



## ENQUIRING ABOUT FAMILY CAREGIVING AND THEIR CULTURAL DIFFERENCES

MAY 22, 2014 | TORONTO

**MOUNT SINAI HOSPITAL**  
Joseph and Wolf Lebovic Health Complex



The Cyril & Dorothy, Joel & Jill Reitman  
Centre for Alzheimer's Support and Training

**IFA**



INTERNATIONAL FEDERATION ON AGEING  
Global Connections



## PURPOSE

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THE PURPOSE OF THIS ENQUIRY WAS TO DISCUSS AND UNDERSTAND THE CULTURAL DIFFERENCES THAT CAN IMPACT THE FAMILY CAREGIVING ROLE.

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This full-day meeting brought together key community leaders from diverse ethnic backgrounds and a wide range of expertise to discuss and learn how cultural differences can impact family caregiving. In doing so, this forum created a medium to understand key elements of what could constitute effective and responsive policies for caregivers.

The forum was organized in the second year of a five year national project titled “The Reitman Centre CARERS Program for the Workforce” developed for the Canadian workforce and funded by the Ministry of Human Resources Skills Development Canada, now encompassed in the newly named Ministry of Employment and Social Development.

The program was designed to reflect three components to stimulate discussion and provide a platform to delve further into how cultural differences can impact the family caregiving role. The three components were:

1. A description of the role that culture may/may not play within the context of care and practice;
2. An enquiry into the translation of research findings into caregiver-related policies and programs in diverse ethnic communities; and
3. An effort to better understand the sensitive topic of caring for someone with Alzheimer’s disease and the influence of cultural diversity in the form of care provided, responses to services, access to resources, and navigating through the system.

## STRUCTURE

Interaction and engagement was an important characteristic of the inquiry. This gathering which attracted 39 delegates from multiple disciplines and sectors was designed to allow inquiry and the asking of questions, not to analyze or promote a particular message. The program was structured as a platform for knowledge exchange through plenary panels, while providing the opportunity for all participants to contribute equally and openly through roundtable discussions.

Representing a broad spectrum of disciplines, plenary panels were made up of expert speakers that work closely with family caregivers from diverse ethnic backgrounds. Moreover, each speaker provided a unique perspective and examples of how culture can be viewed, outside of the context of ethnicity, to include gender, socio-economic status, and familial practices.

Each plenary panel included a discussant who was a community leader representing a specific ethnic background. Discussants were asked to reflect on the panel's presentations and provide insights from their own community's perspective.

Participants were divided into roundtables and engaged in discussions at the end of each plenary session. After participants had sufficient opportunity to

discuss the questions, a representative of each group synthesized the main points discussed. This was an opportunity to engage the entire group to share individual thoughts and provide feedback on what was being said.

## BACKGROUND

Family caregivers provide unpaid care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness, or age related needs.

**The most significant source of care for older people across all cultures in Canada is families, with women in particular providing the most care** (Lafreniere

et al., 2003; Keefe, 2011). The relationships between caregiver and care recipient are diverse and depend on a variety of factors including the age of the caregiver and the care recipient's condition. About half of younger caregivers, aged 45 – 64 years, report caring for a parent while older caregivers, aged 65 years and older, are more likely to be caring for a spouse (Hollander et al., 2009; Sinha, 2013; Turcotte, 2013). Caregivers looking after parents are most likely to be providing help with age related needs (Turcotte, 2013) while spouses predominate as principal caregivers of people with Alzheimer's disease and other dementias.

Data on caregivers in Canada are not systematically collected in census and other household surveys. Data are particularly lacking on the nature of caregiving in culturally and linguistically diverse populations (Duxbury et al., 2009), defined as those from Canada's non-indigenous cultural groups other than the English-speaking Anglo-Celtic majority. Despite the lack of national data, it is clear from data gathered in specific studies that the numbers of caregivers is underestimated. This may be due to several factors including the fact that those

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providing support do not always self-identify as caregivers (Henderson and Forbat, 2002; O'Connor, 2007), may interpret questions differently, or choose not to respond. This is particularly true for people from culturally and linguistically diverse groups.

In Canada, as is evident in many developed countries, the availability of resources specifically targeted to meet the needs of caregivers as distinct from those of the person they are caring for is mixed and many family caregivers do not receive assistance from either family or formal services (Health Council of Canada, 2012). This is equivalent to caregivers from different countries of origin. A study in Australia suggested that 40% of caregivers speaking Arabic, Cambodian, Greek, Mandarin, Polish and Russian had never used a community service to assist them in their caregiving role (Nankervis and Rebeiro, 2000).

Strong cultural expectations of family care are also reported to play a significant role in whether or not formal services are accessed. For many cultures the use of or request for formal services is viewed as inappropriate. Barnett and Cricelli (1990) report that most caregivers of Greek, Italian and Polish background in Australia could not contemplate an option other than providing in-home care to their family member.



Similarly, Misisic (1996) found that caregivers from Chinese, Croatian, Greek and Spanish backgrounds believed it was their responsibility to provide all care, and therefore most did not receive support services.

While there is a strong expectation of family-based care in all cultures (Chappell, 2011; Multicultural Communities Council of SA Inc and Multicultural Age Care Inc, 2005), different cultures make different distinctions as to what level of care is considered reasonable and when formal care is requested (Carers NSW, 2000). For example, services according to Carers New South Wales (NSW) were more likely to be accessed if a loved one's privacy and dignity was diminished due to incontinence, or if their behaviour was challenging and difficult to manage.

Cultural groups are difficult to define and research is complicated by the various attempts to use practical and obvious defining features such as language, country of origin, or religion. One might argue that these are merely proxy concepts which approximate the definition of cultural groups but are flawed.

Moreover, in a country like Canada where diverse communities are most often the product of immigration, the understanding of culture as it relates to health, illness and caregiving is further complicated by the need to take into account factors related to immigration. These include the impact of western influences on beliefs about the determinants of health, understanding of and response to the meaning and causes of illness, intergenerational tensions arising from mixed generations of families of seniors and younger more acculturated members, and lack of general societal support for strongly held beliefs the general good and family.

One could argue that this array of factors is common to the immigrant experience regardless of cultural origin and, moreover, should be considered when trying to distinguish between an immigration artifact and the true features of cultural groups.

## THE MULTICULTURAL FACE OF CAREGIVING IN CANADA AND TORONTO

Canada globalized its immigration laws in the 1960s and since then millions of families have migrated here “in search of a better life.” Data from the National Health Survey (NHS) indicated that in 2011 Canada had a foreign-born population of almost 6,800,000 representing one in five persons of the total population. In the same year, nearly 95% of all Canada's foreign-born population lived in four provinces: Ontario, British Columbia, Quebec and Alberta. Ontario received the largest share of all immigrants to Canada with just over 501,000 settling in the province (approximately 43% of all immigrants to Canada) of whom just over 382,000 (approximately 69% of the province's share) settling in Toronto (Statistics Canada, 2011).

Toronto, with a population of nearly 3 million people (5.5 million in the GTA - Greater Toronto Area) is known to be one of the most multicultural cities in the world with almost 49% of citizens born outside of Canada. Its diversity is expressed by the more than 200 distinct ethnic origins comprised of 28% European; 19% from the United Kingdom (England, Scotland and Wales) and Ireland; 16% East or Southeast Asian; and 10% South Asian.

Toronto is also a mosaic of many languages. Aside from residents whose mother tongue is

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either English or French, the most common first languages are: Chinese, Italian, Punjabi, Tagalog / Pilipino and Portuguese. Diversity can also be measured by the extent to which people speak a language other than English or French in the home. Thirty-one percent of residents do not use one of the two official languages at home with the most frequent being Chinese, Tamil, Italian, Spanish, and Portuguese.

The literature suggests that first generation immigrants face many barriers, including lack of recognition of international credentials and experience, racism and discrimination, lack of affordable housing, and barriers to meaningful employment. However, the data suggest that Canada is recognized by most [immigrants] as a “land of opportunity”. The degree to which this view is held may depend on the age of the immigrant. Younger immigrants may well view Canada as a land of opportunity for themselves and their children. The view held by their aging parents who look forward, perhaps with some anxiety, to ageing in a foreign country, may be very different.

*The experience of caregiving and expectations regarding the appropriateness of service access are often similar for caregivers across cultures. Equally, access to and provision of formal health care and social services that are culturally appropriate can be difficult for caregivers from different countries of origin because of challenges on both sides of the exchange. Immigrants may be unfamiliar with the health and social care system and face barriers due to racism, lack of fluency in English and unavailability of culturally appropriate professional care options while cultural stereotypes may influence the attitudes and behaviours of health and social care professionals. (Dunbrack, 2005).*

The situation can be even more complex when a second generation caregiver, fluent in English and familiar with the Canadian health care system, aims to provide appropriate care to an older first generation family member who

retains the language and care preferences of his/her country of origin (Dunbrack, 2005).

It may be safely said that policy makers and service providers alike recognize and embrace the need to create policies and systems of care for caregivers and care recipients alike that address the needs of diverse cultural groups. However, the issues are very complex and do not yield easily to solutions. Hence, many programs and initiatives include the principles of equity, acceptability, appropriateness and ease of access for all cultural and linguistic groups but falter when it comes to actually changing interventions and initiatives effectively to meet these goals, perhaps partly due to the lack of effective models. Hence, there is an urgent need to learn about diverse caregiving experiences from members of different cultural groups that will allow for effective collaboration in the development of responsive policies and programs that alleviate additional stress on caregivers from different ethnic groups.

## CONTEXT

With increased longevity, caregivers in Canada and other nations will begin to recognize the importance of culturally tailored services for caregivers, particularly working caregivers who are often balancing many responsibilities.

The word “culture” when used loosely, has become a shortcut to define and explain this sense of self. It has essentially become an identifier within the medical model to account for certain behaviours and symptoms and as result, treatment and services offered. However, culture is not static. It is a moving target, where boundaries are constantly contested and income, gender, and inequality influence the definition and perception of culture in modern society.

Categorically, culture could be divided into two definitions: basic and complex. The simplified definition categorizes differences in variables such as language and food preferences to assist our understanding of culture. It is essentially the shortcut that enables individuals to quickly

assess and make assumptions to proceed onto the next decision or action. The second, more complex definition, explores social phenomena such as the complexities of caregiving, religion, spiritual rituals etc. Together, both definitions of culture shape personal relationships, care culture, and underlie how societies operate.

## Canada is the first nation in the world to adopt multiculturalism as government policy.

The priority given to multiculturalism demonstrates the acceptance of diversity within Canadian society and provides a perceived sense of belonging and inclusivity to those not born in Canada. However, with such a broad inclusion of “multiculturalism” within its policies, the nuances of culture and sense of self have often been overlooked.

Part of the challenge of understanding and addressing these nuances of culture and the caregiving role is the proclivity to define people and put them into a box. It is this tendency to follow a pattern and quickly and superficially define individuals based on cultural factors, particularly within the medical sector, that has led to the development of a system that is inadequate in providing culturally appropriate care and services.

The bottom line is that this is complicated. There is no one way of looking at cultural diversity and there is no right or wrong way. However, consideration of culture and its impact on caregiving provides an opportunity to bring the silos together, gather those invested in this issue to form a coalition and garner political will to make changes. With the growing number of older adults, caregivers and, increasingly, working caregivers will yield large political and social capital, and it will be increasingly important to explore how civil society, government, and the private sector can work together to better support caregivers.



## SUMMARY OF THE ENQUIRY ABOUT FAMILY CAREGIVING AND THEIR CULTURAL DIFFERENCES

### OPENING REMARKS

Dr. Joel Sadavoy, Director, The Cyril & Dorothy, Joel & Jill Reitman Centre for Alzheimer's Support and Training, Mount Sinai Hospital welcomed delegates and highlighted the importance of understanding how cultural differences can impact the family caregiving role, particularly for those balancing the challenges of work and caregiving. Moreover, Dr. Sadavoy encouraged open discussion and emphasized the importance of understanding what is required to develop policies and programs that are inclusive of all cultures.

### KEY SPEAKER

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**MR. CRISTIAN RANGEL**, DEPARTMENT OF SOCIOLOGY,  
UNIVERSITY OF TORONTO

"EXPLORATIONS ON CULTURE AND CAREGIVING"

**DISCUSSANT: MS. LJ NELLES**, EDUCATOR, CYRIL & DOROTHY,  
JOEL & JILL REITMAN CENTER FOR ALZHEIMER'S SUPPORT  
AND TRAINING, MOUNT SINAI HOSPITAL

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Mr. Cristian Rangel, Department of Sociology, University of Toronto, provided delegates with an overview of the concept of culture. He discussed frameworks that will assist in understanding the crucial relevance of culture; highlighting how culture shapes the political, social, and material implications which influence the healthcare system and society as a whole.

### KEY POINTS — EXPLORATIONS ON CULTURE AND CAREGIVING

Canada defines itself as a multicultural society. It is a sense of multiculturalism that informs the Canadian belief that all citizens are equal, that all identities must be preserved, and that all citizens should feel a sense of belonging within their communities. "Culture", in this sense, is made up of two dimensions: it is a lens through which society can be examined, a place where people of distinct linguistic and ethnic backgrounds work and live together in a



harmonious manner; and it is the system by which people organize their everyday lives. It can provide a sense of individual and community purpose, it can dictate social position and status, and it can impact heavily on values that shape relationships of care.

**While relationships of care have their unique characteristics, these relationships are often embedded within larger networks; among one's relationships with family and friends, and similarly, among one's relationships with the broader community and society (support systems, care facilities, medical institutions, etc.).**

Considering the fact that culture is the lens through which many Canadians organize their lives, its impact on these broad care networks can be profound.

Of course, this is sometimes problematic in a society like Canada's, in which people are taught to respect each other's cultures, but are rarely given the necessary education to do so by any means. As an example, consider the healthcare setting within which one's culture can potentially have an impact on how he/she wishes to be spoken to about medical ailments, how he/she answers questions about these ailments, and ultimately, how he/she would prefer a given ailment to be treated. If a medical professional does not have an adequate understanding of these cultural preferences, it is highly likely that the quality of healthcare provided to this patient will be affected.

Even more problematic is when care providers begin observing patterns among those of particular culture backgrounds (i.e. skin colour, dress code, language and accent) and

subconsciously begin to use these patterns as cues for how to tailor their interactions and treatments. Cultural categories are rigid, and once an individual is placed into a rigid category, there is a risk of ignoring his/her individual characteristics and the many other external impacts (e.g. socioeconomic status) that can play a large role in shaping personal care preferences.

The need for cultural competency programs in care settings has been well demonstrated, however, there is also an inherent danger that these programs, if not properly administered, can reinforce dimensions of discrimination which tend to flatten an individual's experiences and specific needs.

#### SUMMATION

Culture is an inherently complex entity. Considering this, it is important to consider how care institutions can build a system of trust to engage with culturally diverse communities, to ensure all ethnic groups seek care when necessary, to encourage these groups to speak up and voice their needs, and to reach for more culturally appropriate services when they are available. This is of particular relevance within the formal care system, in which the need to mirror the support networks that a caregiver or

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care-recipient receives within his/her respective community is dire. This will ultimately be achieved when stakeholders speak with a louder voice. As a society, we must discuss how to act as agents of change through sharing research and engaging governments to ensure that the issue of caregiving remains on the agenda.

#### PANEL 1 – CULTURE IN THE CONTEXT OF PRACTICE

**Ms. DIPTI PURBHOO**, SENIOR DIRECTOR, COMMUNITY CARE ACCESS CENTRE (CCAC) TORONTO

“PERSPECTIVES ON CAREGIVERS AND CAREGIVING – WHAT WE HEAR FROM CAREGIVERS”

**Ms. LISA LEVIN**, VICE PRESIDENT, COMMUNICATIONS AND DEVELOPMENT, CIRCLE OF CARE & CHAIR, ONTARIO CAREGIVER COALITION

“FAMILY CAREGIVING IN THE TORONTO JEWISH COMMUNITY”

**DISCUSSANT: MR. ZUL KASSAMALI, PRESIDENT, THE MULTICULTURAL COUNCIL FOR ONTARIO SENIORS**

In order to develop effective programs and policies to benefit caregivers, there is a need to establish a deep understanding of the nuances of culture within and across diverse groups.

In this session, Ms. Dipti Purbhoo provided an overview of what the CCAC has learned from asking caregivers about their critical necessities

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and, more specifically, about which support programs would be most beneficial for them and their loved ones. This was followed by Ms. Lisa Levin who provided culturally specific insight into the caregiving role within the Jewish community in the City of Toronto. In addition, Mr. Zul Kassamali provided a rich reflection about the importance of speaking up as a collective community to ensure programs and services for caregivers are addressed as a critical item on the political agenda.

#### PANEL 1 – KEY MESSAGES

In examining the prospect of developing policies and programs to benefit culturally diverse caregivers, it is important to understand that there are varying perspectives on caregiving and that each caregiver will have a unique outlook that is often shaped by personal life experiences and culture. Of course, when asked directly, caregivers will tell you what they require, but scaling these answers to a generalizable policy presents challenges, including the fact that home care provision and institutional care provision are vastly different entities.

The delivery of home care is comparatively very intimate. It takes place within one’s personal living space, intertwined with one’s family relationships, influenced by socio-economic status, and inherently impacted by the culture that a care recipient practices in his/her home. In these settings, care is not just prescriptive, but must also be dynamic in response to these various dimensions.

Organizations that run homecare services have a role to play as well in ensuring that their staff members are representative of various cultural communities and that the appropriate staff is sent to homes where care recipients have particular linguistic and cultural needs.

The issue of providing care within various cultural settings is becoming increasingly relevant as Canada’s older population continues to grow and becomes more diverse. In designing programs and policies in the future, it

will be vital to move the conversation away from a question of “what services do caregivers need?” to a question of “what services and programs can be provided to help caregivers become better caregivers.” It is only a matter of time before society comes to the realization that effective systems to sustain care recipients and caregivers in this regard can only be designed when we stop viewing caregivers and care recipients as separate entities, but rather as one unit operating within a cultural context.

#### SUMMATION

The need to provide culturally competent programs and interventions to sustain caregivers has been comprehensively demonstrated, yet there is still a need to discuss how best to achieve this objective. How can service providers employ cultural cues, while avoiding stereotyping to understand clients and to assess the level and type of care they require?

There is a potential value in developing a set of caregiver performance measures to assess caregiver ability, but also a valid concern that this could lead to a heightened sense of pressure upon often underpaid and undertrained caregivers.

#### PANEL 2 – DEVELOPING POLICIES AND PRACTICE THROUGH TARGETED RESEARCH

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**Ms. FRANCES MORTON-CHANG**, PRINCIPAL, MORTON-CHANG CONSULTING

“DIVERSITY AND CAREGIVING”

**Dr. ALLISON WILLIAMS**, CIHR CHAIR IN GENDER, WORK & HEALTH, MCMASTER UNIVERSITY

“CULTURAL INFLUENCES ON PALLIATIVE FAMILY CAREGIVING: EXAMINING PROGRAM RECOMMENDATIONS SPECIFIC TO FORMAL SERVICE SETTINGS & SERVICES”

**DISCUSSANTS: Ms. JUDDY BLACKWOOD, MEMBER & Ms. CAROL CUSHNIE, PRESIDENT, AFRICAN CANADIAN HERITAGE ASSOCIATION**

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With rapid population ageing already underway, it is becoming increasingly important to identify research gaps and to ensure these gaps are addressed to better inform effective policy development. The nuances of cultural identities, beliefs and customs are not commonly being examined in the current caregiver research and policy development.

In this session, Ms. Frances Morton-Chang reflected on the importance of sound knowledge exchange and mobilization to cultivate a strong network of up-to-date information to inform policy and program development. In addition to reiterating the importance of knowledge exchange, Dr. Allison Williams addressed the topic of workplace policies and programs and made specific reference to her work with the Vietnamese community.

Discussants Ms. Juddy Blackwood and Ms. Carol Cushnie prompted the speakers and audience with a variety of questions which stimulated a very rich and interactive discussion.

#### PANEL 2 – KEY MESSAGES

**As of 2014, there is a lack of research examining caregiving through the lens of culture.** In practice, this means that there have been few research studies undertaken to explore how best to train caregivers in cultural competencies, and similarly few research studies about how to develop systems to sustain and enhance capacity of caregivers from different ethnic backgrounds. The lack of empirical evidence ensures that neither care providers nor care recipients have effective, culturally tailored services available to support their needs. There is a dire need for a central repository of information to collate the

resources that are available so as to enable collaboration across disciplines and sectors to identify appropriate short-term and long-term responses.

### Attempts to conduct research on this issue are burdened by the inherent complexities of the subject matter.

The topic of culture is abstract and researchers often find it difficult to account for the numerous variables which must be addressed when designing research studies. As an example, one's spirituality which is often intertwined with culture can highly influence how a caregiver views the caregiving role, adding another element of complexity to data collection and analysis. This high number of variables further impacts the ability of policy makers to translate research studies into effective policies and practice.

A lesson that has been learned from the research is an understanding of the importance of accurately pinpointing a caregiver's goals prior to designing policies. It is only through developing an understanding of what a particular cultural community hopes to achieve through caregiving that governments, service

providers, organizations, and researchers are given a framework to inform the development of culturally-appropriate supports and services. Of course, the development of these supports and services is always contingent on political will and, in Canada and particularly within Ontario, changes in government pose a challenge as they disrupt meaningful discussion and the development of coherent policy.

Adding a further layer of complexity to this issue is the fact that many older immigrants arrive in Canada with the intention of staying for just a short period and then returning to their country of origin. Often, external forces intervene and prevent this from being a feasible option, forcing these people to adapt and learn how to seek the appropriate resources in a community in which they are completely unfamiliar.

#### SUMMATION

Ethnic groups are not uniform entities and within and across each group there are many diverse characteristics such as language, dietary requirements, and religion, among others, which impact upon how care is conceptualized, requested and delivered. As a result, there is a need to discuss how a program or policy can be designed to accommodate as many of these dimensions as possible, thereby addressing the needs of the highest number of people. Whether such a program would be most effective at a municipal or provincial level also requires further discussion given the heavy concentration of culturally diverse communities in larger urban settings. Finally, there is a need to conduct more research and discussion about the impact that spirituality has on care decisions. In some communities that are defined predominantly by their religion, religious community leaders often assume the



role of decision maker which can heavily impact care provision.

#### PANEL 3 – BELIEFS AROUND ALZHEIMER’S DISEASE

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**Ms. ODETE NASCIMENTO**, DIRECTOR, OLDER ADULT CENTRE,  
ST’ CHRISTOPHER’S HOUSE

“CAREGIVING IN THE PORTUGUESE SPEAKING COMMUNITY”

**Ms. SUSAN ANSTICE**, CLINICAL SOCIAL WORKER, COMMUNITY  
CARE AND WELLNESS FOR SENIORS, WOODGREEN  
COMMUNITY SERVICES

“SUPPORTING PEOPLE WITH ALZHEIMER’S DISEASE AND THEIR  
CAREGIVERS: RESPONDING TO CULTURAL VALUES AND  
PERCEPTIONS ”

**DISCUSSANTS: DR. PARVATHY KANTHASAMY, CHAIR,  
VASANTHAM – A TAMIL SENIORS WELLNESS CENTRE**

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The diagnosis of Alzheimer’s disease impacts the social and economic fabric of a family and a community. In many communities, it is also often associated with stigma and stereotypical images that impact the wellbeing of a caregiver and the ability to seek timely assistance for loved ones and respite for his/her self.

In this session, Ms. Odete Nascimento and Ms. Susan Anstice discussed beliefs around Alzheimer’s Disease from a perspective informed by their experience and expertise. Both Ms. Nascimento and Ms. Anstice work closely with family caregivers and within organizations where it is part of their mission to provide culturally tailored services to clients and caregivers.

#### PANEL 3 – KEY MESSAGES

Alzheimer’s disease is one of many diseases that present a unique challenge in terms of supporting those afflicted and their caregivers. Specific to Alzheimer’s disease, however, are the prevalent stereotypes and misconceptions which influence the conversation about the disease, and are often detrimental to those afflicted and their caregivers.

In viewing this unique challenge through the lens of culture diversity, it is clear that there is a vital need to design programs and policies which recognize the diverse cultural perceptions of Alzheimer’s disease and of mental illness more broadly and the varying gender roles across cultures which can profoundly impact the caregiving experience.

When examining Alzheimer’s disease through this lens, one specific challenge is that many people with Alzheimer’s disease often revert back to their mother tongue, straining the ability of caregiver and care recipient to communicate with each other.

Of particular concern is that, increasingly, there are simply not enough formally employed caregivers proficient in these languages to provide adequate care. Due to such language barriers, there is confusion when seeking and accepting services, resulting in isolation and, often times, an exacerbation of the issue being addressed.

While important to examine Alzheimer’s disease and all care relationships through a cultural lens, it is also important to



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acknowledge that cultural groups are not homogeneous entities and that there are differences in terms of social class, gender, age, birthplace, and more which can make culturally tailored support services ineffective.

As an example, consider the issue of grief. It is commonly known that caregivers for those with Alzheimer's disease are prone to experience high levels of grief. However, grief and associated coping mechanisms are expressed differently across different cultures. Moreover, a simple 'cultural lens' is often inadequate for understanding the complexity of the issue. For example, within some traditional cultural groups, the idea of seeking grief counseling for taking care of one's parents is considered largely taboo. However, for a member of the same cultural group who is second generation Canadian and more acculturated, this taboo may no longer be a relevant concern. In the end, it all comes down to an individual's personal cultural experience, something which

is defined by much more than simplistic cultural assumptions such as ethnicity.

#### SUMMATION

Unfortunately, there is no 'one size fits all' policy which can address the various dimensions of the complex issue of caregiving for those with Alzheimer's disease in a multicultural society. Yet, in pursuing the best policy possible, it is important to consider how to balance the most pressing variables so as to best support caregivers of people with Alzheimer's disease.

**In designing an effective policy, there must be an emphasis on doing more than simply translating documents to circumvent language barriers.**

Effective programmes must recognize the complexity of the issues and take into account the impact of cultural interpretations on key issues such as grief, dignity, and mental illness.

#### CLOSING REMARKS

This enquiry demonstrated the commitment and passion of community organizations to add to the breadth of knowledge that exists about the emerging issue of caregiving in a culturally diverse community. The day's events were a rich opportunity to gather those closest to the issue to gain meaningful insight into the challenges and the nuances of culture and care. The intent of this enquiry was to provide a medium for knowledge exchange and mobilization with the ultimate objective of improving the quality of life of caregivers from all communities.

It is evident through this enquiry that research in this area is missing and a champion to advance this discussion is required.

However, this cannot be done in isolation and participants of this forum demonstrated a level of commitment to work together to raise awareness and address this increasingly critical concern.

As a nation that has embraced multiculturalism, and as population ageing continues to impact the social and economic fabric of Canadian society, it is important that civil society,

government, and private sector organizations recognize the social capital of caregivers and the diversity within and across this growing community.

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Canada 

The opinions and interpretations in this publication are those of the author and do not necessarily reflect those of the Government of Canada.





## MEETING DELEGATES

**Ms. Susan Anstice**

Clinical Social Worker, Community Care and Wellness for Seniors, Woodgreen Community Services

**Dr. Jane Barratt**

Secretary General, International Federation on Ageing

**Ms. Sarah Begbie**

Mental Health Clinician, Cyril & Dorothy, Joel & Jill Reitman Centre for Alzheimer's Support and Training, Mount Sinai Hospital

**Ms. Juddy Blackwood**

Member, African Canadian Heritage Association

**Ms. Jenny Carlson**

Program Assistant, Cyril & Dorothy, Joel & Jill Reitman Centre for Alzheimer's Support and Training, Mount Sinai Hospital

**Ms. Wendy Chow**

Program Manager, Assertive Community Treatment Team, Mount Sinai Hospital

**Ms. Monica Codjoe**

Client Services Manager – Senior Enhanced Care Team, West Community Office, Toronto Central CCAC

**Ms. Cathy Conway**

Director of Quality Management and Education, Alzheimer Society of Ontario

**Ms. Carole Cushnie**

President, African Canadian Heritage Association

**Ms. Beatrise Edelstein**

Senior Consultant and Program Director, Community Services, Toronto LHIN; Program Director, Community Services, Baycrest

**Dr. Rhonda Feldman**

Mental Health Clinician, Cyril & Dorothy, Joel & Jill Reitman Centre for Alzheimer's Support and Training, Mount Sinai Hospital

**Dr. Adrian Grek**

Psychiatrist, Geriatrics, Mount Sinai Hospital

**Dr. Sepali Guruge**

Associate Professor, School of Nursing, Ryerson University

**Dr. David Harvey**

Chief, Policy and Program Initiatives, Alzheimer's Society of Ontario

**Ms. Carol Holmes**

LTC Best Practice Coordinator, Provincial Projects, Registered Nurses' Association of Ontario

**Mr. Eric Hong**

Executive Director, Yee Hong Centre for Geriatric Care

**Ms. Allison Howard**

Manager, Community Support Services, Region of Peel

**Ms. Sherlyn Hu**

Mental Health Clinician, Mount Sinai Wellness Centre

**Ms. Sarafina Hui**

Health Promotion Manager, St. Paul's L'Amoreaux Centre

**Dr. Parvathy Kanthasamy**

Chair, Vasantham, A Tamil Seniors Wellness Centre

**Mr. Zul Kassamali**

President, The Multicultural Council for Ontario Seniors

**Ms. Gita Lakhanpal**

Mental Health Clinician, Cyril & Dorothy, Joel & Jill Reitman Centre for Alzheimer's Support and Training, Mount Sinai Hospital

**Ms. Lisa Levin**

Vice President, Communications and Development, Circle of Care

**Ms. Cherly Lochnan**

Ontario Society Coalition of Senior Citizen's Organizations

**Ms. Sandra Macleod**

Senior Policy Analyst, Seniors Policy Division, Employment and Social Development Canada, Government of Canada

**Mr. Peter Marczyk**

Social Worker, Alzheimer's Society Toronto

**Ms. Frances Morton-Chang**

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**“CULTURE, INDEED, SHAPES HOW WE CARE IN OUR RELATIONSHIPS, THE  
INSTITUTIONS OF OUR SOCIETIES, AND THE MATERIAL WORLD ITSELF.”**

-MR. CRISTIAN RANGEL-

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