

Understanding Program Participants & Family Caregivers
in a Japanese-Canadian Dementia-Friendly Program

IKI IKI PROGRAM

RESEARCH REPORT

2014-15

Nikkei Seniors
Health Care &
Housing Society

seniors.nikkeiplace.org

“

I always look forward to it.
I've never missed a day.

Program participant

”

INTRODUCTION

The Iki Iki Program (pronounced “*eekee eekee*” meaning “*lively*” in Japanese) is an initiative that was started in the Japanese-Canadian community by the Nikkei Seniors Health Care and Housing Society (NSHCHS) to find new ways to keep older adults engaged and to prevent social isolation. It is a weekly social program for older adults living at home who manage daily life on their own, or with help from caregivers. It targets people with dementia as well as those who prefer slower-paced activities.

In the Iki Iki Program, participants socialize with each other and with volunteers. They exercise, enjoy a Japanese lunch, and participate in activities that take their cultural background into consideration.

The program began in 2013, and as of September 2015 it is operating at Japanese-Canadian community centres in Burnaby, Vancouver and Richmond.

This report summarizes feedback collected in Burnaby through program participant interviews and family caregiver surveys conducted in July 2014 and six months later in January 2015. This summary of the findings provides a glimpse into their lives. Detailed summary of their needs and preferences in the program are covered in a separate report.

NSHCHS would like to thank the program participants and their caregivers who took part in this study. We would also like to thank the researchers at the Centre on Aging at the University of Victoria for

their help in developing the study, as well as the Vancouver Foundation for financial support. The findings will help improve the Iki Iki Program, not only in Burnaby, but also at other partnering organizations and beyond.

The Nikkei Seniors Health Care and Housing Society is a registered charitable organization based in Burnaby, British Columbia, Canada. It provides housing and services for older adults in the local Japanese-Canadian community. NSHCHS owns and operates: Nikkei Home; an assisted living facility. New Sakura-so; an independent living housing complex. As well as community outreach programs. More information at seniors.nikkeiplace.org

SUMMARY

Everything is nice. I enjoy it very much. *Program participant*

For some, the Iki Iki Program is the only scheduled activity for the week. For others, this is the only place where they talk about culturally familiar things in the Japanese language and enjoy Japanese food. After coming to the program for several months, the program participants confidently replied in the interviews that they come to the Iki Iki Program on Fridays at 10am, regardless of whether they experience challenges with memory or not.

Based on the interviews and surveys, overall, participants and family caregivers said that they were satisfied with the activities and the program set up (i.e. start/end time, location of the facility, room, lunch menu etc.). All program participants and their family caregivers responded that the Iki Iki Program has met their expectations.

Iki Iki staff show my mother care,
respect and compassion.

Family caregiver

Everyone is so nice there!
Program participant

IT'S THE PEOPLE

At the core of this weekly social program is the community of program participants, their caregivers, the program coordinator, volunteer activity leaders and volunteers. When asked what participants and families like about the Iki Iki Program, the conversation often turned to the people in the program and the interactions held with them. When program participants were asked about their source of happiness, the conversation often turned to family and others around them.

“

I am very appreciative of the support and care my mother receives at the Iki Iki Program. The program leaders are kind, respectful and very knowledgeable about seniors' care and needs. Mom loves going to the Iki Iki Program! Thank you so much for all of your support! *Family caregiver*

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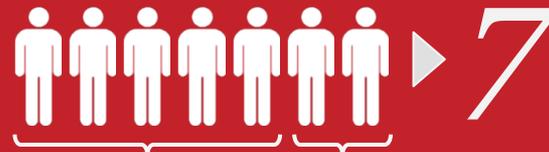
RESEARCH

PARTICIPANTS

PROGRAM PARTICIPANTS



FAMILY CAREGIVERS



Son/daughter *Husband/wife*

A total of nine program participants were interviewed in person, and seven of their family caregivers completed surveys in July 2014 and six months later in January 2015. In July 2014, all eleven participants who were registered in the Iki Iki Program were interviewed. Before the six-month follow-up, one passed away, and one moved into an assisted living facility, withdrawing from the program. One of the nine participants who was followed up in January 2015 had transferred to the Iki Iki Program at another location in September 2014; responses from

this individual were included in the analysis.

During the study, the number of participants in the program increased to fourteen. Only those who were interviewed in July 2014 were approached for the follow-up.

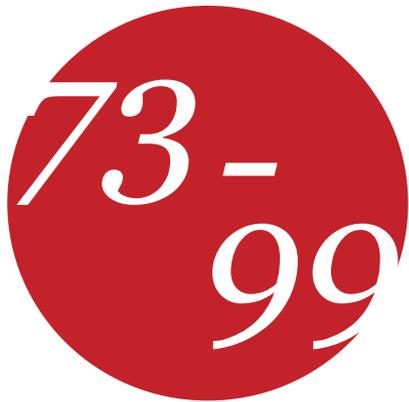
The list of program participants who took part in this study included two participants who were reported to not have dementia, alongside those who showed signs of cognitive impairment. Dementia diagnosis was not collected. If the individual

seemed to have difficulty understanding or answering questions in the interview, the questions were skipped.

The primary caregiver of the family was asked to complete the survey to provide input from their perspective. In addition, one family caregiver also provided survey responses from a paid care provider who interacted with the program participant daily; this information was referenced to supplement responses from the program participant.



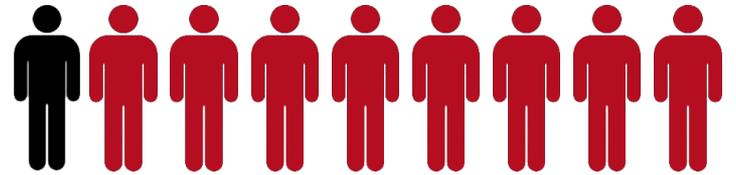
AVERAGE AGE



AGE RANGE

PROGRAM PARTICIPANTS

The age of the program participants provides insight into 1) activities, songs, conversation topics etc. that are familiar to them and 2) the level of physical activity that is suitable in the program. The age range for this group implies that what one individual recalls from her 20's would not be familiar to someone who is younger.



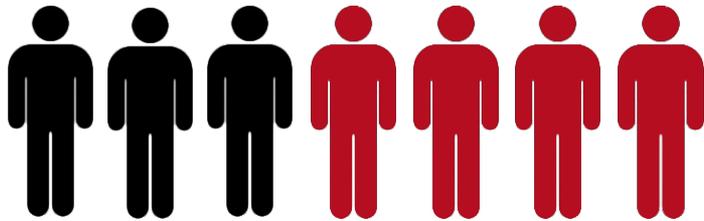
MALE/FEMALE DISTRIBUTION

Gender distribution also has an implication on the kinds of program activities that the participants would enjoy. The group of participants in this study was predominantly female and the program incorporated activities such as crafts and cooking. Accommodating needs and preferences of both genders helps make the program engaging for male and female participants.

FAMILY CAREGIVERS

Family caregivers of program participants may be their spouse or child. Children who are caring for their parent(s) are often working and are also taking care of their own family.

MALE/FEMALE DISTRIBUTION



AVERAGE AGES

61

85

SON/
DAUGHTER

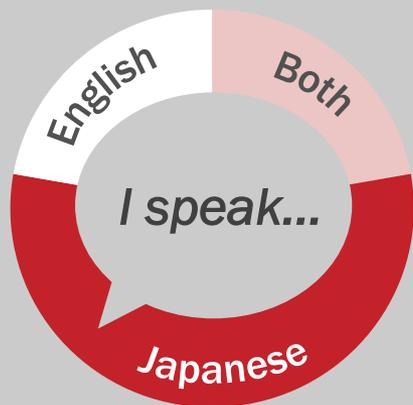
WIFE/
HUSBAND



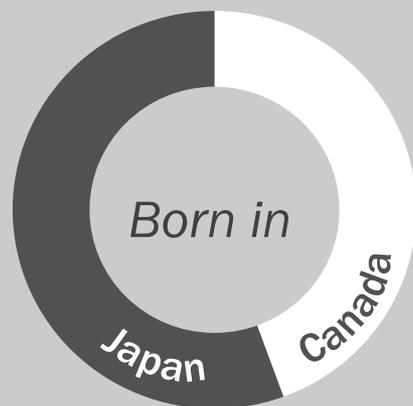
LIVING ALONE / LIVING WITH FAMILY

Some family caregivers were living with the program participant while others lived separately. Of the nine program participants in the study, three were living with family who provided care. The other five either lived alone, in a care facility or with a live-in paid care provider.

LANGUAGE & COUNTRY OF BIRTH



PROGRAM PARTICIPANTS

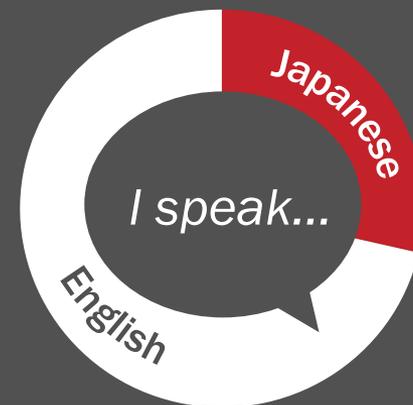


The country of birth and preferred language have great implications on program design. In the Iki Iki Program, the coordinator and volunteers are often reminded that what is common in Japan may not be familiar to Japanese-Canadians raised in Canada.

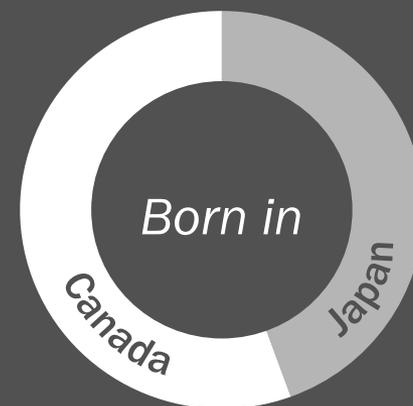
Most program participants preferred speaking Japanese (5) or were comfortable in both languages (2). On the other hand, a majority of the family caregivers (5), especially the children of the program participants, preferred speaking English.

During this study, one participant who spoke predominantly in English in the initial interview switched to speaking only Japanese six months later.

Five participants were born in Japan and immigrated to Canada, and four were born in Canada. In contrast, all except two family caregivers (spouses) were born in Canada.



FAMILY CAREGIVERS





Mom is at the point in her disorder where she is not motivated and/or doesn't always know what she needs to do to keep healthy. For example, she forgets to eat/drink and needs to be reminded. Cognitively, all these activities are helping. Her last 2 test scores taken months apart didn't show any deterioration, but we know this is temporary.

Family caregiver



HAPPINESS

In general, program participants are satisfied with their life as a whole and are feeling happy. Eight participants said they are “Very Happy” or “Quite Happy” and one responded “Not Very Happy”. Seven out of the total of nine program participants responded “Satisfied” or “Somewhat satisfied” and two answered “Neutral”.

Happiness for program participants is strongly related to their connection with people - spouse, children, and/or neighbours. In other words, people, especially family members, are their source of happiness. The second reason for happiness is a sense of autonomy reflected in this comment, “I can live the way I want. I can do everything I want.”

On the other hand, lack of connection with family was a reason why one respondent with children said that she was not happy – “I live alone.”

There was a slight change in the responses to the questions regarding happiness and satisfaction over the six months, but the difference was not significant.



HAPPINESS

I'm together with my husband and son.

I feel that I have strong ties with my children.



SATISFACTION WITH LIFE

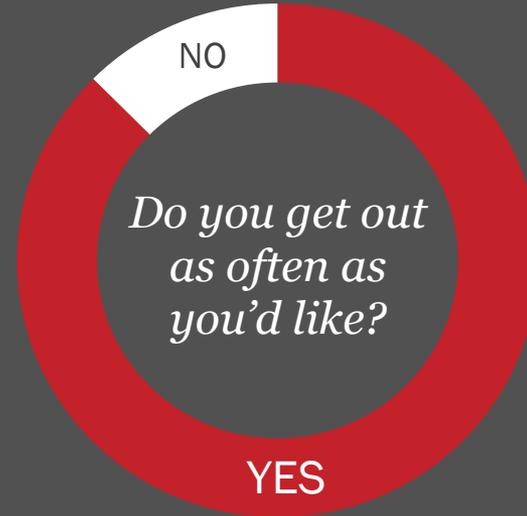
OTHER

ACTIVITIES

Some program participants go to a number of programs every week. For others, this is the only program.

Taking part in community activities is one way to stay connected and to avoid social isolation. When asked if they get out as often as they would like, the majority of program participants replied, “Yes” both in the initial and six-month follow-up interviews. Family caregivers were asked the same question about the participant and most believed that their spouse/parent got out as often as they would like. A few were concerned that their spouse/parent did not get out enough.

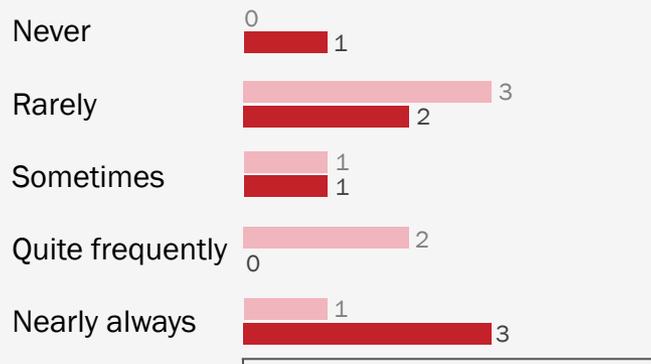
The programs and places they go to range from English-speaking adult day programs to other Japanese-Canadian programs. Depending on the program/activity, they go alone or with family.



Programs, Places & Activities

- Other Nikkei Centre programs (Kui Do Raku, gateball)
- Tonari Gumi (Vancouver) programs
- Hobby groups (*shigin*)
- Buddhist temple
- Adult day programs (Fellburn, Kinsmen)
- Japanese-Canadian community events (Mochitsuki, plant/craft sales)
- Go out with family (meals, shopping)
- Go for walks around the house

1 Do you feel that because of the person you care for that you don't have enough time for yourself?



2 Do you feel stressed between caring for the person you care for and trying to meet other responsibilities (work, home) ?



FAMILY

CAREGIVER

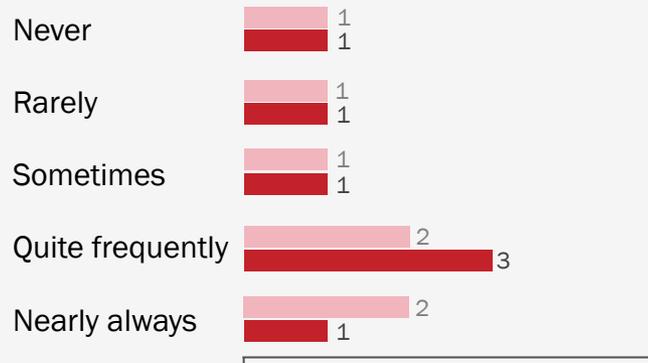
BURDEN

The family caregiver surveys incorporated four questions from the Zarit Scale of Caregiver Burden, a widely used tool for measuring caregiver burden. The questions were taken from the four-item screening version which correlates with the full 22-item version.

The four questions were asked both in the initial and six-month follow-up surveys. There were some changes in the response pattern, but there was no significant difference.

July 2014
January 2015

3 Do you feel strained when you are around the person you care for?



4 Do you feel uncertain about what to do about the person you care for?



Other family members are busy and I can't go out unless I take my wife.

I'm busy taking care of own children and husband.

I'm also busy with work.

July 2014
January 2015



As my parents' dementia continues to progress, I feel increasingly overwhelmed, stressed and guilty. I am spending at least 3 – 4 days a week with them and feel they are taking so much of my time away from my own family and friends.

At the same time, I love my parents and feel lucky that I am able to support them when they need me most. They were the *most* wonderful parents ever and I feel that it is now my turn to help them.

Family caregiver



When she was younger (before Alzheimer's) she loved to socialize and go out. Now she *needs* to go out or at least be engaged. She is often home alone when all family members are at work and her default activity is sitting and watching Japanese TV. *Family caregiver*

FAMILY CAREGIVER WISHES

Three main areas of family caregivers' wishes for the program came out of analysis:

- **To provide stimulating activities that are good for the body and the brain**
- **To keep the person occupied**
- **To provide an opportunity to interact with others**

Conversely these wishes could also be interpreted as things families think are missing in the lives of those they care for:

- **Engagement with the society**
- **Interaction with other people**
- **Motivation to do things**

Some caregivers, mainly children of program participants, also mentioned that they value the Japanese aspect of the Iki Iki Program as it is an opportunity for their parent to get a regular exposure to Japanese language, culture and food.

CAREGIVER

SUPPORT

The survey asked family caregivers to select or list support that they wished they were receiving:

Caregiver support group

Respite

Referral to health care and/or social support professionals

Information about diagnosis

Financial support

Placement in Japanese-Canadian care facility for people with dementia

I wish that my brothers would offer to help me more. The majority of [my parents'] care lands on my shoulders and my health is not that good. It would be nice to have some respite support.

It would be helpful to find less costly but suitable transportation [to go to the Iki Iki Program] ... Mom pays \$60 per day for transportation that is safe for her. Other transportation programs such as HandyDart, volunteer drivers etc. were not suitable or even more expensive.

I wanted to let you know what is happening to our family as I do not feel the survey looked at the next generation but also in the hopes that more resources will be developed for other families who will be facing similar situations as the “baby boomer” generation ages.

I often wondered why Japanese Americans in Hawaii etc. seem to fare so much better economically, in politics and in real estate, than Japanese Canadians. I recently learned that Japanese Canadians were not as well compensated for their financial losses during the war years. So, even though they were honest and hard-working, it was difficult for our parents to provide for their children and certainly for their children’s future in the form of inheritance, etc. As well, Japanese Canadians are often humble and reluctant to ask for help. So I feel there are probably many JC seniors

and their family members who are having difficulties.

On a personal note, I was hoping that by attending Iki Iki at Nikkei Centre, mom would feel more comfortable about the Centre and its staff and that when a place for Alzheimer’s patients is established that she would be more willing to be included.

Although I am retired from paid work, I have a daughter with special needs who lives with us and requires 24 hour/day care. I do 24-30 hours per week, and hire support workers for the rest. Our oldest brother has been diagnosed with dementia, and also requires care. I try to coordinate the care of all 3 with the help of my other siblings. My siblings do the personal care, cooking, household tasks, and yard work, repairs, bill paying etc. and I take mom, eldest brother, and daughter to all medical appointments and try to

implement doctors’ advice.

I have applied for low income supplement for my oldest brother as he was a commercial fisherman and has not had any income for several years, and, consequently no savings. It is stressful for my sister to manage his finances.

Mom needs to move more frequently than she does as she has arthritis (double hip and one shoulder replacement) and constant pain in left shoulder. She also continually develops bed sores because her default activity is sitting and watching TV. She is on her own at home quite frequently as both sisters work full time. So in the not-too-distant future, she will need to be in a place where there is 24 hour supervision and more activity for her.

Family caregiver

Iki Iki Program Research Report 2014-15 | Written by C. Keiko Funahashi

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