 2020; Hassan et al., 2024; Isaac et al., 2017). Many of these studies found that there may be misconceptions and stigma about dementia amongst adolescents (Farina et al., 2020; Hassan et al., 2024; Isaac et al., 2017). However, a study conducted in the United Kingdom found that participants who knew a person living with dementia were more knowledgeable about dementia (Isaac et al., 2017).

The idea that having connections with a person with dementia may have benefits is the rationale for intergenerational initiatives (Galbraith et al., 2015). An Irish qualitative evidence synthesis explored the experiences and perceptions of participating in intergenerational programs for youth, below the age of 18, and people living with dementia.

The study found that there may be benefits in intergenerational interventions as they may help people living with dementia stay socially connected, while also providing youth with the opportunity to learn about dementia (Houghton et al., 2022). Overall, there were a few benefits noted for both youth and people living with dementia across the interventions (Galbraith et al., 2015). The review found that youth learned behavioral and social skills needed to interact with people living with dementia, while also developing their understanding of dementia (Galbraith et al., 2015). People living with dementia also shared improved mood, sense of self, and social engagement (Galbraith et al., 2015). Thus, intergenerational interventions may be one way to increase understanding of dementia among young adults and have positive impacts for people with dementia at the same time.

Many scholars who have co-designed resources with ethnic communities focus on cultural appropriateness (Brijnath et al., 2023; Patel et al., 2022; Siette et al., 2023). If we consider the spiritual values and cultural beliefs of Arab communities (Allam et al., 2023; Hammad et al., 2024; Kane et al., 2021; Yaghmour et al., 2019), it may be that some Arab communities may also need educational resources that consider spiritual beliefs due to the significance of religion in such communities. Additionally, some interventions have insightfully shared that addressing stigma in ethnic communities can have multifaceted challenges that range from communication barriers to cultural barriers (Middleton et al., 2023, 2025; Siette et al., 2023). Consequently, there is a need to have multiple interventions at multiple levels, such as individual, community, organizational, and structural dimensions (Siette et al., 2023). Although there are some co-designed interventions in Canada that engaged various underrepresented communities, which includes ethnic minority groups (Middleton et al., 2023, 2025; Siette et al., 2023), there is still a need to build relationships with other ethnic minority groups, such as some Arab communities. As highlighted by Middleton et al. (2025), these relationships can take time and effort to build, and it may be particularly challenging to reach communities that have a stigmatized perception of dementia. Therefore, it is important for future researchers to proactively build relationships

with ethnic minority groups that may have stigmatized perceptions of dementia, including Arab communities.

Future research may benefit from including Arabs living with dementia and their care partners in dementia research to gain a deeper understanding of their perceptions and experiences. The existing literature conducted in the MENA region mainly focuses on epidemiological data. However, global research that focuses on the perceptions of dementia amongst Arab communities or Arab care partners is limited, and research that focuses on the experiences of Arabs living with dementia is extremely scarce. This suggests a need for dementia research to include Arabs living with dementia and care partners in dementia research. Additionally, if communities are slowly beginning to talk more about dementia as described by the participants of this study, future researchers may find greater insights as participants may feel comfortable when sharing their perceptions.

4.1 Implications

Although there remains much to learn about how Arab communities perceive dementia, this research offers a few preliminary implications. First, it may be beneficial for public health professionals to co-design culturally adaptive dementia educational resources with Arabs living with dementia and their care partners (Brijnath et al., 2023; Brijnath et al., 2019; Patel et al., 2022; Siette et al., 2023). These resources should consider the community's spiritual beliefs, cultural values, and preferred terminology. One example is the Australian short film *It's not a disgrace...it's dementia*, created by Dementia Australia (Dementia Australia, 2012). This educational intervention features Arabs living with dementia and their care partners speaking about their experiences in Arabic (Dementia Australia, 2012). The goal of the project was to address stigma in a way that resonates with Arab communities in Australia (Dementia Australia, 2012). Media-based interventions may be valuable as dementia gains visibility in Arabic media. Second, it may be helpful to consider places of worship as a leverage point for dementia interventions if it comes from the Arab community of interest. I would imagine that the goal of engaging communities through places of worship

may help reframe dementia by steering away from fatalistic perceptions, such as dementia is ‘the end’. For example, this may look like focusing on the more positive religious perceptions that may help communities cope and recognizing dementia as a collection of conditions that impact cognitive function. Third, there may be benefits in adapting an intergenerational intervention in Ontario that can improve the understanding of dementia amongst youth, while also support people living with dementia. Fourth, healthcare providers should recognize that cultural and spiritual beliefs significantly shape how dementia is understood and how individuals and families seek support (Hammad et al., 2024; Kane et al., 2021; Taiebine et al., 2024). Awareness of these influences can help providers practice cultural humility and deliver more effective, person-centered care. (Hammad et al., 2024; Kane et al., 2021; Taiebine et al., 2024).

4.2 Strengths and Limitations

The main strength of this study is that it provides initial insights into the perceptions young Arab adults from Ontario, Canada have surrounding dementia. As this study is exploratory in nature, it contributes to the literature by acting as a steppingstone for future researchers. Specifically, this study provides future researchers with a broad perspective on the divergent perceptions of dementia among young Arab adults in Ontario.

A second strength of the study is associated with the insider perspective. The graduate researcher conducting this study is of the same Arab ethnicity as the participants. Because of the shared ethnicity, the participants may perceive the researcher as an insider who understands their experiences. This is a strength because participants may feel more comfortable sharing their perceptions and experiences with an insider relative to an outsider. However, the researcher needs to be more intentional about asking follow-up questions as participants may assume that the researcher knows what their experiences are.

A third strength of this study is that participants felt comfortable having an open conversation about a stigmatized topic – contributing to the richness of the quotes gathered from the participants. A third strength is that the study contributes to the limited dementia

research in Canada that includes ethnic communities, particularly Arab communities. The findings of this study contribute to the limited literature by capturing a wide range of perceptions of dementia among Arab communities. Participants shared a wide range of perceptions surrounding dementia; some of these perceptions were perceptions of the participants, and others were participants' perceptions of their communities. However, the wide variety of perceptions can also be a limitation of this study. The variability of perceptions makes it challenging to know if there are differences between Arab communities' perceptions of dementia.

A second limitation is that the countries of origin for many of the participants were close in proximity (i.e. Egypt, Palestine, Jordan, Syria, and Iraq). This means that the findings of this study exclude Arabs from other countries in the MENA region, such as Sudan or Mauritania, among other countries. In turn, there may be unique perspectives that are not captured. Future researchers should, therefore, consider recruiting Arabs from various countries of origin, communities, and educational backgrounds. As future researchers develop their understanding of how Arab communities perceive dementia and seek dementia support, it may be helpful to focus their research on a particular Arab community. For example, much of the literature may reveal that a particular community may have unique experiences, and it may be helpful to focus on that particular community (Ajrouch et al., 2017; Bridi et al., 2023b).

A third limitation is that the participants of this study were highly educated, which may play a role in how they perceive dementia. For example, Ghayda is in the process of attaining a PhD, and she explicitly highlighted the role education played in shifting her understanding of dementia to be more scientific. A fourth limitation is the self-selection bias (Collier & Mahoney, 1996). Self-selection bias is when potential participants decide to participate based on their own personal beliefs, characteristics, or preferences (Collier & Mahoney, 1996). Most of the participants mentioned that they decided to participate because they were interested in the topic or had information they wanted to share. However, there could be other individuals who qualified for the study but did not participate because they did not

know much about dementia. As a result, the views of those potential participants would not be reflected in the findings. In addition, the self-selection bias may play a role in why the sample of participants is highly educated.

4.3 Reflections on Being an Insider Researcher

A critical reflection to note is that building meaningful community relationships takes time and intention. As an insider researcher it likely is easier to build trusting, meaningful relationships with community members relative to an outsider. However, there is still a need to intentionally connect with various communities. For example, I need to actively connect with Christian Arabs because most of the Arabs in my network are Muslim. Since most of the local Coptic churches I tried to connect with did not respond to phone calls, creating personal connections to access Christian communities became very important.

4.4 Conclusion

This study aimed to understand the perceptions of dementia among young Arab adults in Ontario. The findings revealed many different perceptions of dementia, which may be attributed to the difference between the participants such as nationality, education, socioeconomic location. Overall, some of these perceptions may indicate stigmatized perceptions towards dementia. Despite the existing stigma, it may be that some in Arab communities are more willing to talk about dementia. When the causes of dementia are discussed, there are many perceptions surrounding spiritual and religious causes. Religion and culture play an important role in Arab communities' perceptions of health and illness. This study shows the value of developing dementia resources that are both culturally and spiritually sensitive for Arab communities. Involving community members in co-creating educational tools, working with places of worship, and acknowledging the role of cultural beliefs in shaping care can help make public health efforts more effective. As for future researchers, there is a pivotal need to include Arabs living with dementia in Canadian research.

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Appendix A: A Map of the MENA Region

Map of the Middle East and North Africa (MENA) region

Figure 1

Countries in the Middle East and North Africa (MENA) region



Map based on Longitude (generated) and Latitude (generated). Color shows details about Countries.

Appendix B:

Interview Guide

4.5 Interview Questions

1. Can you tell me a little bit about yourself and what made you interested in participating in this study?

I would like to ask you a question about how you perceive or think about dementia.

2. Can you tell me what you think of when you hear the word “dementia”?

I would like to ask you a couple of questions about how people in the Arab community talk about dementia.

3. Can you speak to some ways culture or religion may influence how your community views health?
4. Can you speak to some ways culture or religion may influence how your community views dementia?
5. From your experience, how is dementia talked about in the Arab community?

Probe: Is the term ‘dementia’ used? If not, how do members of the Arab community refer to people living with dementia?

Follow-up to those who say that dementia is talked about (at least to some extent): In your opinion, when dementia is talked about in the Arab community, who is part of those conversations (family members, the broader community)? Is dementia something you ever talk about among your friends? If so, what’s the nature of those conversations?

6. Based on your experiences with your faith or religion, is there anything about your region or faith that may influence how people look after or care for those living with dementia?

If the person mentions a value/ belief, follow up with: You mentioned [reference value], can you elaborate? What does this belief or value mean for you?
I am going to circle back to asking you a couple of question about how you perceive dementia.

7. Based on your understanding of dementia, how would you define or describe dementia?

8. Do you have any personal experiences with dementia?

If answer is no, then ask ‘What do you know about dementia?’

If answer is yes, then ask ‘If you feel comfortable sharing, what kind of experience do you have with dementia?’

9. Based on your experience, do you think that there might be differences between how different generations define dementia?

10. If you were to imagine caring for a parent who is living with dementia, what do you think that experience would be like?

Follow-up if gender was brought up: You mentioned gender, can you elaborate on how you think gender may influence your caring role, if at all?

11. How would you feel if one of your relatives developed dementia?

Follow-up: Would feel any differently if it was a closer relative (like your mom) or a distant relative (like your aunt)?

[Depending on participant’s body language or response you may need to remind that there is no obligation to answer any question they do not want to answer]

12. Is there anything else you would like to share about your perceptions of dementia?

4.6 Demographic Questions

Before we finish off, I would like to ask you a few questions about you. The questions will help me describe the group of individuals who take part in this research.

1. What is your gender?

2. If you do not mind me asking, what is your age?

3. What is the highest level of education that you have completed?
 4. What is your country of origin?
 5. What is your religion?
 6. Who was the first in your family line to immigrate to Canada?
[Based on participant's response, following with asking about father/mother side]
 7. Who do you live with?
 8. What culture do you identify with?
- Is there anything else you would like to add before we finish the interview?

Appendix C:

Consent Material and Thank You Letter

4.7 Information Sheet and Consent Form

Title of Study: Perceptions of Dementia amongst Young Arab Adults in Ontario

Student Investigator, Department, Institution:

Ruah Al-Saghier, School of Public Health Sciences, University of Waterloo

Supervisor, Department, Institution:

Carrie McAiney, School of Public Health Sciences, University of Waterloo

You are being invited to participate in a research study because you are (a) a young adult who is between the ages of 18 and 30 years and (b) is a member of the Arab communities in Ontario. The study will require a one-on-one, 45 to 60 minute interview either in person, online (Zoom), or over the phone, depending on the participant's preference.

To decide whether or not you want to be a part of this research study, you should understand what is involved and the potential risks and benefits. This form gives detailed information about the research study. Once you understand the study, you will be asked if you agree to participate in the study. Please take your time to make your decision. Feel free to discuss it with others.

What is the purpose of the study?

The purpose of the study is to investigate the perceptions of dementia amongst (a) young adults who are between the ages of 18 and 30 years and (b) are members of the Arab community in Ontario.

What will you be asked of you if you agree to participate in this study?

Participation in this study is voluntary. If you agree to participate in this interview, you will be asked questions on:

- How members of the Arab community speak about dementia,

- Your perceptions on dementia,
- Demographic information such as your age, classification of generation status, length of stay in Canada, country of origin, and religion.

With your permission, the interviews will be video/audio-recorded so that we are able to capture all the information you share with us. Prior to the first interview, the interviewer will contact you by phone to review the study purpose and consent form.

Is participation in the study voluntary?

Participation in this research is entirely voluntary. As the study is voluntary, you may choose to skip any question with no explanation required – simply inform the interviewer, Ruah Al-Saghier. Additionally, you can decide to end your participation in the research at any time without penalty. If you decide to end your participation, simply tell Ruah Al-Saghier or Dr. Carrie McAiney that you no longer want to participate. You do not need to provide a reason. If you decide to end your participation in the study, your data can be destroyed if requested, but this cannot be guaranteed if data analysis has already begun. Data analysis will start approximately one week after you have participated. If possible, audio files and transcribed electronic files will be permanently deleted within two weeks of withdrawing.

Will you receive anything for participating in the study?

You will receive a \$10 gift card (for Shoppers Drug Mart or Tim Hortons, based on your preference) as a token of appreciation for participating in the interview. Gift cards will be distributed at the end of the study period, either electronically by email or physically by mail, depending on their preference. The amount received is taxable. It is your responsibility to report this amount for income tax purposes.

What are the potential benefits of your involvement?

We cannot promise any personal benefits to you from your participation in this study. However, the information you share with us will be used to understand the perception of dementia among young adults in the Arab Community.

What are the possible risks and discomforts associated with this project?

There is the minimal risk of the participants feeling short-term discomfort or embarrassment when sharing their views and perceptions of dementia. If you experience any feelings of discomfort, please let the researcher know. You may also skip any questions you do not want to answer. You may also end your participation in the study at any time by letting the researcher know of this decision.

Confidentiality and management of data

Any identifying information will be removed from the interview transcripts. Audio-recordings will be stored on a password-protected research drive only accessible to the researchers.

Audio-recordings will be transcribed. Once transcribed and confirmed for accuracy, the audio-recordings will be destroyed as soon as possible and within no more than two years of being recorded. Further, all electronic copies of study materials and data collected from you will be kept for a minimum of 7 years on a secure, password-protected data storage system in the Faculty of Health at the University of Waterloo. Your name will not be included in any presentations or publications resulting from this study; however, with your permission, anonymous quotations from your interview may be used.

The interview will be conducted over an online platform, Zoom. Zoom has implemented technical, administrative, and physical safeguards to protect the information provided via the Services from loss, misuse, and unauthorized access, disclosure, alteration, or destruction. However, no Internet transmission is ever fully secure or error-free. When information is

transmitted over the internet, privacy cannot be guaranteed. There is always a risk your responses may be intercepted by a third party (e.g., government agencies hackers). University of Waterloo researchers will not collect or use internet protocol (IP) addresses or other information which could link your participation to your computer or electronic device without first informing you.

Your personal information will be held confidential except in cases where disclosure is required by local, provincial and federal laws, and any other regulations (e.g., elder abuse or neglect).

If you wish to withdraw consent to participate, contact Ruah Al-Saghier at raalsaghier@uwaterloo.ca. Only researchers associated with this study will have access to study records. All records will be destroyed according to University of Waterloo policy.

Who is funding this study?

This study has received no external funding.

How will I find out about the findings of this study?

If you are interested in receiving a summary of the study findings, we will ask for your email or mailing address, and we will send a copy of the summary when the results are available in 2024.

Whom do I contact if I have questions or concerns?

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Board (REB # 46219). If you have questions for the Board, contact the Office of Research Ethics, toll-free at 1-833-643-2379 (Canada and USA), 1-519-888-4400 or reb@uwaterloo.ca.

If you have questions about the study, please feel free to contact Ruah Al-Saghier, ralsaghier@uwaterloo.ca or Carrie McAiney at carrie.mcainey@uwaterloo.ca.

4.8 Consent Statement: Verbal Consent

Title of Study: Perceptions of Dementia amongst Young Arab Adults in Ontario

Student Investigator, Department, Institution:

Ruah Al-Saghier, School of Public Health Sciences, University of Waterloo

Supervisor, Department, Institution:

Carrie McAiney, School of Public Health Sciences, University of Waterloo

By agreeing to participate in this study, you are not waiving your legal rights or releasing the investigators or involved institution from their legal and professional responsibilities. Your responses to the section below will be asked and recorded at the beginning of the interview.

Participant

I have read, and the researcher has explained verbally the information presented in the information letter about a study being conducted by Ruah Al-Saghier at the University of Waterloo. I have had the opportunity to ask any questions related to this study, to receive satisfactory answers to my questions and any additional details I wanted. I am aware that I may withdraw from the study without penalty at any time by letting the researchers know of this decision.

I consent to the following:

- ☐ To participate in an interview
- ☐ To have the interview audio-recorded to ensure accurate transcription and analysis
- ☐ To use anonymous quotations in any presentation or publication that comes from this research

When this study is completed, we will write a summary of the results. Would you be interested in receiving a copy?

- ☐ Please e-mail/mail me a summary of the results.

Contact information _____

- ☐ I do not wish to receive a summary of the results.

This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Board (REB # 46219). If you have questions for the Board, contact the Office of Research Ethics, toll-free at 1-833-643-2379 (Canada and USA), 1-519-888-4400 or reb@uwaterloo.ca.

4.9 Verbal Consent Script

Introduction:

Hello,

My name is Ruah. It is great to meet you. Thank you for your interest in this study. To give you a bit of background, I am working on my Master's degree at the University of Waterloo, and I'm looking into understanding the perceptions of dementia amongst young Arab adults in Ontario. While other research has explored the perceptions of dementia among different groups in Ontario, we have not found any research on how dementia is perceived amongst young Arab adults, that is, individuals from the Arab communities who are between the ages of 18 and 30.

[If the LOI was provided in advance]

Have you had time to read the Letter of Information I sent you?

[If the LOI was provided in advance and the participant responds that they have read the LOI]

Great, then I would like to take a moment to review some main points from the Letter of Information before we continue.

[If the LOI was provided in advance and the participant responds that they did not read the LOI]

I will give you a moment to read the Letter of Information; then, we can verbally review the main points.

Confirm the following to the participant:

- Your participation in this study is voluntary.
- If there are any questions you prefer not to answer, just let me know. We can take a break at any time.

- You can decide to stop at any time, even part-way through the interview, for whatever reason.

If you decide to stop during the interview and withdraw from participating, I will ask you how you would like me to handle the data collected up to that point: destroying it or using the data collected up to that point.

- You can ask to remove your data from the study up until approximately one week after the interview.
- This study has been reviewed and cleared by the University of Waterloo's Research Ethics Board. Do you have any questions or want me to go over any study details again?

Consent questions:

Do you agree to participate in this study?

If yes,

- Would you like a copy of the study results?

If yes, where should we send them (email, mailing address)?

- Do you agree to have the interview audio/video-recorded to ensure accurate transcription?
- Do you agree to the use of anonymous quotations in any presentation or publication that comes from this research?

4.10 Thank You Letter to Study Participants

Title of Study: Perceptions of Dementia amongst Young Arab Adults in Ontario

Student Investigator, Department, Institution:

Ruah Al-Saghier, School of Public Health Sciences, University of Waterloo

Supervisor, Department, Institution:

Carrie McAiney, School of Public Health Sciences, University of Waterloo

Dear [Study Participants]:

We would like to thank you for participating in the recently conducted research study, which focuses on the perceptions of dementia amongst young adults who are between the ages of 18 and 30 years and are a member of the Arab communities in Ontario.

We want to remind you that your identity in connection with any information you shared with us about your experiences will be kept confidential. Your name will not be included in any presentations or publications resulting from this study. However, if you provided permission on your consent form, anonymous quotations from your interviews may be used. This study has been reviewed and received ethics clearance through a University of Waterloo Research Ethics Board (REB # 46219). If you have questions for the Board, contact the Office of Research Ethics, toll-free at 1-833-643-2379 (Canada and USA), 1-519-888-4400 or reb@uwaterloo.ca.

Again, we want to thank you for your contribution to this study. If you have any questions or concerns, please contact Ruah Al-Saghier, ralsaghier@uwaterloo.ca and we would be happy to assist you.

Sincerely,

Ruah Al-Saghier and

Dr. Carrie McAiney

Tel. 538-994-7096

519-888-4567, ext. 45642

Emails: ralsaghier@uwaterloo.ca

carrie.mcainey@uwaterloo.ca

Glossary

Arabs: Arabs are an ethnic group that are connected by a shared identity based on heritage, history, and language (Al-Kandari & Gaither, 2011). Historically, Arabs used to identify on the basis of language – meaning anyone who spoke Arabic was Arab (Jawad Ali, 1961). Over time, different groups mingled and developed a shared identity (Jawad Ali, 1961).

Collectivism: A social system made up of people who are bound to one another by shared values that focus on supporting the collective (Brewer & Chen, 2007). Therefore, the social benefits and needs are superior to the needs of the individuals in a collectivist society (Brewer & Chen, 2007).

Culture: Culture usually asks the question ‘What are we?’ and provides meaning to one’s ethnicity (Nagel, 1994). In other words, culture is how groups of people choose to live and express their values (Kashima, 2019). Culture includes traditions, customs, clothing, music, and art (Kashima, 2019).

Dementia: Dementia is a term used to describe a collection of conditions that have a shared set of symptoms that impact cognitive functions (US Preventive Services Task Force et al., 2020).

Ethnic Identity: Ethnic identity presents a set of boundaries that define an ethnicity (Nagel, 1994). Ethnic identity asks, ‘Who are we?’. Ethnic identities are dynamic and constantly changes (Nagel, 1994).

Ethnicity: Is a product of actions expressed by an ethnic group and shaped by ethnic identity and culture (Nagel, 1994). Ethnicity is made up of ethnic identity and culture, and similar to culture and ethnic identity, ethnicity is also dynamic and changing (Nagel, 1994).

Ethnic minorities: Are ethnic groups who are not a part of the dominant group in terms of privilege and social location (Milhorn, 1990).

Racism: Racism is a social system that discriminates against different ethnic groups by using inferiority ideology to justify the lack of allocation of societal value and resource to ethnic minority groups (Bhopal, 2004).

Structural racism: Structural racism refers to the racism expressed by rules, policies, traditions, and everyday practices that are used to uphold a larger system (Braveman et al., 2022). Structural racism may occur when systems are structured in a manner that supports privileged members of society and places barriers on ethnic minorities (Williams et al., 2019). Structural racism is an outcome of racism that impacts ethnic minorities' health and wellbeing (Williams et al., 2019).