

MEANINGS ATTRIBUTED TO
FAMILY COUNCILS AND RELATED
CONCEPTS BY IMMIGRANT
RESIDENTS OF LONG-TERM CARE
AND THEIR FAMILY CARERS

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Introduction

Immigrant older adults are increasingly moving into residential long-term care (RLTC) homes. Amongst visible minority immigrants in British Columbia, this is perhaps most true of those of Chinese origins, who account for the largest proportion of immigrants to the province and make up its highest proportion of visible minority older adults. Despite the diversity of residents' ethnocultural and linguistic backgrounds, however, the vast majority of RLTC homes were designed and continue to be run in accordance with Anglocentric norms and values. In British Columbia, the predominant language of care delivery in all but a handful of RLTC homes is English. If they are lucky, immigrant older adults in care—especially those without English—have family members who can bridge the linguistic divide and advocate for their needs.

This study explores the extent to which family members who regularly visit Cantonese-speaking residents in two RLTC facilities in British Columbia understand and utilize Family Councils, which have been established to provide family members with a collective voice. Studies with 'mainstream' residents show that family participation in Family Councils increases family inclusion in decision-making that is reflected in improvements in the *quality of care* of the residents as well as their *quality of life*. Accordingly, our study also sought to explicate how the residents and family carers interviewed perceived these two indicators of quality, and how these perceptions corresponded with their views on Family Councils.

Background

Family Involvement in Residential Long-Term Care (RLTC)

Over 250,000 frail, older Canadians, 70% of whom have dementia, live in RLTC.^{1,2} RLTC is an essential and evolving part of the Canadian healthcare system, providing 24-hour nursing care for seniors with complex care needs.³ In Canada, RLTC is provincially mandated. At any given time, 7% of Canadian seniors live in RLTC and over 50% of adults will spend a portion of their life living in this setting.^{4,5} In BC, an accelerated period of restructuring during the first half of the 2000s resulted in a healthcare context in which the resident population is much more medically complex, residents and families have minimal choice about where a senior will reside, and staff are more transient, as they are less likely to be employed by a facility.⁶ Increasing pressure on the system is expected with the rapid growth of the population aged ≥ 85 years,^{7,8} and seniors with dementia.⁹ Research reveals that these demographic shifts and macro-level policy changes influence micro-level, or every day, interactions between family and staff.¹⁰ This is important in light of the sector's reliance on care provided by families, who contribute tens of millions of hours of care yearly, but often feel frustrated and disempowered in their new role as "visitor."¹¹⁻²⁴ Yet there is a paucity of research into the roles and experiences of families in the care of older adults in RLTC and recent recognition that this knowledge gap must be addressed in order to broaden the focus of person-centred care and address conflict between families and staff.²⁵⁻²⁹

Family Councils, are defined as independent, self-determining groups comprised of residents' family members who have assembled with the main purpose of protecting and improving the quality of life of those living in RLTC.³⁰ Family Councils are a mechanism by which families can collectively have input into broader organizational practices to improve quality of care, by encouraging greater accountability from the facility.³¹⁻³³ Family Councils are shown to increase and enhance family inclusion,³⁰ provide emotional support for family members who are transitioning out of their roles of primary caregivers,^{30,34} and are effective as a means of conflict resolution for families of residents.³⁴ They can help families to overcome barriers to advocacy that arise from their

perceptions about their lack of insider information³⁰ and from concerns that they may further jeopardize quality of care by speaking out.^{13,35} *However, there is currently no research on Family Council involvement or perceptions of immigrant seniors/families in RLTC.*

Immigrant Seniors and their Families in RLTC

Understanding the relevance of Family Councils to immigrant seniors in RLTC and their family members is critical for two reasons. *First*, RLTC is less accessible to immigrant seniors due in large part to the incompatibility between their cultural mores and those of most RLTC facilities which are designed in accordance with dominant (Eurocentric) cultural norms.⁴⁰⁻⁴³ Family Councils have the potential to increase the capacity of families to advocate for their elders by facilitating a dialogue that is less confronting than direct communication with facility staff. Yet we cannot be certain that Family Councils will be acceptable to immigrant families.

Family Councils have been found to exert a positive influence on family inclusion and the quality of care for and quality of life of older adults residing in RLTC. But the cross-cultural transferability of these concepts cannot be assumed. Accordingly, we need to know how immigrant seniors in RLTC and their families understand the constructs of and the relationships between ‘Family Councils’, ‘family inclusion’, ‘quality of life’, and ‘quality of care’ in the context of RLTC in British Columbia. The goal of this study was therefore to understand what these terms meant for older Chinese immigrant residents of RLTC and their family members and if and how this related to their participation (or not) in Family Councils.

Relationship to P2P Themes

Our research addresses two interrelated themes of interest to the Pathways to Prosperity (P2P) research group: (1) At-risk populations of immigrants in Canada, and (2) The health and wellbeing of immigrants in Canada.

At-Risk Populations of Immigrants in Canada

This study is especially salient to two at-risk populations: older immigrants and women. Seniors represent the fastest growing segment of the population and average more than two times the number of physician contacts per year compared to persons under the age of 65.⁴⁴ Visible minorities aged 65+ comprise more than one-quarter of the senior population in the Vancouver Census Metropolitan Area. Of these, more than 85% are Chinese, South Asian, and Filipino.⁴⁵ Between 2002 and 2006, the majority (88%) of *foreign-born seniors* immigrating to BC arrived as Family Class immigrants (*i.e.*, parents and grandparents sponsored by children/grandchildren) and almost two thirds had no official language ability.⁴⁶ Family class immigrant seniors have poorer health than long-term immigrants and the Canadian-born population.⁴⁷⁻⁴⁹ Compared to immigrants overall, arrivals in this class have lower levels of education and English language ability. Age and immigrant status are thus key identity markers to consider in relation to experiences of residence in RLTC and relationships with younger family members.

Although the aging process can be positive, it also presents challenges related to both physical and social losses, which are more often and more acutely experienced when they intersect with gender and immigrant status.⁵⁰ Sixty percent of Family Class immigrants to BC are female.⁵¹ Barriers to healthy aging have been identified in health policy, service delivery, and clinical practice.⁵² Oppressions experienced earlier in life by the current cohort of *older immigrant women* have often left them with low levels of social capital (*i.e.*, education, literacy, experience outside of the domestic sphere),^{53,54} which in turn influences determinants of health and the resettlement experience.^{55,56} In Canada, they encounter new forms of oppression based on their immigrant status, racialization and status within the family which, in combination with low social capital, can render them vulnerable to isolation and loneliness,^{57,58} family conflict (possibly even abuse and neglect),^{57,59,60} and economic insecurity,^{50,61} all of which can negatively influence mental health.^{52,55,62} The increased vulnerability of older immigrant women thus reinforces the need for a gendered approach that nonetheless pays

heed to intersections with other identity markers, such as SES and immigrant status.

As in the Canadian population overall, women are also most likely to predominate as *family care providers* in immigrant families of South Asian and Chinese origins.⁶³⁻⁶⁶ These roles are shaped by intersections of culture and gender as well as SES and the timing of immigration of the carer and care recipient. For example, daughters-in-law who grew up in Canada, speak English and are able to drive are much more self-assured and independent and hence have a very different relationship with their husband's parents than do those who arrive from India with little education subsequent to the in-law's immigration.^{54,67} The quality of these relationships can be expected to influence the care that these younger women provide to ailing in-laws in RLTC. Moreover, in the absence of the extended family and community supports in which the ideal of familism took root, the familial obligations that women juggle with work in the immigrant context are difficult to fulfill⁶⁸ and can have negative physical and mental health outcomes.⁶⁹ Moreover, we must consider "the underlying assumptions of family obligations in policies ... that ... place the onus of responsibility on the person in need of care and his/her family (particularly on women), and can render both parties vulnerable to exploitation and abuse."^{59,70}

Health and Well-being of Immigrants in Canada

Placing an older family member in RLTC is stressful for any family, but this stress is amplified for immigrants who must contend with the departure this represents from cultural mores that emphasize values such as familism or filial piety, norms that place precedence on the solidarity of the family over the needs of the individual and includes the duty to provide care for aging family members.⁷¹ Failure to observe such cultural norms is often perceived as shameful, for both the elder and their family.^{57, see also 72} As a result immigrant seniors are under-represented in long-term care,⁷³ they also underutilize other community-based and health supports.^{55,74} For example, support groups for dementia carers have been shunned based on the fear that "community members would judge them negatively for not being able to cope with their responsibilities on their own."⁷⁵

Admission of sponsored (Family Class) immigrants into RLTC is complicated by their sponsorship status, both in terms of their financial dependency on their sponsors, and because of complex regulatory barriers that vary across jurisdictions.^{57,76} Sponsored (grand)parents are legally and economically dependent on their sponsors for twenty years. If their physical or mental health fails during that period, sponsors may struggle to meet the demands of their medical care and the accommodation co-payments required for RLTC.

Even if families can afford them, most RLTC homes do not meet the cultural, spiritual and linguistic needs of many immigrant residents, particularly those from racialized, predominantly non-English speaking populations, such as those from Canada's two largest immigrant source countries: China and India.^{40,42,52,77} As a result, the families of immigrant seniors in care provide a disproportionate amount of support to their elders, particularly in the form of translation, interpretation and food provision.^{40,43} Baumbusch found in her research that included residents of RLTC without English, that a granddaughter was able to help staff identify why her grandmother would not eat; the son of another screaming resident identified that his mother needed an enema rather than the tranquilizer that the staff were about to dispense.⁴³ Without family support, immigrant seniors are too often mistakenly placed in secure Special Care Units (for dementia residents) when communication, not dementia, is the problem. While non-English speaking residents at one RLTC Site constituted 7% of the overall resident population, they accounted for 35% of residents in the Special Care Unit.⁴³

Many family members of immigrant residents are also disadvantaged by their own relative lack of knowledge about the Canadian health care system,⁶⁸ the Euro-Canadian values that inform the structure of RLTC and day to day care practices within them,^{41,43,52} and by their own disadvantaged position in the Canadian economic system as relative newcomers.⁷⁸⁻⁸⁰ For example, many immigrants

work below their qualifications in minimum wage jobs with little flexibility. Moreover, some do not have the language skills necessary to either interpret for their elders or communicate effectively with medical and other care personnel in RLTC.^{40,52,74,81,82} This said, there is considerable variability within the immigrant population with respect to identity, community relationships and the extent to which their social and political capital provides them with the means to combat discriminatory attitudes against them.^{79,83,84}

Methodology

Theoretical Approach

The theoretical perspective guiding this research is Critical Gerontology and Intersectionality. Critical Gerontology examines how cultural-contextual factors at the macro-level (e.g., *organizational factors*: facility size, ownership, geographical location; *systemic factors*: provincial policies, philosophical approaches to care) shape the micro-level of daily experiences.^{85,86} An Intersectionality approach explores how multiple social locations (e.g., age, gender, class, immigration status, illness categories) operate simultaneously to reflect the dynamic nature of health and social processes.⁸⁷⁻⁹⁰ We employ both anticategorical and intracategorical approaches that probe the ‘givenness’ of categories of difference and zero in on neglected points of intersection of multiple master categories, respectively.⁹¹ These approaches privilege the “process by which [categories] are produced, experienced, reproduced, and resisted in everyday life.”^{91, p. 1783} Together these approaches allow for more-in-depth understanding of how cultural-contextual factors and social locations influence the prevalence, structural features, role, function, and participation in Family Councils. As well, they enhance our understanding of how Family Council policy shapes families’ ability to engage in collective advocacy for, and information sharing about quality of care and residents’ quality of life in RLTC.

Research Site and Sample

The RLTC sector in BC is the setting for this study. BC is an ideal setting for this research as it is one of only three provinces to have Family Council policies, as set forth in the Community Care and Assisted Living Act: Residential Care Regulation, Section 59.³⁶ Participants were sampled from two RLTC homes in Vancouver, B.C. whose characteristics are summarized in Table 1.

Table 1: Site Characteristics	Site 1	Site 2
<i>Number of residents</i>	196	99
<i>% of residents who are non-English speakers</i>	Almost 60%	~ 90%
<i>% of residents who are Cantonese speakers</i>	Almost 25%	~ 80%
<i>% of residents with cognitive impairment</i>	> 80%	Majority – mild - moderate ~ 20% - severe
<i>Type of rooms</i>	Private = 16 2 beds/room = 8 4 beds/room = 41	Private = 16 2/3/4 beds per room = 26
<i>Family Council</i>	Yes ~ 12 years	No

Purposive sampling was used to select residents that (a) had lived in the RLTC for ≥ 3 months, (b) were aged 65+, (c) and identified Cantonese as the language they speak the most. Family members interviewed had a relative who met these criteria and lived in one of the two study Sites that they visited regularly. Recruitment was complicated by the high proportion of residents with cognitive impairment at both Sites. Our final sample included 11 family carers and nine residents (see Table 2), of which 4 (1 carer and 3 residents) were from Site 2, and the remainder from Site 1. Residents at

Site 2 appeared to be frailer and their carers were less frequently present than at Site 1, and hence were more difficult to match to our inclusion criteria and/or recruit.

As anticipated, our sample included more women than men which speaks to the greater longevity of women and hence their over-representation in RLTC³⁷, as well as the gendered nature of caring work, whereby women—particularly daughters—are more likely to be providers of care for family members.³⁸ Six of the nine residents interviewed were women, as were all of the 11 family carers. All but one member of the resident sample were 75+, and half of these were aged 85+. This is consistent with the overall composition of residents in RLTC who tend to be older and frailer than the wider populace of older adults.³⁹ Nine of the 11 family carers were aged less than 65, which reflects the fact that the majority (n=7) were daughters of the resident and one was a daughter-in-law. Two were wives and one was a paid companion.

Seven of the nine residents had come to Canada as Family Class, or sponsored immigrants, whereby they were sponsored by an adult child. One male resident came under the economic class and a female resident was the wife of an economic immigrant (here referred to as a secondary economic immigrant, a class that also includes children of the principle economic immigrant who migrate at the same time). By contrast, only three of the 11 carers were sponsored, seven were economic immigrants (two of them secondary), and one preferred not to reveal her immigration class or time spent in the country.

Of the remaining participants, all but one resident had been living in Canada for 10+ years. This time period is significant because it is the minimum amount of time sponsors are financially responsible for older Family Class immigrants (as of 2014, this time period was increased to twenty years).⁹³ In fact, the remaining 8 residents and 8 of the 11 carers had been living in Canada for 20+ years. Thus we can assume that, barring one resident, all participants were eligible for health and social services from the Canadian government.

Table 2: Sample characteristics

	Age	Facility	Gender	Immigration Class	Time since Immigration	Carer's Relationship to Resident
Family Carers	<65	Site 1	Female	sponsored	20+y	Daughter
	<65	Site 1	Female	economic	10-20y	Daughter
	75-85	Site 2	Female	economic	20+y	Wife
	<65	Site 1	Female	sponsored	10-20y	Wife
	<65	Site 1	Female	economic	20+y	Daughter
	<65	Site 1	Female	sponsored economic	20+y	Daughter-in-law
	<65	Site 1	Female	secondary	20+y	Daughter
	<65	Site 1	Female	economic	20+y	Daughter
	<65	Site 1	Female	Unassigned	Unassigned	Companion
	<65	Site 1	Female	economic child	20+y	Daughter (*)
Residents	85+	Site 2	Female	sponsored	20+y	Son
	75-85	Site 2	Female	sponsored	20+y	Son
	<65	Site 2	Male	sponsored	20+y	Sibling
	75-85	Site 1	Female	sponsored	20+y	Daughter (*)
	85+	Site 1	Female	sponsored	<10y	Son

85+	Site 1	Female	economic secondary	20+y	Adult children
75-85	Site 1	Male	sponsored	20+y	Wife
85+	Site 1	Female	sponsored	20+y	Son
75-85	Site 1	Male	economic	20+y	Wife

* Dyad members

Limitations

Our target sample originally included Punjabi speakers who used to be present in higher numbers in the two study samples. However, the numbers dropped so dramatically prior to our commencing the research that the confidentiality of any Punjabi speaking participants would have been impossible to secure. We therefore narrowed our language inclusion criteria to Cantonese speakers. While we had originally hoped to interview dyads of residents and carers, we found that the population of residents who were sufficiently cognitively intact to understand the consent process and participate in an interview was considerably smaller than we had anticipated. The vast majority of residents in the two homes had some degree of dementia. Our research assistant visited the two care homes at different times of the day, including later in the evening and weekends, when the majority of family members visited. However, he found that the residents who were capable of speaking to him did not have family members who visited them often. Conversely, family carers who were most often present at our study Sites were attached to a resident with dementia who did not meet our eligibility criteria. Hence we secured only one resident-carer dyad. As a result, we lost the opportunity to compare responses relating to expectations of care across the two halves of each dyad to identify the extent to which perceptions differ intergenerationally within and across families. The advantage, however, is that we have gained valuable perspectives of family members about their experiences of providing care to persons with dementia in the RLTC setting, and on their perspectives on their family members' quality of life and quality of care. This is important given the preponderance of persons with advanced dementia amongst the RLTC residents.

Data Collection and Analyses

Data were collected between January and March, 2016. Participants were recruited and interviewed by a bilingual (Cantonese/English) research assistant (Li). To gain an understanding of the context of the two Sites and to allow residents and staff to become familiar with him prior to data collection in order to facilitate recruitment into the study, Li engaged in participant observation of approximately 8 hours between the two Sites. This occurred in periods of 1-2 hours at a time, at different times of the day so as to observe residents engaged in different activities, such as a music program, or dining, and at Site 1, he attended a Family Council meeting.

Subsequently he conducted in-depth dialogic interviews with residents and their family members in which he simultaneously explored (a) the indivisible identity markers that underlie people's experiences of intersecting oppressions such as ageism, sexism, and racism⁹⁰ and (b) the meanings they attribute to *Family Councils* as well as *the potential outcomes of participation in them* – i.e. family inclusion, quality of care and quality of life. Interviewees were also encouraged to speak about their experiences with the health care system and the RLTC in which the older person resides. The interview protocols used for each group are provided as Appendices A and B.

All participants were interviewed privately in the language of their choice, *i.e.*, Cantonese or English. All but two carers chose Cantonese. Interviews were 60-90 minutes in length, and were broken up into smaller units of time, when necessary. All interviews were audio-recorded and simultaneously translated into English (as necessary) and transcribed by the bilingual RA.

Interview transcripts were thematically coded with qualitative data management software, NVivo 10® by Li, an NVivo trainer, with codes reviewed and revised by PI, Koehn, and discussed with Baumbusch and Reid. Careful cross-coding allowed us to explore the impact of different

combinations of identity markers on the meanings assigned to Family Councils and their potential outcomes.

Research ethics

Approval for the study was jointly obtained from Simon Fraser University and Providence Health Care and followed the guidelines set forth in the Tri-Council Policy on Ethical Conduct for Research Involving Human Subjects.⁹² To protect their confidentiality, quotes from participants provided in our findings are identified by unique alphanumeric identifiers (e.g. R01, C02 ...) that distinguish between residents (R) and family carers (C). Given the small sample size, we do not distinguish between participants by Site, since they may be readily identifiable by staff and administrators at those Sites. For the same reason, we do not identify the gender of the residents interviewed or to whom carers refer and gendered pronouns in quotes are rendered neutral (i.e. s/he, him/her, his/hers). Since all carers interviewed are female we retain their gender identification in the quotes.

Findings

Family Councils

During the data collection period, research Assistant, Li, was able to attend one Family Council meeting. He noted that of the 15 participants, four were Asian, but none were Cantonese speakers.

A couple of residents in the sample, particularly at Site 2 where no Council had yet been established, said they had not heard of Family Councils, nor did they understand their purpose. However, the majority of respondents indicated some awareness of the existence and purpose of the Family Council as an opportunity for family members to discuss matters concerning the RLTC, to advocate for their relatives' needs, and to learn about central concerns, such as dementia. Some mentioned that they had learned about the Family Council from postings in the elevator. Within our sample, only three family carers indicated that they or another family member attended those meetings, and then only occasionally.

One of these felt that they had a responsibility to do so at least once a year, so as to "know what's going on" and "to see around the table who's there" (C07). She felt that the immediacy of the responses to her questions provided by attending staff, and opportunity to place the communication in context (in contrast to email) was a distinct advantage.

Others nonetheless saw the value of a Family Council even if they or their relative didn't actually attend:

"There should be an opportunity to get together and chat. We can improve on the already good, add what we currently lack." (C04)

"Yes, it's useful. ... The hot water system was broken, they [family members] brought it up in the meeting and the manager bought a new system." (R03)

"When your relatives have something to say, there's a place to voice out. Two ways. For example, for me as a relative I may ask, "Why do you do such and such?" They can explain why they're doing this. It's two ways it's not one way." (C08)

"Of course it's useful. It's very useful. ... [I]f you're a doctor, I tell you my comments, you're the only one who knows. However, in a Family Council meeting, I can say something and everybody knows about it. ... Everybody knows. There are conclusions, then they can make improvements." (C10)

Barriers to participation

The low attendance of Cantonese-speakers in the Family Council meetings appears to contradict

the value that many residents and their families in our sample seem to place in having one. Several reasons for this emerged.

Some interviewees expressed their reservations about the utility of the meetings. A prevailing belief was that attendees' voices would not be heard. In one instance, this belief was expressed by a carer who had brought up a concern at a meeting and felt that this concern was dismissed and that nothing had changed:

"They ask for our comments and opinions but their mind is already made up. There is nothing we can do, they won't listen." (C02)

In most cases, however, the belief that they would not be heard was based on their broader experience in the residence and their conversations with others rather than direct experience with the Family Council itself:

"I also have an intuition that it's useless to attend. ... Other people have tried to voice their concerns, but nothing's changed. The staff don't even like family members getting too close among themselves on the same floor." (C03)

"Like the relatives go to the meeting and want to complain about various things, about some things to be changed, they can't. They only argue. It's very hard to bring something up. That's why [another family carer that I was talking to] says now, "I'm not attending these meetings." He/she only types the complaints out on a computer and emails to the boss. "I am not coming to these meetings." Sitting there for two hours in a meeting, nothing will be solved. It's just argument." (C05)

"No, there isn't much use. Like now they [staff] don't like people complaining too much, therefore nobody says anything anymore." (C05)

The limits of what the Council could accomplish in the face of systemic barriers were also raised:

"I think that there is not much use attending. I mean you can say all you want, but whether they do something about it is completely a different story. Even if we say something, will it be acted on? No one knows because the authority to make changes does not lie with the Council itself. The power is in the hands of the staff ... The Council cannot force changes."(R08)

"[H]ow much can they change? It's hard to change everything promptly, but do it gradually." (C04)

Others felt that a Family Council was unnecessary because their own needs were minimal:

"I have not much to say. I think those who attend are those with lots of opinions. Saying a lot of things to complain. They usually complain, but I don't have complaints. I feel that I don't need it [laughs]." (C06)

"I don't think there needs to be much improvement." (R02)

The following quote nonetheless raises the question as to whether residents minimize their own need for their families to advocate for them out of consideration for the needs of the family carer:

"I am doing fine and don't want [my adult child] to come here and go to the Family Council meetings. Sometimes his/her neck hurts and he/she couldn't

drive.” (R02)

One resident minimized his/her needs and questioned the efficacy of introducing the Family Council as a third party because he/she could more readily communicate problems directly to staff:

“[W]e don't need a meeting for it. Because if I have some needs, they won't be huge needs. ... They [my children] will tell the head nurse. I tell my daughter to say it. I can also tell them myself. ... I think if there's something special, I can tell them immediately. We don't have to think for a long time. ... If you wait too long, it's not effective” (R06)

Others point to the cultural constraints against speaking out in public:

“Based on my years of experience being here. In general Chinese don't participate. Compared to westerners, we Chinese come more regularly to visit our family. But if you ask them to attend a meeting, none of them will come. ... They could be complaining to other Chinese members but once you ask them to speak about them in a meeting they have all sorts of excuses not to attend. They shut their mouths.”(C02)

“I think that Chinese, Asians are afraid to say something bad. Most likely it's like, “Good, it's quite good.” An easy example is you ask, “Is it [the food] tasty?” The reply is, “Yes, it's quite delicious.” Maybe it's not delicious, it may be too hard. They [Chinese] are afraid to voice their true opinions.” (C04)

Three carers mentioned the difficulty for people with limited English to participate meaningfully in meetings conducted in English only. To get around these language and cultural barriers, some Chinese carers said they feel that they are better off sharing their concerns with another (non-Chinese) member of the Family Council rather than attending themselves:

“I mean they can reflect on things, there is a system, or someone who can say things [tell the truth], isn't it better? Some of them may be mindful,” Would I be considered troublesome if I say too much? Be considered too demanding.” There could be a third party saying our concerns.” (C04)

“There is a man downstairs who is a family member, he is here day and night almost. His [parent] lives here and he is a westerner. He seems to be the head of the Council. If we have any complaints, we can simply tell him” [C09]

“He told me to tell him whatever I needed to tell him, we are quite good friends. He said he could fight for our rights, something like that. ... I think it's somewhat useful, someone is here voicing our concerns.” (C11)

The most commonly supplied response to why people did not attend the Family Council was that they or their family members did not have the time. One resident said that both his/her adult children worked 7 days a week, for example. The all-female carers interviewed reflected the gendered nature of care work whereby they were torn between providing care for an elderly parent as well as their own children and spouses, often on top of working full-time. They further reminded us that they were at the residence to provide care for their family member:

“The timing is not right. Everybody needs to work—6:15 pm is not the right time. I need to clean my mom. ... If it's 7:00 pm people have eaten dinner at home

already, who wants to come out again?” (C02)

In sum, while some Chinese residents and/or their family carers perceive that a Family Council is needed and could be beneficial, very few carers actually attend. A plethora of reasons were offered:

- their voices are not heard,
- the Family Council doesn't have the power to make change,
- going through the Family Council is less effective than communicating directly with a care provider,
- there is no need for them because either the residents' needs are minimal or the residence already meets those needs well,
- Chinese are culturally averse to airing their complaints in public,
- non-English speaking carers face a language barrier, and
- many carers cannot find time in their busy lives or the timing of the meeting does not fit their schedule.

Some get around these barriers by speaking to the readily available (non-Chinese) chair of the Family Council in whom they trust to express their concerns. Being personally asked to attend by the Family Council chair was an impetus for one carer to attend two meetings.

In the following section, we'll explore the veracity of these statements in relation to what our participants told us about (a) the quality of care provided and (b) the quality of life experienced by residents in RLTC facilities. Studies with mainstream older adults have identified a positive association between both when family members participate in Family Councils, but we do not know what these concepts mean to Chinese origin older adults and their families and hence cannot predict the nature of their relationship with Family Councils.

Quality of Care

In public RLTC homes in British Columbia, “You pay up to 80% of your after tax income on a monthly basis to cover the cost of housing and hospitality services including meals, routine laundry and housekeeping, subject to a minimum and maximum monthly rate.”⁹⁴

Both Sites in our study are public and interviewees were emphatic in their assertion that this was reasonable. For example,

“Of course this is reasonable. For 80 per cent, she's got medical care, and medical staff taking care of her, and everything including three meals, diapers, etc. I think this is really really reasonable. She still has 20 per cent left for her personal use, for example, styling her hair. For here, I think the government needs to subsidize heavily for her.” (C08)

Some carers compared the value of what their family member received favourably to other countries, such as Hong Kong. One resident commented on how it was so much more affordable than the private residence where she had previously lived. One mused that it would be nice to be able to afford a single room rather than the 4-person room currently occupied.

For the most part, residents needed assistance to use the toilet. One resident pointed out that the toilets were sometimes in use for bathing and residents were left waiting to use them; he/she thus concluded that more toilets were needed. For the more able-bodied among them, getting assistance simply involved pressing the call bell to alert the care staff to this need. Residents and carers were satisfied that the bell provided them with a level of safety that could not be achieved at home.

More frail residents required the use of a lift to transfer them between bed, wheelchair and toilet.

One carer complained that

“They tried to use a ceiling lift to move her to a commode. But she had no strength in half her body. Also, everything was rough work, they wouldn't align her perfectly on the portable toilet. They couldn't do that work delicately. She was very uncomfortable and afraid.” (C03)

Another carer whose family member did not have the strength to tolerate the lift anymore said

“I encourage her to use the diapers while in bed. ... If there is a problem during lifting, she will again be in pain. That's why we don't lift her up.” (C10)

One resident and one carer commented positively on the responsive pain management received. As C12 remarked,

“The pain control and whatever things that come up. You know little things come up when they're at this age, right? So when things come up, they're attended to. And they are by the way. So that's what's important to me, her medical issues are taken care of.”

Interviewees had a lot to say about staff, both as individuals (with respect to skills and attitude) and as part of the organizational structure, particularly with respect to the influence of workload. Not surprisingly, reviews of the individual qualities of staff are mixed, even within a single interviewee's account. Overall, there appears to be a positive relationship between the level of training (and hence compensation) of the staff member and the interviewees' assessments of them, with nurses and nutritionists receiving the highest praise, although some among them are less helpful. As C10 diplomatically stated,

“Perhaps their work hours are long or they're getting older and are tired. It's hard to say, right? However, the majority, 90 per cent are good. When you call them, they come immediately. But then in whatever workplace, even with ten fingers some are longer and the others are shorter. Nowhere is perfect, right?”

Most specific complaints are directed at care aides, with concerns centering on communication of the residents' needs, in large part because this component of the workforce is much more fluid. As C12 observed,

“I do have a concern though in the sense that I feel that the care aides, the communication is not always clear for them, because you know, it's a place that has a lot of people that come and go, and it's not always the same care aides, they have substitutes, they have weekend people and all this and that. ... I just feel that because of the number of care aides that the turnover or the cycle or whatever, the new ones that come, even if they're subbing in for somebody, they should get an understanding of each patient.”

This carer suggests that the lack of continuity of the care aides' connection to the residents negatively impacts their ability to provide appropriate care:

“[My parent has] deteriorated, s/he's not the same person as when s/he got here, so s/he's not able to get up and go to the wheelchair, s/he needs assistance but the care aide didn't seem to understand that and when I told her that, she was not very receptive. So I'm concerned about that in terms of communication.”

Other complaints speak to task-orientation that precludes taking the extra time to understand what the residents really need, as illustrated by the following examples:

“When the staff is not free, they would say, “I am on a break, don't poop yet.” Or they would say, “This is the morning, what do you have to poop, wait until the afternoon.” In the afternoon, staff from another shift would come. But those from the afternoon shift may say, “Don't poop anymore, it's getting late, let's go to bed.” Then they don't poop all day long. This is difficult for them.” (R03)

“[T]here was an old lady who lost her false teeth. Without her false teeth, of course she couldn't eat that well. The old denture didn't fit anymore. She stopped eating because she couldn't chew on the food. We saw that the staff could pay more attention to them. The old lady could tell the staff that the food could be more tender and in smaller pieces. She agreed, “Yes, can you tell the nutritionist about this?” This could allow the old person to eat again, right? Instead, the staff thought, “You are not eating, must be full.” They didn't pay attention to her.” (C04)

“The care aide used to clean my [parent]'s hair and s/he's lost all his/her hair. Now I wash my [parent]'s hair and it has all grown back. The first thing in the morning bringing my [parent] to shower. The water is sometimes hot sometimes cold. The care aides rush it through in 10 minutes.” (C02)

Many interviewees recognize that scenarios like these arise from constraints at the organizational level that influence staffing ratios and contribute to high workloads:

“The ratio of nurses to patients is too small. I mean RN, registered nurse. They need to look after too many patients. They move around too much, and there are casual nurses. There are not many full-timers. One person needs to look after a couple dozen residents. When I go to talk to them I feel that I am disturbing them.”(C03)

“It's just sometimes I ask them to do things, they refuse. [laughs] Like sometimes I ask them, “My [family member] wants to change diapers now, can you do it?” They said, “No, my shift is almost up, you have to wait until the next shift.” They don't do it then I have to do it myself. I can't wait for half an hour, an hour for the next shift. That's why I do it myself. You can't ask them to do things half an hour before the end of their shift. You need to ask them an hour in advance. ... Sometimes I can't predict when s/he poops, s/he poops when s/he has to. If it happens to be the time there is a shift change, they all go home.” (C05)

Overall, however, having staff available to help around the clock—even if there are fewer at night—was greatly reassuring for family members, who recognized that overall, the most urgent needs were met. Despite her own and her parent's observations that staff often did not respond quickly to call bells, one carer admitted,

“when I saw that [when] her roommate began to choke, the nurses came quickly with the oxygen to breathe, I could see that it was okay.” (C11)

Another facet of the organizational structure that was noted by two carers is the difficulty of changing the culture of care from the top down. Both commented on how care aides, located at the

bottom of the hierarchy, resented input from family members even when it was supported by management and clinical nurse leaders. As a result, it was very difficult to address even the most basic problems, such as a broken call bell, an insufficient number of oxygen machines, and a First Aid suction apparatus that was not fully charged:

“The whole institution worked together to find excuses and evaded their responsibilities” (C03).

When family members have tried to remedy the situation, frontline staff have become defensive. A carer explained that

“It causes tensions sometimes, when people complain about something, and if things are changed immediately, [the person who makes the changes] receives complaints.” (C05)

When asked if they had any suggestions as to how the quality of care could be improved, carers in particular had plenty to say. Their comments are summarized in the table below to illustrate the type and range of concerns which stand in stark contrast to claims that they have no opinions to offer to the Family Council:

CLEANLINESS/QUALITY OF TASK COMPLETION	
C02	Bedsheets drag on ground – risk of infection
C02	Sinks and toilets “could be cleaner”
C11	Residents need “higher quality cooking. Like not using frozen fish, sometimes it's so smelly we can't eat it.”
C10	Some staff do shoddy work – they need to be educated to improve the way they do things.
STAFF RESPONSE TIME/TIMING/STAFF AVAILABILITY	
R04	“When I press the [call] bell, they should come more quickly.”
C03	Staff not readily responsive to call bells (wishes they could afford a 24/7 companion)
C06	“[T]he time between breakfast and lunch is too long. ... [T]he meal times, I made suggestions a few times in the last three years, not much has changed.”
C07	More staff would be ideal
C11	Residents have to wait a long time for someone to help them. More nursing staff are needed. “I heard that they cut the budget significantly.”
C04	“[S]taff should show more care. They could be more attentive” to the residents’ needs, especially those without many visitors.
C05	Staff should chat more with residents, especially those who don’t have family visiting, to understand their needs and relieve their boredom. Residents need to “feel heard.”
C11	“[S]howering once a week is not enough, especially in the summer. Sometimes I can smell the males when they walk past.” You have to contract somebody privately for somebody to shower a resident more than that.
C11	Staff do not have time to spend walking my family member to rehabilitate them. The only option is to hire somebody to spend that extra time to exercise the resident.
C12	My parent can only sit for half an hour, but staff are too busy to get her out of bed and then put her back in such a short space of time, so she doesn’t get up at all.
LANGUAGE INCONGRUITY	
C03	Staff don’t all speak Cantonese (wishes they could afford a 24/7 companion to translate all needs to non-Cantonese speaking staff)
C10	Being able to communicate with more staff in Cantonese would make a positive

C12	<p>difference</p> <p>Cue cards in Chinese and English that indicate to staff that a resident needs to go to the bathroom, for example, do not work well when the resident has dementia and cannot easily recognize their needs.</p>
C12	<p>There are only a few staff who speak Cantonese so a family member who can translate from Cantonese to English needs to come daily to ensure that all of the parent's needs are met.</p>

The most frequently voiced concerns speak to low staffing levels and the task orientation of overworked staff that this engenders. Complaints such as these affect all residents regardless of their ethnocultural background. Concerns about language incongruity between staff and residents are more specific to the minority language residents in RLTC homes in which English is the primary language of care delivery, as is the case in both Sites studied, despite the large proportion of Cantonese speakers at Site 2.

Language barriers were discussed at length both with reference to quality of care and quality of life. Some family members were emphatic about the enormity of the problems introduced by moving their relative into a care facility in which the primary language is English, particularly when their family member moved from a facility where Chinese languages were spoken by all staff:

"[My parent] had no exposure to English at all. On top of those, there was another stress for her. She couldn't communicate, it's a communication issue. It was a very stressful, very upsetting thing."(C03).

"English is the main issue. When there is no one to translate, the misunderstanding is huge! It's like chickens talking to ducks [Chinese proverb]." (C02).

Interviewees at Site 1 told us that there were one or two nurses who spoke Cantonese, and that some of the care aides knew a few words of Cantonese, such as "pain, hungry, toilets, words like these" (C12). More staff at Site 2 were Cantonese-speaking, hence we heard less about this issue from interviewees at that Site. Without a common language, many of the residents and their family carers told us that they resorted to body language and gestures. Some were more capable of doing so than others, depending on their levels of confidence, education, confidence and so forth. One resident told us,

"Communicating is inconvenient. However, finding someone to relay the message is quite convenient. I mean after finishing up a medication, I don't throw it away, I bring it to the nurse and tell him/her that there is no more. He/she will give me a new one."(R08)

Family members who visited regularly were most often interpreters and came daily to ensure that all of the resident's needs were met. However, this solution is not available to families wherein the carers are also not fluent in English, or simply do not or cannot visit regularly. Language was also noted as a barrier to participation in the Family Council meetings. One carer (C12) suggested that these meetings either supply an interpreter or that separate meetings be held in Cantonese for Cantonese-speaking family carers so as to be more inclusive of monolingual families.

One family had hired a companion for their parent, but she did not speak English either, so the family provided interpretive notes as well as their phone numbers which are taped up prominently in their parent's room, should staff need to call them to interpret. The notes work well for simple matters:

“Her family wrote a lot of notes in English, for example, going to class, I don't know English, and I can show the health care staff the note to let them know that she's going to class, for example. Everybody in her family knows English, going to class, taking a shower, finishing class, eating a meal, all of these written in notes in English. Now I can ring the bell and show them the note "Go to class." When she first moved in, I needed the family to write those notes to show the staff here.” (C10)

Even so, the notes are insufficient to communicate more nuanced messages,

“But when she has some illnesses or feels uncomfortable and I don't know how to say it, then I call her daughter, her daughter and the family know both Chinese and English, then I tell them, "Your mom is like this and this." Then they will call the nurse and talk to them. I don't have to talk to them.” (C10)

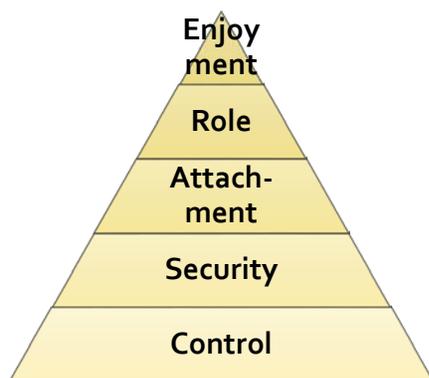
Nor do they work well for residents with dementia when no companion is available, since the resident can neither assess their own need nor show staff the correct note.

Quality of Life

Koehn and colleagues⁹⁵ have recently used a framework developed by the U.K. National Centre for Social Research (NCSR) to understand the quality of life experienced by residents in three Assisted Living homes in British Columbia, one targeted at Chinese and another at South Asian older adults. The NCSR framework is described in the following box. The attributes of quality of life in the model⁹⁶ resonated with the ethnoculturally diverse tenants at all three Sites, which they interpret as a positive indication that use of the model can help us to pay attention to concepts that have meaning across cultures, even if these concepts assume different shapes between groups.⁹⁵ These concepts thus informed the questions on quality of life included in our semi-structured interview protocol [see Appendices A and B].

Given that quality of life is a social construction, research has established that a sound measure must be based in theory⁹⁷⁻⁹⁸, but grounded and validated in the realities of research participants.^{99,100} This measure should permit comparisons between groups and must distinguish clearly between determinants (influences on quality of life) and the attributes of quality of life; the same influences are not experienced in the same way by different people and, therefore, have different effects on quality of life.⁹⁷⁻⁹⁸

For this study, we draw on the work of researchers at the U.K. National Centre for Social Research (NCSR)^{96,101-102} who have developed an approach to understanding quality of life among older adults that meets these criteria and is also grounded in the realities of ethnically diverse older adults. Grewal



and colleagues⁹⁶ qualitative research with older adults determined that their quality of life was contingent on their capability to pursue five conceptual attributes of quality of life, which have been adapted from Maslow's well-known hierarchy of needs: *attachment, role, enjoyment, security and control*.¹⁰³⁻¹⁰⁴

They further draw on Sen's¹⁰⁵ assertion that quality of life is contingent on an individual's ability to convert goods into 'functionings' or capabilities. These capabilities can be promoted or undermined by the sociocultural determinants of health and aging and by the experience of discrimination. An

individual's capacity to marshal their resources to pursue these attributes is further influenced by factors such as their personal characteristics and the social and physical environments in which they find themselves.

Of particular interest to this report are the attributes of quality of life that participants felt were *primarily impacted by the facility characteristics*, rather than by individual or family characteristics. In relation to the frequency with which the topic was discussed, this included first and foremost the residents' enjoyment, followed by their safety and security, their decision making capacity and their attachments, most especially those to the world beyond the long-term care home. Also mentioned, to a lesser extent were attachments to staff, other residents and family members.

Enjoyment

Residents and carers commented on features of the residences and their recreational programming that had both positive and negative impacts on their quality of life. Mobile residents enjoyed playing mahjong with other Chinese residents. One of them joked, "It's not for real. There is no money if I win [laughs]" (R08). R08 and R09 commented that they enjoyed the opportunities they had to exercise, but R05 complained of the lack of occasions to do so. All three resided at the same Site.

Several carers commented that their family member enjoyed gatherings, such as concerts, at which they served coffee and treats. Music therapy and karaoke provided an opportunity for residents to sing the old songs that they could still recall. However, several participants commented that they did not enjoy listening to English music, especially when there was no escape. For example,

"Four-person rooms are narrow, sometimes noisy. There are times when someone sits there and watches TV. It's all right if it is in Cantonese, when it is in English, I don't understand. The DVD plays some unknown English songs, that's noisy." (R03)

More than half of the residents and some carers mentioned the occasional outings, usually to a Chinese restaurant to which a handful of residents would be invited. Most said that these were a source of great pleasure, although C03 commented that her parent was uncomfortable on the bumpy ride in the bus and did not enjoy these events.

Residents could watch Chinese TV. At Site 1, there was a main TV room, in which the channels were often changed by the most mobile residents, and a smaller room in which they were more likely to be able to continue watching a Chinese channel, although it was not guaranteed. One family had therefore invested in a TV for the resident's private room, so they could watch the Chinese channels uninterrupted. Having windows that enabled them to see outside and let in fresh air was also noted as very important to residents and their families.

Site 1 has a garden in which residents can sit in the sun and even grow a vegetable during the summer. Several families commented on how important this was for the residents:

"Once summer comes, everybody goes outside to get some sunlight. There is a garden outside for people—for residents to grow some tomatoes, each of them can grow one plant. There is a small farm like the size of a bed, we can go and say we have adopted this land, our family has adopted this piece of land and we can insert our name there. We can grow tomatoes or whatever. The residents then have a high sense of belonging, the family members can bring them to see, "Oh, the tomatoes are growing bigger!" I mean this is very important for their physical and mental health." (C09).

Several Site 1 families also mentioned that walks in the neighbourhood and at a nearby park where sports teams often play also provide enjoyment and a sense of reconnection to the world for residents who are confined to wheelchairs. These comments also speak to ‘attachment’ as an attribute of quality of life and demonstrate the importance to residents of being able to maintain some connection to the world outside of the care home.

The most common complaint leveled at the facility that detracted from the enjoyment of residents concerned the food. For some, food was no longer appetizing because the resident was restricted to a pureed diet. Other complaints, however, can be attributed to lack of cultural congruity, even though the facilities had tried to offer some Chinese cuisine:

“[A]s a Chinese elderly, we like to drink hot drink. The drinks are cold and his/her health is going down.” (C02)

“She was used to eating home-made food.... They have chicken legs and Chinese cuisine, but she isn't used to those so I bring her some foods.” (C06)

“The foods they cook do not fit the tastebuds of us Chinese people.” (R09)

“[T]hey don't provide home-made style. Do you understand? [I: They provide western Chinese food, right?] Yes, exactly.” (C09)

“[His/her] daughter-in-law brings foods here almost every day. [The resident] doesn't drink the soup here. S/he seldom eats the foods provided here, because s/he's become bored of them. At first s/he ate the food, now s/he doesn't eat it. ... S/he drinks the liquids, like the soup, the congee, [but] if the soup is western-style, she's not used to it, right?” (C10)

“[T]here have been only twice that the rice was very very hard to chew, s/he couldn't eat it. Another time ... the food was the worst-tasting in all of the world! ... I don't know how to complain.” (C11)

Ostensibly, this is an important issue that negatively influences the quality of life of many Chinese-origin residents that warrants discussion in a Family Council meeting. While food may be one source of complaint for other non-Chinese residents, the nature of the complaints of our Cantonese-speaking sample is specific to them.

Safety and security

The added safety and security that RLTC facilities offer in comparison to living at home is, in essence, the reason our interviewees or their family members are there. They listed off numerous such benefits as follows:

- Availability of equipment such as wheelchairs, lifts, safety mats to break falls, etc.
- Regular equipment maintenance
- Accessibility of spaces for wheelchairs to permit maximum mobility
- Staff to move residents between different spaces
- Call bells (and timely attention)
- 24-hour care (so relatives can work, shop, enjoy recreation, sleep etc. without worrying)
- Regular and timely dispensing of medications and food
- Prompt medical attention in the event of a fall or medical emergency (no transportation needed)

- Secure systems to prevent people with dementia from wandering
- Sprinkler systems and safety plans in the event of fire
- After-hours sign-in/out and staff-controlled entry of visitors

Interviewees acknowledged that some safety features came at the cost of a perceived loss of control by the resident. For example, a shortage of care aides to sit with a carer's (C02) unsteady parent means that the resident has to remain in a wheel chair most of the day in order to be safe. Similarly, another carer concedes that

“If I were a care aide and if I was not free, I would not let this person get out of bed no matter what. When I was not keeping an eye out on someone, no matter how the resident yelled, I would not let him/her get off the bed. It's always safety first in these kinds of seniors home. I feel that often times they can deliver on this.” (C08)

In order to prevent wandering of dementia patients and to ensure that residents do not come to any harm (e.g. have a fall) while out of their reach, the facilities stipulate that residents can only leave the building accompanied by a known visitor or staff member who is willing to take responsibility for their safety. While this is understood by most, it can be hard for some residents to accept this loss of self-determination. Another way this loss of control plays out in the interests of safety is when alarm bells ring to indicate that somebody has tried to leave the building. The noise of the bell, along with the announcements can be very loud if the speakers and/or alarms are directly outside the residents' room, one resident (R03) told us. Finally, despite safety systems in place in case of fire, this same resident pondered how those in wheelchairs would actually be safely evacuated.

Decision-making

Residents and family carers alike acknowledged that the resident's move into RLTC had involved relinquishing a great deal of power to make decisions about their daily routines. They no longer have much of a say in when they get up and go to bed, when or where (and often what) they eat, and whether or not they can go outside. The transition from home to institutional living is therefore a difficult one:

“Like ... at the beginning, s/he wasn't used to it, that's one. Second, it's not like at home, he can't do this, s/he can't do that. S/he can do whatever s/he wants at home, but here s/he couldn't do a thing. Everywhere s/he went, there was someone accompanying her/him, s/he didn't like that and threw a tantrum. Now, perhaps s/he is used to it; s/he doesn't scold people anymore.” (C05)

Over time, however, some residents were able to negotiate some compromises. One (R03) was originally put to bed immediately after dinner, around 6 pm, but has now managed to convince staff to let him/her stay up as late as 8 pm. Yet doing so means that he/she is rushed in order to fit into staff routines. This same resident has nonetheless found small ways to reassert a sense of control over his/her life using passive resistance techniques: “They give you breakfast at 8:30 am every morning. You can choose to eat it or not. You can choose not to get up, lay in bed until the afternoon and that's fine.”

In many instances, there were alternate interpretations of the control exerted over residents that highlighted the trade-off of loss of control for increased safety, already noted. For example, one carer puts a more positive spin on the routines imposed on residents:

“[T]he routines are all set, so s/he does not have control about if s/he wants to

sleep the whole day. S/he can't have that because that really, because I think the staff are very good about trying to keep that routine going from day to day to day.... [H]aving a routine is very important for someone like her/him, because if left to their own devices I think most of them will only sleep. They will become isolated in that sense, and it's not healthy....[R]egularity is very very crucial, or else why would anyone want to wake up? Because they have no purpose anymore.” (C07)

Similarly, another carer is grateful that the staff insist that her family member take their medications regularly:

“They impose that s/he has to take all the medication, otherwise they won't leave. Sometimes s/he doesn't take those, s/he throws them away [laugh], nobody knows about it, that's why they have her/him take all medications.” (C05)

Another family carer pointed to the additional freedom that living in the long-term care home conferred in terms of mobility and opportunities to socialize:

“I think the facility is great in the sense that it allows people who are not mobile to still get around and do things and go to different parts of the facility, and especially like in winter months when it's dreadful and cold outside, you can't get out. They can still go from the main floor to the upper floor to the atrium, to the dining room, to the TV room. There are just so many options as opposed to just staying in their own room.” (C12)

Of course, all of the observations made to this point in this section are likely equally applicable to non-Chinese residents. The question of control over the television, however, invokes more ‘us and them’ thinking:

“In the past once [the resident] came out, s/he asked me to turn the TV on. But then the lady here scolded us and told us not to turn it on. ... The western lady in the office. ... She doesn't let us. She says we are wasting electricity, we're not watching it and are sleeping. She doesn't let us talk loudly. We need to whisper [laughs].” (C05)

“There are also Chinese channels on the TV in the main dining room outside, and another one downstairs on the big TV in the private room. But those TVs, because there are westerners, we can't always switch to the Chinese channels.” (C06)

In this sense, the power imbalance is perceived both as the facility controlling the resident, and also in more racialized terms whereby Chinese-speaking residents and their families reference their minority status in Canada and the residence itself.

Attachment

As discussed in the previous sections, the residents feel trapped on the one hand by restrictions on their ability to leave the care home alone. However, most were appreciative of the periodic field trips, especially when they went to a Chinese restaurant. They also liked spending time in the garden at Site 1 and getting out with family members in the neighbourhood, weather permitting.

Free parking was strongly emphasized by two carers (C09 and C10) as a key feature that promoted family visits and hence the maintenance of their attachment with the residents:

“[I]t's free parking here, very good. For someone like us, each time we come we stay for a few hours. What if we need to refill the parking meter once every few hours? And a lot of people are like us who come every day. If it costs \$10 a day, 30 days will cost \$300. It's a huge burden for the family if we need to pay.” (C09)

Another carer (C12) appreciated the ability to visit her family member at any time of the day, which allowed her to fit her visits into her busy schedule. A resident at Site 2 wished they had a room in which family members could meet with them to talk more privately.

Three residents (R01, R07, R08) said that living in the care facility gave them the opportunity to interact with their age peers more frequently than they had while still at home. They especially enjoyed getting together to pursue common interests, such as *mahjong*. A family carer similarly remarked that her parent

“... sees more people here and greets them. Even though s/he cannot speak or hear, but their body language is amazing, s/he smiled to or waved at others, even westerners, that indicates that they are friends. ...My [parent] is different living here. S/he'd be depressed staying at home.” (C02)

To the contrary, R05 said that because the groups of residents that typically gather together are so big, there is no opportunity to interact with any of them one on one. S/he did not feel that the activities provided promoted resident to resident attachment. Similarly with the staff, some interviewees felt that they were friendly and caring and had developed attachments to them that seemed to improve their quality of life, whereas others thought they could be more friendly and attentive.

For the most part, residents' attachments were to their family members, and whereas some families devoted considerable time to the residents to ensure their wellbeing, others were unwilling or unable to visit often. While this must be recognized by the administration of long-term care facilities from the perspective that family involvement cannot be taken for granted, it is largely beyond the control of care facilities to influence this domain of attachment.

Conclusions

Attendance in Family Council meetings by Cantonese-speaking family members at Site 1, or the interest in establishing a Family Council at Site 2, is very low. The majority do in fact understand the role and purpose of such meetings, although some confused it with the annual interdisciplinary care conferences held with families to discuss a specific resident's care. Therefore some clarification in Cantonese of the nature and purpose of the Family Council is warranted. The data collected in this study on perceptions of the quality of care delivered to and the quality of life experienced by Cantonese-speaking older adults living in residential care indicate that residents and family carers do indeed have issues that could benefit from discussion at a Family Council meeting. Thus the carer and resident rationale that they do not attend because they have no issues to raise is negated. The majority of issues raised are most likely common to many other residents – hence it would be beneficial to the residence as a whole to hear these contributions.

Three factors were identified as necessary to improve participation of this numerically important group of residents' families. First, it must be recognized that carers' time is precious and care-work is gendered. The majority of carers are women who are dividing their time between younger and older family members, as well as their spouses, and often participate in the paid workforce as well. If they are going to spend an hour at a Family Council meeting, the timing and topic need to be congruent with their schedules and interests, and the agenda should be apparent. Moreover, non-English speakers either need an interpreter or meetings held exclusively in their own language. Finally, when

complaints are made, the process of seeking out and implementing solutions needs to be transparent. Family members are discouraged from attending and making their concerns known if they are always dismissed, since this reinforces the notion that to complain is in fact shameful.

The Cantonese-speaking residents in our sample, as well as the residents to whom the family carers are connected are all long-time immigrants to Canada, with the majority having lived here for more than twenty years. Yet only a minority spoke English. Some had learned but forgotten the language as their cognitive impairment progressed. The lack of linguistic congruity with care providers influenced both the quality of care received (as when they couldn't express the level of pain experienced, for example), and their quality of life. Residents did not understand and hence could not participate in many of the planned activities, they were often unable to select or continue watching Chinese language television shows that they could understand, they had a hard time connecting with non-Chinese staff and residents, and--without a means of expressing themselves--their decision-making capacity, already stripped bare by the structural demands of institutional living, were further diminished. Similarly, they could not fully understand safety protocols, such as wheelchair evacuation procedures in the event of a fire. Even at Site 2, where 80% of the residents are Cantonese speaking, less than a third of the staff speak Cantonese. The unwillingness of family carers to raise these issues in the context of the Family Council may be read as a culturally informed reluctance to complain out loud. However, this interpretation is not strongly supported by our data; instead several carers expressed frustration with not being able to raise topics of concern to them and no action being taken to address their concerns. Their resignation may thus reflect repeated experiences of marginalization across the lifecourse as racialized immigrants. Efforts to engage Chinese carers thus need to begin with efforts to address this perceived imbalance of power.

Importantly, it must be acknowledged that while bottom-up solutions need to be elicited from residents and carers, the most effective solutions must be fully supported throughout the organization from frontline staff up to the highest levels of policy and staffing formulae.

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Appendix A: Interview Guide (Resident): Version 10/12/15

1. To begin, please can you tell me a little about yourself – who are you?

- a. Note apparent gender

PROMPTS:

- b. Age or year of birth
- c. Country of birth
- d. Marital status
- e. Schooling
- f. Work history
- g. Offspring (how many, gender, where born, where are they now?)
- h. Migrations
- i. Year of arrival in Canada
- j. Type of immigrant (sponsored/family class, economic class, retiree, investment)
- k. Living arrangements from arrival until immediately prior to move into RLTC.

2. Thank you. Can you tell me now about living here in the [name of RLTC] residence.

PROMPTS:

- a. Move in date (month, year)
- b. Reason for move-in (health condition; circumstances preceding move, e.g. hospitalization)
- c. Whose decision? (their own, family, health care provider)
- d. How did you feel about moving in at the time?
- e. How do you feel about it now?
- f. Who visits you / calls you?
- g. Who do you see the most?
- h. Who do you feel closest to?

3. So, you've talked a little about what it's like to live here. I'm going to ask you now to tell me in a little more detail about a couple of concepts that we're interested in. The first of these is the idea of **QUALITY OF LIFE**. Of course different things bring quality to our lives at different times, but I just want you to tell me about the sorts of things that add to or take away from your quality of life now that you're living here.

PROMPTS:

- a. Physical environment (inside and outside)
- b. Social environment (relations with staff, other residents)
- c. Organizational environment (rules and regulations)

4. How about your family and friends (who don't live here) (**FAMILY INCLUSION**)

PROMPTS:

- a. How often do they visit?
- b. Their involvement in care?
- c. Relationship to quality of life? (previously addressed? If not, probe further)

5. What does **QUALITY OF CARE** mean to you?

PROMPTS:

This question may have been answered above, if so, rephrase previous comments in relation to quality of care to ensure that response was in fact related to the concept and ask if they have anything to add if confirmed. If not, proceed with prompts.

- a. What contributes to quality of care?
 - b. What detracts from it?
 - c. Have your family members been able to influence it?
6. Finally, we'd like you to tell us about the idea of a **FAMILY COUNCIL** in long-term care.
- PROMPTS:**
- a. Have you heard of it before?
 - b. If so, do you know what the purpose of a Family Council is?
 - c. Good idea/bad idea – why?
 - d. Do your family members attend FC meetings?
 - i. **If so**, who and how often?
 - ii. What are your feelings about the family member's participation? (pleased/displeased)
 - iii. Has it influenced your quality of care and/or quality of life in any way? (+/-)
 - iv. **If not**, why not (don't know, don't think it's useful, barriers to inclusion)?
 -
 - e. Are there any changes that could be made to Family Councils to make them more appealing/accessible?
 -
 - f. Do you have any different ideas about good ways for family members to be involved in the care of residents like you at [name of RLTC] residence?
 -

Appendix B: Interview Guide (Carer): Version 10/12/15

1. **To begin, please can you tell me a little about yourself – who are you?**
 - a. Note apparent gender

PROMPTS:

 - b. Relationship to resident
 - c. Age or year of birth
 - d. Country of birth
 - e. Marital status (*spouse supportive?*)
 - f. Schooling (brief)
 - g. Work history (brief)
 - h. Offspring (how old? Whereabouts? *Determine mainly to know if younger carer has conflicting caregiving roles/support, or older carer (spouse) has support*)
 - i. Migrations
 - j. Year of arrival in Canada (before/with/after resident)
 - k. Type of immigrant (sponsored/family class, economic class, investment)
 - l. Did they sponsor resident?
 - m. Resident's living arrangements from residents' arrival until immediately prior to his/her move into RLTC.
 - n. **If adult child/g'child** - siblings - #, gender, whereabouts (*supportive?*)

2. **Thank you. Can you tell me now about [resident's name] time living here in the [name of RLTC] residence.**
- **PROMPTS:**
 - i. Move in date (month, year)
 - j. Reason for move-in (health condition; circumstances preceding move, e.g. hospitalization)
 - k. Whose decision? (resident's / family's – interviewee/others/joint decision [degree of agreement/not] / health care provider's)
 - l. How did you feel about [the resident] moving in at the time?
 - m. How do you feel about it now?
 - n. Who visits / calls [the resident]?
 - o. Who does [the resident] see the most?
 - p. Who do you think [the resident] feels closest to?
3. So, you've talked a little about what it's like for your family member to live at the [name of RLTC] residence. I'm going to ask you now to tell me in a little more detail about a couple of concepts that we're interested in. The first of these is the idea of **QUALITY OF LIFE**. Of course different things bring quality to our lives at different times, but I just want you to tell me about the sorts of things that you believe add to or take away from [the resident's] quality of life now that he/she is living there.
- PROMPTS:**
- d. Physical environment (inside and outside)
 - e. Social environment (relations with staff, other residents)
 - f. Organizational environment (rules and regulations)
4. Can you tell me now about the relationship that you and other family and friends outside of [name of RLTC] have with [the resident]? (**FAMILY INCLUSION**)
- PROMPTS:**
- a. How often do you and others visit?
 - b. What is your involvement in [the resident's] care?
 - i. How about other family members?
 - c. Relationship to quality of life? (previously addressed? If not, probe further)
5. What does **QUALITY OF CARE** mean to you?
- PROMPTS:**
- This question may have been answered above, if so, rephrase previous comments in relation to quality of care to ensure that response was in fact related to the concept and ask if they have anything to add if confirmed. If not, proceed with prompts.*
- a. What contributes to [the resident's] quality of care?
 - b. What detracts from it?
 - c. Have you or other family members been able to influence it?
6. Finally, we'd like you to tell us about the idea of a **FAMILY COUNCIL** in long-term care.
- PROMPTS:**
- a. Have you heard of it before?
 - b. If so, do you know what the purpose of a Family Council is?
 - c. Good idea/bad idea – why?
 - d. Do you or other family members attend FC meetings?
 - i. **If so**, who and how often?

- ii. What are your feelings about the your own or others' participation? (pleased/displeased)
- iii. Has it influenced [the resident's] quality of care and/or quality of life in any way? (+/-)
- iv. **If not**, why not (don't know, don't think it's useful, barriers to inclusion)?
 -
- e. Are there any changes that could be made to Family Councils to make them more appealing/accessible?
 -
- f. Do you have any different ideas about good ways for family members to be involved in the care of residents like [the resident] at [name of RLTC] residence?