

DEALING WITH DIVERSITY:

Aged care services for new
and emerging communities

August 2018



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Photograph: Diversity focus group attendees, 11 May 2018, with National Seniors Australia Interim CEO and Research Director, Professor John McCallum, and Australian Unity Diversity Capability Development Manager, Elleni Bereded-Samuel (used with permission).

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EXECUTIVE SUMMARY

Background and purpose

A diversity focus group was coordinated by National Seniors Research in conjunction with Australian Unity on Friday, 11 May 2018.

The purpose of this research was to identify the impacts of diversity on the ability of culturally and linguistically diverse (CALD) people to access government services such as aged care, particularly when these services require a high level of digital literacy. Participants were asked about their needs, interests and barriers when accessing the aged care sector, their level of digital literacy, use of translation and interpreting services, and their attitude towards family caregiving.

The focus group was attended by a total of 20 people representing the following communities:

- African Australians from the Horn of Africa
- European Australians from various places of origin
- Filipino Australians
- Karen Australians from the Thai-Burma Border
- Spanish-speaking Australians from Central and South America.

All attendees represented CALD groups in Australia of various arrival times and experiences of Australian aged care services. Attendees of Greek, Lebanese, Turkish Cypriot, Filipino, and Salvadoran background are from established CALD backgrounds. The other participants represented more recent arrivals, known as new and emerging communities (NEC), namely Horn of Africa, and Burmese Karen participants. Participants contributed their opinions and views by microphone with increasing confidence throughout the session, with some speaking via interpreters from within their group. Many participants expressed their gratitude for the opportunity to have their views heard by policy-makers and the wider community.

Findings

Participants attended the forum to increase their aged care literacy for either family and friends, for their own benefit, or to benefit their communities, in which many offer advocacy and support to their peers. They also wanted their views and needs passed onto policy-makers.

Many issues occurring in their communities were expressed, including:

- The way language barriers affect their ability to access the aged care sector, the impact of having spent time in refugee camps on English Language proficiency, consent and privacy issues in accessing My Aged Care as a translator for family members, and the extra time it takes to access services when using interpreting services.
- The importance in their culture of ageing in place and dying at home, the extra burdens on informal carers when the family member has dementia, the extreme resistance of their elderly to residential aged care and the taboo nature of choosing to place a family member into a residential home, and issues in residential care for CALD people, such as adjusting to the food.

- The difficulties associated with caring for family members at home, the burden of care this places on CALD women, the loneliness of older CALD people when their family members are at work or school, and the isolation felt by CALD carers.
- The difficulties associated with caring for people with dementia at home, and the anxiety of leaving them home alone.
- The importance of community support for ageing in place, especially having places for community gatherings.
- The importance of transport services to support aged people and their caregivers in CALD communities.
- Not knowing where to go for information, particularly amongst NEC groups who lack experience using Australian government services.
- Digital issues in accessing aged care information related to the cost of using digital technology and having to access websites in English, exacerbated for refugees, for whom language and digital literacy become even greater barriers to entry. CALD people from NEC groups urgently need support to become digitally literate and to learn how to access digital services.
- The long wait times for aged care (Home Care Packages).
- Having to return to their home country to care for aged family members, a common transnational issue for migrants. The transnational caregiving responsibilities of newly arrived CALD people further suggests the need for better digital literacy, not only to enable access of aged care and other government services, but to help people maintain contact with family members.
- The problems when seniors don't have family members to help them.
- The responsibility seniors feel to increase the unity of the whole community.

Many participants advocated for grassroots, bottom-up solutions to the issues experienced in their communities, and some were already actively involved in supporting their own people, as well as CALD people generally. These community leaders are willing to support their elderly with aged care access, but they need more information and resources to do so. It was notable that many participants took the floor to offer advice, information and encouragement to the other people gathered for this focus group, and established groups invited other groups to become involved in their community activities. Established groups were once new and emerging, and they identify with the issues NEC groups are experiencing. This supports the benefits of facilitated interactions between established immigrants and new groups as well as between emerging groups themselves. Clearly, a significant level of intercultural interaction occurs in CALD communities that cuts across cultural boundaries, suggesting that these channels can be used to facilitate better access of information on the aged care sector.

Conclusion

While the experiences and characteristics of CALD people are diverse, there is now a body of research into older people from CALD backgrounds. Research into NEC groups remains scant. For this study, the barriers and issues that were identified have been compared to a similar Australian study of new immigrants published 28 years ago:

- The major issues were consistent across nearly three decades: bridging language and cultural barriers, grassroots local solutions, burdens on women, support for carers, and access to services in the home;
- The new issue, not evident at all in 1990, was the need for digital literacy to access benefits and services; and
- With new inflows of immigrants, these predictable issues need to be addressed constantly, with special attention to new challenges such as the one posed by the need to access government services digitally.

The findings are used to review performance against the 6 Goals of the 2015 Department of Social Services *National Ageing and Aged Care Strategy for Culturally and Linguistically Diverse Backgrounds*.

The pursuit of fair access to services for CALD people, including aged care, health, translation services, and digital literacy, accords with the 'United Nations Principles for Older Persons', that they have access to health care, community support, social services, institutional care, and educational and recreational resources. It also aligns with the UNs promotion of a human rights-based approach to migration.

National Seniors regularly receives comments from members on the responsibility of government to its citizens and the support for a 'fair go' regardless of who you are:

Every society is judged by how it takes care of those members who are disadvantaged (F, 71).

A measure of a civilised, wealthy society must be the opportunity given to those on the lowest socio-economic scale to live productive and fulfilling lives (M, 72).

Acknowledgements

National Seniors Research acknowledges Australian Unity, particularly the work by Mrs Elleni Bereded-Samuel, in organising this forum and would like to thank the participants for attending.

INTRODUCTION

Background

A focus group consisting of 20 people from CALD backgrounds was coordinated by National Seniors Research in conjunction with Australian Unity on Friday, 11 May 2018.

This study uses the term CALD, as per the Australian Government and My Aged Care. In their chapter ‘Cultural Diversity, Health and Ageing’ in *Ageing in Australia*, Radermacher & Feldman indicate that, like others in the field, they find the term CALD problematic and prefer ‘ethnic minority’. CALD replaced ‘Non-English-speaking background’ (NESB) in 1996, “to acknowledge that people from English-speaking nations can still have cultural identities distinct from the mainstream population” (Radermacher & Feldman, 2017).

In 2015, the Department of Social Services released the *National Ageing and Aged Care Strategy for People from Culturally and Linguistically Diverse (CALD) Backgrounds*, with the principles of inclusion, empowerment, access and equity, quality, and capacity building (DSS, 2015). Its stated goals include:

- The shaping of aged care policies by input from CALD people;
- That CALD people have the confidence to access aged care services, and the knowledge to make informed choice in aged care;
- That services are monitored to ensure they’re meeting the care needs of older CALD people, and that the CALD sector has the capacity to themselves provide aged care services; and
- The achievement of better practice through research, for example, in collaboration with research organisations.

National Seniors 2018 diversity research informs the research aim of this National Strategy.

The Aged Care Roadmap of 2016 also identified the need to ensure that older Australians with different needs are supported in accessing the sector, regardless of cultural or linguistic background, as one of its destinations. This includes government monitoring “to identify and address any barriers so that consumers will be able to access the care they need” (Aged Care Sector Committee, 2016). This research seeks to identify the ongoing barriers faced by CALD people when accessing the aged care sector, with special emphasis on the new and emerging community (NEC) groups from the Horn of Africa and the Burmese Karen state.

The Emerging Ageing Project Literature Review states that: “Only Australia commonly refers to the concept of ‘new and emerging’ communities” (Feldman & Radermacher, 2017). The term usually refers to small, recently settled communities that lack established family networks, support systems, community structures and resources relative to more established communities. Many have entered Australia as refugees. *New and Emerging Communities in Queensland* states that:

Such groups, often lacking earlier generations of settlers or an Australian-born second generation, generally lack organised advocacy or social networks, have difficulty accessing government services, and may require substantial assistance and time to settle effectively in Australia (Multicultural Affairs Queensland).

For older NEC Australians, the Queensland report discusses aged care strategies for addressing their disadvantages, including:

- Ethnic groups forming partnerships with mainstream service providers;
- Clustering, whereby people of similar ethnic backgrounds are co-located in mainstream facilities, with culturally appropriate care provided for the group;
- A multicultural model, where different ethnic groups pool resources and develop a multicultural, multi-purpose facility, a solution that assumes ethnic groups have the resources and expertise to develop such a strategy.

There is a variant on the multicultural model in which language (e.g. Spanish-speaking) groups, or groups with a similar religious background (e.g. Hindus from around the world), work together rather than in groups with the same ethnicity. Generally, as this focus group demonstrates, established CALD communities in larger population centres do have the tendency to both cluster and co-locate for the purposes of community establishment, as well as to pool resources and information across multicultural groupings to facilitate the integration of people from NEC. In regional and remote areas, this will be less possible. Such intercultural interaction is currently being discussed as a way of promoting active interaction and dialogue between different groups of CALD people and within the broader community.

Other NEC issues raised in the Queensland report that appeared relevant to our Melbourne forum members include:

- Lack of community transport adding to the isolation of older people already at risk of loneliness, and for which they suggest lobbying of public transport providers; and
- Language barriers for accessing aged care services (sometimes exacerbated for CALD people by cognitive decline if they regress to speaking in their native language).

The Federation of Ethnic Communities' Councils of Australia agrees that older CALD Australians experiences disadvantages due to language barriers, that they often lack awareness of the services available to them, and have both digital access and digital literacy issues. As well:

(T)he particular issues for some Australians in older age such as low levels of home ownership, low superannuation balances and low levels of savings are likely to be compounded for many CALD Australians whose lifetime earnings have been severely restricted by the process of migration and re-settlement (FECCA, 2015).

The language barrier for ageing CALD people increases the need for family members to act as interpreters, and can sometimes limit health-seeking behaviours: “It therefore follows that fundamental to any successful service system is the availability of a pool of accredited interpreters and translators” (Feldman & Radermacher, 2017), and the use of interpreter services needed to access My Aged Care was raised during this study. Cultural identity remains important as people age, and regular communication with family and friends from their country of origin, or visits to the home country are valuable for CALD people in Australia, according to Feldman & Radermacher. For some participants in this study, these visits were necessary to care for aged parents.

Participants

- Australian Unity, a mutual organisation dedicated to “helping Australians to thrive”, has been working with a group of older members of CALD communities in a project called the Australian Unity Community Capacity Building Project. The majority of the group members live in Wyndham, Hobsons Bay and Brimbank (representing Burmese Karen, Horn of African ethnic groups, Filipinos, Spanish-speaking Latin Americans, and others) with the remaining Afghani group members living in Dandenong.
- Participants for this study were recruited by the Australian Unity CALD Alliance Advisory Group. Many CALD people involved in the Glengala Community Centre arrived in Australia from Europe post-war, and thus represent long-established ethnic communities.
- Australian Filipino immigration increased during the 1970s, with the Filipino population of Victoria increasing from 3,455 in 1981 to 38,004 in 2011, and many arrivals entering Australia under the Family Reunion Program. About 73 per cent of Victorians born in the Philippines speak Filipino or Tagalog at home, and most are Catholic (Museum Victoria Australia, n.d.).
- There are currently 3,142 Salvadorans in Victoria who associate with the broader Spanish-speaking community. Australia accepted Salvadorans after the 1981 civil war under the Special Humanitarian Program. Over 90 per cent speak Spanish at home, and the majority are Catholic (Museum Victoria Australia, n.d.). More recently, groups from Central American countries came into Australia under arrangements with the USA.
- In the 2016 Census, there were 11,792 Ethiopian Australians (ABS, 2016). Victoria has the largest population of Ethiopian-born migrants in Australia, a recently established community, with many accepted under refugee and humanitarian programs after political persecution during the 70s and 80s (Museum Victoria Australia, n.d.).
- There were 7,699 South-Sudanese-born Australians in the 2016 Census (ABS, 2016). The Sudan-born community is the fastest growing immigrant community in Victoria, with 20 per cent of the community living in Brimbank. Australia assisted in resettlement of the worst-affected civil war refugees from Sudan between 2001 and 2006.
- The Karen people are another new and emerging community, originating from Burma, who began arriving in Australia in 2003 after a long history of persecution (Lane, Pitruzello, & Dunne, 2015). In 2014, there were approximately 3000 Karen people living in Australia (Australian Karen Foundation Inc., n.d.).

Study purpose and strategy

The purpose of this diversity research was to identify the impacts of diversity on aged care service literacy, and discuss participants needs, interests and barriers when accessing the aged care sector, including digital literacy. These expressions were recorded in writing simultaneously during the session and statements were clarified during individual contributions to the forum.

The major 2018 survey of members, the National Seniors Social Survey (Wave 7) focused on service and digital literacy issues. New and emerging community (NEC) views and levels of service literacy cannot be easily accessed except through trusted intermediaries in those communities in face-to-face interactions. This was achieved through a research partnership with the Australian Unity CALD Alliance with new immigrant groups in West Sunshine serviced by Brimbank Council. Issues of digital literacy are combined with English language and cultural difference as well refugee status. The issues facing the ageing cohort of NEC groups are easiest to identify at the community grassroots level.

DATA AND METHODS

Design

Studies of immigrant groups usually require different strategies to mainstream population research, not only to deal with language and cultural boundaries, but also to gain access to groups. For example, a previous National Seniors study on diversity (National Seniors Productive Ageing Centre, 2011) reported findings from Census data. The current study had different design requirements because it was seeking to record NEC comments and experiences.

An examination of the current Australian Census 2016 data shows that 18% of those born overseas had arrived since 2012. Further ABS statistics for target groups include the following:

- 67% of the population were born in Australia;
- 49% were either born overseas (first generation Australian), or had one or both parents born overseas (2nd generation Australian);
- Of those born overseas, 18% arrived since the start of 2012;
- 83% of the overseas-born live in a capital city, while 61% of Australian-born live in a capital city;
- 21% of Australians spoke a language other than English at home.

Of the 18% arriving after 2012, it is difficult to identify specific NEC cases and make contact with those from NECs.

The 2018 National Seniors Social Survey (Wave 7) member survey of people over 50 had 7.01% of participants identifying as CALD, and a total of 76.55% born in Australia. The majority had arrived in the years 1951 to 1990.

Figure 1: Year of arrival in Australia (NSSS 7, 2018)

Year arrived in Australia	Freq.	Percent	Cum.
1950 or before	87	6.87	6.87
1951-1960	248	19.57	26.44
1961-1970	372	29.36	55.80
1971-1980	262	20.68	76.48
1981-1990	175	13.81	90.29
1991-2000	69	5.45	95.74
2001-2010	50	3.94	99.68
2011 or later	4	0.32	100.00
Total	1267	100.00	

The NSSS respondents had a low representation of people arriving after 2010 with less than 10 per cent of survey participants arriving since 1990.

The study targeted NEC communities and, therefore, required a strategy to recruit outside National Seniors organisational and member boundaries to access NEC groups. By recruiting participants predominantly from a local area with high NEC numbers, we were not only able to access hidden groups but also able to use focus group and case study methodologies. A case-study forum in outer suburban Melbourne was designed to collect information about a specific demographic: CALD people over age 50, particularly those from new and emerging communities, with established communities for comparisons. The diversity forum was run as a focus group on the ability of CALD communities to access the aged care sector.

The focus group consisting of 20 people from CALD backgrounds was coordinated by National Seniors Research in conjunction with Australian Unity Diversity Capability Development Manager, Elleni Bereded-Samuel, on Friday, 11 May 2018. The forum was facilitated by National Seniors Australia Interim CEO and Director of Research, Professor John McCallum.

This strategy, targeting a local community, was necessary to National Seniors research goals but it is relevant, as well, to service communications and information sessions for NECs provided by government staff. The Commonwealth Department of Health has been informed of the findings.

Data

Data for this study were collected at a focus group conducted at Glengala Community Centre, West Sunshine, Victoria, from 10:30am to 1:30 pm on Friday, 11 May 2018. The forum was attended by a total of 20 people, consisting of six women and 14 men, representing the following communities:

- African Australians from the Horn of Africa
- European Australians from various places of origin
- Filipino Australians
- Karen Australians from the Thai-Burma Border
- Spanish-speaking Australians from Central South America.

Attendees of Greek, Lebanese, Turkish Cypriot, Filipino, Salvadoran and Nicaraguan background represent established CALD groups in Australia, while Horn of African and Karen state participants represent more recent arrivals, and are thus part of Australians new and emerging CALD community. The Brimbank Mayor, a Lebanese immigrant, was also present, as well as a Councillor of Vietnamese background, who stayed after the welcome because she had recently been her mother's carer while working full-time.

Method

Forum participants were recruited through the Australian Unity CALD Alliance Advisory Group. Participants were given time to read the Participation Information Statement and give their consent to be part of the study. Every participant was invited to the microphone to introduce themselves and indicate their particular interest in aged care services. The discussion was then guided by the facilitator, National Seniors Interim CEO and Research Director, Professor John McCallum.

Forum discussion was broadly guided by six open-ended questions suggested in the Participant Information Statement:

1. Have you used aged care services?
2. Do you care for a family member?
3. How easy is it for you to find information on health and aged care services?
4. Do you use a computer or mobile to access the internet and find information of any kind?
5. Do you use translation/interpreting services when finding information?
6. Do you think aged care should be done by the family or the government?

Participants contributed their opinions and views by microphone with increasing confidence throughout the session, with some speaking via interpreters from within their group. All contributions were noted by National Seniors research staff on the day.

Many participants expressed their gratitude for the opportunity to have their views heard by policy-makers and the wider community.

Analysis

Forum notes were read to identify the themes related to the needs, interests, and barriers of the participants when accessing the aged care sector.

FINDINGS

1 Reasons for attending the forum

1.1 To learn about aged care for themselves

Participants expressed a strong desire to know more about aged care services for their own benefit, to learn about government programs that are available to them, and how to find out about aged care services now that they're ageing. There was an awareness that there are services available to help them, that aged care funding is an issue with increasing demands on the sector, and that changes had been made in the recent Federal Budget that may affect them:

I want to know more about what the government can do for us (F).

*I want to know what the government can give us as seniors.
I'm 71, I'm getting old, and hopefully we will get insight about the future (M).*

*It is very important for us to know something about aged care.
In this budget the government will give \$100M to aged care. We can know what question to ask, to see what service can give to us when we have some disability, some problem. The nursing homes are full and can't accommodate all the old Australians.
We must know what to expect for us. This is a beautiful opportunity for us ask questions (M).*

1.2 To know more about aged care to help others in their communities

Participants were very keen to know about aged care so that they were empowered to help others in their communities:

I want to know how I can help fellow seniors (F).

Aged care is a great thing, I visit 3 or 4 nursing homes each week to see how they are supported, my dream is for people to be able to live at home (M).

I'm here to learn how to help old people. We must know more about that (M).

I like to help my people. I like to know more about aged care (M).

Today an important period to find what the elderly and relative can get support at home. A lot of chance to understand for not just yourself but for the elder in your community (F).

I'm grateful here to be with you so we can learn what to do with elder people. So, I will do the work for people of my age, how can we know what to get (M).

Many already offer advocacy and support to their peers or to the aged people in their communities. They were clear about needing more information about the aged care sector to fulfil the responsibilities of their role:

It's great to be part of this discussion and to learn more about aged care. I work at a centre and see a lot of elderly people. They need more help. Their mind is stronger than the physical body, and they need much more help and I'm happy to learn about aged care services (M).

I didn't (yet) reach this golden age, but I have to support aged care, working in my own community. For my old people, I'm happy to be here. In my community they don't have access to come and join today so I want all of you to support my community (M).

Some participants attended because they worked informally as translators for others in their communities who had less English proficiency:

At home we are surrounded by many problems. Age is one of them. My community is not like other communities because of the language. Some cannot speak English. This is why they are isolated. This is why it is a privilege for me to come here and learn (M).

I'm a social worker and support worker and I come here with some of the seniors translating for them. I come here to learn what governments give services. Most don't know what they need to know. I want to learn more how the services do aged care, and say to people (M).

1.3 Desire for their views to be heard by policy-makers

A few participants expressed the desire to be advocates for the needs of the people in their communities who require more assistance in accessing the aged care sector:

I'm always passionate to bring the voices to the policy-makers. I'm here today to learn, to give our concern to National Seniors from people who don't have a voice (M).

We are coming to this beautiful country to live as our home. I'm doing this for when I get older. The people who came first we have to give back to them. Australian Unity CALD Alliance can sit and talk to you about aged care. There is no aged care for some cultures, no services out there. We should lobby government to do what we would like to do to help our seniors.

The network now is very strong, and I'm grateful to have the chance to tell the government what we need and we will be in a journey together (F).

2 Issues

2.1 Language barriers

Many forum attendees mentioned the issues raised by the low levels of English Language proficiency:

The mainstream service providers think people have English and understand, but that is not the case (M).

My community is not like other communities because of the language, cannot speak English, this is why they are isolated, this is why it is a privilege for me to come here and learn (M).

This is exacerbated for refugees, who have spent time without access to computers or language courses. English language courses are the focus on arrival in Australia:

Some of these might have been in refugee camp a long time. You are not able to access other skills like writing, learning other languages (M).

I came from refugee camp, first came to Australia and no understand English and I go to school two years (M).

It is common for CALD people with poor English skills to use family members as interpreters, yet, as this man says, there are consent and privacy issues when people try to access My Aged Care on behalf of their family, and this increases the length of time it takes to get services in place:

My mum's 71, and she suggest aged care. When I talk to My Aged Care, sometime it take long. They say, "Can I talk to your mum?" and they need interpreter. Now my mum, her case just refer aged care again. Her, not me, need to contact for her own case. We need consent (M).

While the information on the My Aged Care website is available in 18 other languages, not all languages are available, and many need to access interpreter services. In addition to this barrier, many older people are illiterate in their own language. Using interpreting services is a lengthy process:

(Translator speaking for another participant) He got a call from My Aged Care just in English, so very difficult. They automatically end if you say no English. They call you again, waste time. The process takes very long, more than one year. We have this exactly every time I have to explain aged care, how it works. The senior people come to me and I refer them to My Aged Care. We tried to explain to our community what to do (M).

2.2 The importance of ageing in place and dying at home

There was a general consensus at the forum that CALD communities prefer to keep their family at home as they age:

If the family has taken him there and it is not his wish to go the nursing home, the family has the right, but it is not his wish to go to the nursing home. There should be support for these at home (M).

We have in our culture and religion that our family stay together. All today stay with family. We don't like our family to go out of our eyes. They can go to the grandson or other. Most of our culture respect our family and they want us to stay (M).

A few participants understood the need for dementia patients to go into residential care, but they believe that in all other cases people should age in place:

My dream is for people to be able to live at home. This is the best way possible. The ones in nursing homes without dementia don't live long enough. They need to stay in their own home and be supported (M).

There are services for caring at home and cleaning. The nursing home is indeed for the ones suffering dementia. They can go to nursing home but the ones who still got it, they can benefit from staying at home. The family can look after them quite well, even blind people are okay. It's a great thing we can keep them at home, and great for Australia (M).

One participant described her mother's initial home care arrangements, then her mother's extreme resistance to the prospect of residential care and how hard this was for her:

I think with my community, if we send a parent to the nursing home it will be a big effect for them. They think we don't love them, and they get lonely and depression. For my mum I have support from the government and they send people with, you know, the home care. They send people to take her shopping and to the group.

When I arrange for my mum to go to the nursing home, she hide away, she think we don't love her anymore. In my community they all have the same situation. They always want to stay in their home. They feel more comfortable, more support, and love all around them.

In the home they have problem with their language and the food, and they want to pray. My mum just pass away. I still get the feeling, it very hard. Everything when I caring for my mum is difficult. I the only child of the family and no relative. Hard on my back too.

But the government have a lot of service to provide for the elderly who would like to stay at home (F).

Another participant vividly described the taboo nature of sending parents into residential care, and the desire in his community for people to die at home:

In African Australian community, letting your parent to go to residential care is the last thing, it is taboo. One of our members sent his 75-year-old father to residential care. The whole elder in the community came to me not to send his father, even the priest. I said there is no way we can intervene. Another man had cancer and they said he had to go to palliative care and the family said no. All African want to die at home rather than send their family to residential care (M).

One forum member described what he believed is the Australian tendency to neglect family members who are admitted to residential care, and said that he found residents don't like the food and have trouble sleeping in care homes:

The Spanish community is never sending the elderly people to the nursing home. We keep them at home. Only in very sick case, have dementia or disease or operation, we can send them to the health centre but we tried to keep them at home always. Nicaragua is a small country in Central America. Very poor but they keep the family at home. But in Australia is different. They send family in home and they forget them there. Another thing, when the people go into the nursing home they don't like the food, they don't sleep properly because another patient next to them. They are expecting some family to see them. They waiting, waiting. The Spanish community is very close to the elderly people. We know they grow up like us. When they reach 85 or 90 they need support from the family (M).

2.3 The difficulties associated with caring for family at home

As included in 2.2, one participant described having issues with her back when she looked after her mother at home, and the difficulties involved when you don't have siblings to share the care burden. Another mentioned that it was usually the women who provided informal care:

It will be women (caring) most of the time, if there's a choice (F).

A participant described the kind of tasks involved in caring:

We feed them and give them baths, we read books in their own language, tell stories about the past (F).

The inability to tell one's biography and stories from the place of origin to friends, relatives and younger people is a form of isolation that can be felt by CALD seniors. Loneliness and isolation are accentuated when they're at home alone and can't access news and other media in their own language:

Just a few points from NEC point of view, what happen with our elders is the children go to work, the grandchildren go to school. They can't read the newspaper, can't watch the television, the whole week they have nothing (M).

The social isolation of the carer was also mentioned, as well as the benefits to both the care recipient and the carer in being involved in community activities:

Mental health is a big issue. The carers are the most disadvantaged people in the community. You can't just leave your mum in bed. You feel guilty. There is a need to look after the carer and empower them as well. In HACN, the Karen elderly and African elderly come together, share food, go to the garden and do the planting. Carers come too and it's the happiest day for them. Sometimes these days are the only time these people get out into the community and dress up for the day. Hundreds lock themselves inside (F).

2.4 Dementia care

While there was a great preference for care at home, a few participants described how difficult it is when dementia patients need to be left at home alone:

There is loss of memory in the elderly now. A lot of elderly people are scared to get into aged care centre, but they feel lonely and scared by themselves at home. What can we do? (F).

Another participant also described the risks for dementia patients who venture out without a carer:

The person having dementia is already at risk. Should he go outside without relative that means he can be hit by a car. My question is, who is the advocate for those people sitting there and in need of support? (M).

These comments suggest that there are informal carers in CALD communities in need of respite care, or people with dementia in need of home support services to go on outings, and that many are either not aware of the services available to them, or they don't know how to access the services they clearly need.

2.5 The importance of community support

Forum participants were also unanimous in advocating for the importance of community gatherings, so that the elderly stay involved in the community:

Most of the Filipino elders, 80% love to live independent. In our communities we have lots and lots of social gatherings. We see to it that all our elderly are joined together, are happy, are socialised. We give them understanding of how to live in their own lives. One in my community is 95 years old and she comes in the bus. It's helpful for the family, make them very more socialised and that helps a lot (F).

Many described the intercultural nature of the communities they are involved in:

We are people from different homes from America – Chile, Salvadoran, Argentinian, Bolivia, doesn't matter. People learn from each other, taste the food, learn to say things in Italian to those people in this centre. I learn something from Vietnam. Many benefits for the community. For those who live alone they can do nothing. They forget to put off the gas (M).

One man made a strong plea for a community centre so that his people could have a place other than church to gather together in Australia, as they were able to in their home country:

It's difficult for us to meet because we don't have place to meet. We don't have a place to come together, but we used to have this at home (M).

2.6 Transport

Many said transport services are essential for the elderly if they're ageing in place:

Here many different nationalities, more than 150 in our city use transport, 10 mini buses. Those buses cater for senior citizens. We drive around to all clubs each week and take people to shopping centres once a week. We have a special number for people to call. It's a great place here for people to get their people together (M).

The isolation of getting older is getting very serious. The depression kicks in and people end up in a mess. When we send our bus, the demand is unbelievable. For NEC there must be something from the Council that is accessible to our elders. If they don't have a community centre or community transport, that's where the government needs to give the money (M).

From many of the comments, it was apparent, as also identified in the Multicultural Affairs QLD report, that transport in outer suburban areas is less developed than in inner cities requiring either local council or family support:

Things we need to address: 1 transport – we volunteer ourselves to take them to church and take them to the doctor, 2 – transport for the senior to go around, we are forced to pick them up (F).

This is a need for you to look after my community. We don't have transport. HACN look after us but if no bus we can't bring people (M).

2.7 Needing help at home and not knowing where to go for information

Not knowing what services exist is a well-known barrier to accessing aged care services for all older Australians. It is worse in CALD communities, particularly for NEC who may lack experience using Australian government services:

My brother-in-law needs help. My sister wants to work till 65. She's 64 now. She's paying for help, because he's a big man. He cannot walk straight or sit down straight and needs help. She's got no equipment inside the house. Maybe the government help these kinds of people (F).

2.8 Digital issues

In a report on a similar topic published in 1990 (McCallum & Gelfand, 1990), digital issues did not rate a mention, as they were not a central part of life. Digital literacy is now part of all information-seeking behaviour. As is the case for many senior Australians reported in a prior National Seniors study on the digital divide (McCallum, Rees, & Maccora, 2017), many NEC people find technology costs prohibitive and have the tendency to only use mobile phones for phone services, and not for access of service information or transactions:

What I came for concerning the issue we have many things affecting us, 1 – to get access it costs a lot of money (M).

(Translator) He uses mobile phone only for phone (M).

Using technology in English adds another layer to the digital divide for those from NEC:

Technology, 90% can't access it because the language. Even in their language it's so difficult to operate it (M).

For refugees who may have experienced trauma, language and digital literacy become even greater barriers to entry:

Those from other cultural background (African), our situation, some of the elderly people they never been to schools. It is very difficult. They can't use computers, that's one thing. Number 2, some of these might have been in refugee camp a long time, you are not able to access other skills like writing, learning other languages (M).

One participant eloquently described the many complexities associated with accessing government services in Australia, the language barrier, poor digital skills, lack of physical access to technology, and the need for intermediaries and courses:

My community is isolated from social things and some don't know how to operate the small device which is mobile phone. They need someone to help them press to call their son. Computer, they have to go and login, and they don't know what to do it. They don't know how to do the myGov for themselves. Centrelink, they don't know. They spend 3 hours there because they are told to go to the computer, they don't know what to do. We need the office to teach them what to do. Bring the people to come and participate in the service like laptop, computer, mobile phone. Some my people didn't learn English, didn't learn other language. Our community very new and they don't have facilities (M).

Many participants believe a grassroots approach to digital access of aged care is the ideal solution, as we discuss further below. One suggested that, if community support people know how to achieve access, they can pass it onto others who either don't have computer access, or who experience language barriers in accessing aged care services:

Any problems that we have especially for isolation, things like that for non-English speaking community, how can we access this information to the aged care website? For our community, how can we disseminate this information? Most of our community can't have access. We can do that as part of our program. We can educate the senior citizens with computer and invite family members so they can understand the services offered by the government because we are ignorant what the government is giving us. If we know what the government is giving us then we can give the information (F).

National Seniors recent study of Centrelink experiences found that people of CALD background have a more negative experience applying for the Age Pension (National Seniors and Retirement Essentials, 2018). The Centrelink study was based on the 2018 National Seniors Social Survey (Wave 7) of the National Seniors membership, comprising people who answered questions online and in English. Very few respondents in the Centrelink study were recent arrivals, and we know NEC groups have more significant issues accessing digital services in English.

2.9 Long waiting times for aged care

Long waiting times are common in aged care services, as well as in Centrelink processes where CALD applicants also have long waits, as above. This is a form of rationing which is a surprise to newer immigrants.

I think the problem with aged care they say no waiting time, and then (there is) long waiting time. Is not actually supporting the person who is in need (M).

2.10 The need to return to home country to care for aged parents

Transnationalism has never been easier with regular and affordable airfares. For NEC groups, this allows fulfilling of family obligations without having to go through family reunion migration. Male participants were the ones who expressed this as a way of exercising their duty of care for family members left at home:

I came in 2003, I went back in 2006 and I take care of my dad. In Africa the son take care of you. No government care, so I went back. In 2013 he died age 101 (M).

Maybe I will go home, South Sudan. My Grandmum, if she's getting old I might have to go back. She is 79. Maybe if God gives her more than that, maybe 10 years, maybe I will have to think about it. She gave me the money to come here and I want to see her before she dies (M).

This provides an interesting contrast to the dominant role of women in providing informal care in CALD communities.

2.11 Some don't have family to help

The fragmentation of extended families through refugee immigration is felt most acutely in the early phases of residency:

We in the community need more awareness program on what aged care program can do for our seniors and what we can do in our community. Many are isolated and don't have the families (F).

I have two uncles. One has the family in Melbourne. The other also above 70s and he now has the problem who will take care of him. We were looking to bring one of his daughters, still in Africa. We in Africa are different. Only your wife and your child take care of you (M).

2.12 Senior community members have a responsibility to unite the community

And, finally, reiterating the importance of strong community feeling, one participant pointed out that seniors play an important role in keeping community and family members together:

The unity has to be done by the senior. It is difficult for the young people, but if we as the senior citizen do that, then our country will be a good country. I appreciate the work of my brother bringing people together. I work with the Uniting Church, voluntary (M).

3 Solutions

3.1 Grass roots solutions

Rather than national, standard options, NEC groups said that community level solutions will work best for them. One man recognised that information is available but it's not accessible to most people in his community, especially those with digital literacy issues. He suggested that community leaders need to be the ones disseminating information at the grassroots level:

For those people I'm thinking of engaging the community leaders, the community prominent group advocate for those. They can disseminate the information to those group. Still traditional people can't actually use the technology. The only way we can access is through services like Horn of Africa. People coming into those facilities are coming into a problem. They need the resources but the people which are in need are not getting them. The resources are sitting somewhere and they are somewhere else. I propose these resources are somewhere to reach, we need to reach the grass roots (M).

When aged care services are changed or updated, one woman asked if the government would make sure the new information is disseminated through non-English media channels:

For the migrant community, background non-speaking English, I think the government information on the update on services, you can change to the different language and give it to the community. Does the information get put in the newspaper of the community, the radio? The elderly people, they love to listen in their own language. If people get training in the update and then someone can come to the community and speak in your language. We encourage the government can support the new migrant coming. The new don't know what happen here, what services provided and need the information in their language (F).

Another participant also felt that this was the best way to teach NEC groups digital skills:

We need the office to teach them what to do, bring the people to come and participate in the service like laptop, computer, mobile phone. Some my people didn't learn English, didn't learn other language. Our community very new and they don't have facilities, this is a need for you to look after my community.

This suggests that digital options could be used more creatively to bridge communication, information and cultural barriers but only if people have access to digital devices and skills. Plainly, digital solutions don't work at all if you're not connected, and there appears to be little innovation in this area compared to other service areas.

3.2 Participants offering advice, information and encouragement to each other

Within the group there was a generosity of sharing experiences and knowledge with one another. For example, when a request for knowledge was expressed by Horn of African groups, a Vietnamese participant explained her access of aged care for her mother:

If in your family you have elderly people you can apply to have an assessment about your parent's level. Level 2 they can still do it but need to go shopping, to the meeting, the church. Carer only for a few hours a week. Up to level 4, they can't do anything by themselves, need assistance. The government can provide equipment to lift up to go the toilet. If you are 64, put the application in. There will be a long list so the service already there for you. You only pay very little and the other will be paid by the government so you don't pay a lot. If you request they can have the person speak in your language. The council can have the service too. To have assessment, they can send someone to help you, whatever your age, your condition, you're always in good hands (F).

Another participant offered specific information about where to go for an assessment in the local area:

You can ask for home care and ask in your own language. You need the assessment, so first talk to them (address of centre offered and explanation of how to request assessment and request own language). Book in from the council (F).

A CALD Alliance member offered assistance to NEC members at the forum:

At Australian Unity CALD Alliance we are available to mentor an organisation on how you can organise yourself or organise the community centre. We have done this before. Easy access to our CALD Alliance. Talk to us and get our number. That's our role (F).

3.3 Engaging with NEC groups

Australian Unity CALD Alliance were chosen for this study for their engagement in grassroots facilitation of new and emerging groups. They promote intercultural exchange in assisting Horn of Africa and Burmese Karen people to meet together. Such activities improve service literacy and access of services by NEC groups.

Councils in areas with a high number of NEC residents are at the forefront of engagement with their needs at the grassroots. Brimbank City Council, who were also in attendance, engage proactively with CALD members of the local community and provide transport, social support and recreational programs for seniors, such as:

- Assistance with the operational costs of 87 registered seniors' groups through a grants program;
- An annual event for Victorian Seniors Month;
- A Brimbank Seniors Directory updated every two years;
- Community transport services;
- Volunteering opportunities and training;
- A Community Register that provides contact for isolated older people;
- A Community Meals Program;
- Neighbourhood Houses with activities such as U3A, community gardening, and other support groups;
- Leisure Services, including walking groups and fitness classes;
- Affordable hire charges for Council facilities; and
- Funding through a Community Grants Program.

DISCUSSION

Communities at the grassroots

Recent research with CALD communities has discussed a change from the term “multiculturalism” to “interculturalism” as it “prioritises active interaction and dialogue over passive tolerance” (Ballantyne, Ford, & Malhi, 2017). While the need for this change requires further debate, the Australian Intercultural Index provides a questionnaire for local governments to assess themselves on their commitment to supporting minority ethnic groups within their jurisdictions. The use of this tool may bring about changes at the local level of the kind advocated by the findings of this study. The evidence provided here is that NEC groups greatly desire grassroots solutions. Local government commitment to CALD communities could ensure:

- Greater participation of CALD people in political life and policy decision-making;
- Support for newly arrived residents through a package of information on the local area;
- Monitoring of the community transport needs of seniors;
- Better advocacy for ageing CALD people; and
- Increased culturally and linguistically appropriate services to support ageing CALD people to access the aged care sector.

The data collected for this study demonstrates that a significant level of intercultural interaction occurs in CALD communities, with established groups providing information and support to NEC groups in a way that cuts across cultural boundaries. It’s possible that CALD people don’t have a preference for what this process is called at organisational and government levels – they just get on with it! Many CALD community leaders provide high levels of advocacy and networking for new arrivals, helping them to settle into Australian life and to utilise the government services available to them appropriately. Digital and service literacy is best facilitated through the use of these grassroots connections. The findings also provide support for the suggestions contained in recent Emerging Ageing research by the Ethnic Communities’ Council of Victoria (ECCV), for a welcome and information kit for migrants and asylum seekers, and neighbourhood spaces for intercultural connection (Jordan & Rukas, 2017).

Digital literacy

National Seniors is continuing to study the impact on seniors of having poor digital literacy. While there is evidence of a senior digital divide, in which many Australians over 50 are digitally savvy, others have limited use of digital devices and services, and some are completely left out of the digital world (McCallum, Rees, & Maccora, 2017). The momentum of digitisation of service delivery appears unstoppable, and there are positives from this if people can be connected. Evidence gathered for this study suggests that CALD people from NEC groups urgently need support to become digitally literate and to learn how to access digital services.

The Victorian Government interpreting and translating service, LanguageLoop, launched a mobile video interpreting app to provide interpreting services for CALD patients in public hospitals run by Western Health:

LanguageLoop recognised how VideoLoop could meet the organisation's challenges, where on-site interpreting was often not an option at short notice, or where it was limited by location, availability and costs. To address this problem, which is typical in health settings, the team at LanguageLoop looked for a proactive way to deliver a seamless service through technological innovation (LanguageLoop, 2018).

This innovation in the digital delivery of interpreting services demonstrates how improved digital literacy will enable CALD people in their access of health and aged care services. Current trials have also indicated that remote translators, rather than local, help avoid sensitivities about discussing health and personal issues.

Transnationalism in practice

For many years, the experiences of new migrant populations have been described by the term “transnationalism”, where immigrants build social fields across national boundaries by merging continuing networks and activities from their homeland with new patterns of life in their host country:

With respect to migration, being connected to several places at once – or “being neither here nor there” – has long been a defining feature of the experience of being a migrant. Leading transnational, multi-sited lives means that exchanges and interactions across borders are a regular and sustained part of migrants' realities and activities (IOM, 2010).

One of the considerations raised in this study was the need to return to the country of origin to care for ageing parents, with some participants staying for many years until death of a parent occurred. Another participant mentioned the need to bring a family member from home to Australia to care for an ageing parent here. Ageing and aged care issues clearly involve many disruptive elements for CALD people, particularly the newly arrived.

In *Families Caring across Borders: Migration, Ageing and Transnational Caregiving* (2007), West Australian researchers found that digital technologies such as email, mobile phones and digital cameras help non-local kin maintain transnational family relations. Many have frequent contact via these channels, as well as visiting, providing financial assistance and emotional support. There are not only travel and communication costs involved in transnational caregiving, but the reality of negotiating national borders, visa restrictions, consequences to employment, and differences in health care services and telecommunication infrastructures between countries. The authors comment on the gender of transnational caregiving in ways aligned with the themes that were evident for our participants:

The usual argument is that caregiving is primarily the responsibility of women ... we can begin to reassess this claim by acknowledging the obligations that are placed on males to provide care, particularly (but not solely) in non-Western families (Baldassar, Baldock, & Wilding, 2007).

The transnational caregiving responsibilities of newly arrived CALD people further suggests the need for better digital literacy, not only to enable access of aged care and other government services, but to help people maintain contact with family members.

Aged care literacy

A 2015 review of research on older CALD Australian by the Federation of Ethnic Communities' Council of Australia (FECCA) found that, while this is not an homogenous group of Australians, one common theme is "a lack of knowledge in navigating Australian systems and services, particularly for migrants who arrive in Australia at an older age" (FECCA, 2015). According to FECCA, studies have shown that CALD people have lower rates of access of services, and lower rates of use of information technology. This combination should raise alarm bells for vulnerable CALD people trying to access the aged care sector, particularly NEC groups, as My Aged Care is essentially a digital gateway.

The findings of this study reveal that people working as advocates in CALD communities are willing to support their elderly with aged care access, but they need more information and resources to do so. They indicate that changes in the delivery of aged care services are best provided to them through their existing media outlets, including newspaper and community radio. They are keen to attend information sessions at community centres, and would like aged care information to be delivered in this way.

Another implication of low aged care literacy is later diagnosis of dementia in CALD populations. The FECCA review suggests this may be connected to less understanding of the signs and symptoms of dementia, but also reduced access to residential care. This study provides evidence that CALD people resist residential care, even for family members with dementia. There is some reluctant acknowledgement that dementia patients cannot always be cared for at home, but when they are, it seems that home care services are under-utilised, with informal carers going to work feeling anxious about their elderly left at home alone. This suggests CALD people may not understand the services available to them, as the FECCA review also found:

Families from some CALD backgrounds provide higher rates of informal care to older family members and there is a body of literature relating to their experiences. The research suggests that family carers may be unaware of services such as respite or home care, and financial support, that are available to support their role as a 'carer' as these are often unfamiliar concepts to older people from CALD backgrounds (FECCA, 2015).

The Aged Care Sector Committee Diversity Sub-group's forthcoming *Actions to support Culturally and Linguistically Diverse people* (2018) aims to further empower the consumer, families, and carers with the information to know what they're entitled to, after wide consultation with CALD older people and their representatives. This text recognises that lack of aged care literacy creates a barrier that prevents CALD people accessing aged care services.

Ageing in place

Staying at home in the later years is the preference for most Australian-born older people, and Australians from CALD backgrounds place a high priority on this for their ageing family members. The participants in this study were aware of recent Federal Budget measures to increase home care packages, and they support these aged care changes. However, accessing the services they need does appear to be an ongoing problem.

In order to provide community support for their elderly, CALD communities need centres in which to house their gatherings, and community transport services. Grassroots networking, the sharing of information, and intercultural interaction clearly occur spontaneously when CALD people have the opportunity to gather together. This type of community building facilitates ageing CALD people to be adequately supported to age in place. As reported in a prior National Seniors publication, *The Ageing Experience of Australians from Migrant Backgrounds*:

While mainstream health and welfare systems will remain important to the health and economic well-being of CALD older adults, their social well-being is much more dependent on their families and ethnic communities. This is particularly the case when they do not speak English very well or have a tradition of strong family networks that encourage co-residence and co-dependence across generations. Families and CALD communities therefore have an important role in enhancing the ageing experience of their older members (National Seniors Productive Ageing Centre, 2011).

The participants in this study made a strong plea for their communities to be supported by governments through transport services and community centres. These services not only support older people living at home, but also their informal caregivers.

CONCLUSION

A 1990 focus group study of daughters caring for older migrants in Australia, *Ethnic Women in the Middle*, found that the main issues were language and cultural barriers to government services, the need for more support for carers, grassroots local solutions, the care burdens on women, and an emphasis on care at home (McCallum & Gelfand, 1990). Comparing the current study to this previous research on diversity in the Australian aged care system reported 28 years ago, the issues remain the same excepting digital access. It isn't the case that these issues haven't been addressed, but that they need to be re-addressed with refreshed approaches as new and emerging groups come into the aged care system with different languages, cultures, and immigrant experiences.

On the positive side, the increased focus on services delivered into the home, and the introduction of Consumer Directed Care, will align with the preferences of NEC groups, once barriers are overcome. As well as all levels of government, established groups play active roles in providing information and support because they've had similar experiences. There are new issues, however, that need new approaches, and the major one in 2018 is the digitisation of information and service management systems. This has provided another layer of difficulty for which solutions are only beginning to be developed. It is also clear that most issues and solutions are best dealt with in communities and by local grassroots activities.

From the CALD communities and local region studied in this report, the *National Ageing and Aged Care Strategy for People from Culturally and Linguistically Diverse (CALD) Backgrounds* (DSS, 2015) can be assessed, as follows:

Goal 1 – CALD input positively affects the development of ageing and aged care policies and programs that are appropriate and responsive:

While this is active in Melbourne, reach into the NEC community and region studied is still weak.

Goal 2 – Achieve a level of knowledge, systems capacity and confidence for older people from CALD backgrounds, their families and carers to exercise informed choice in aged care:

This is yet to be achieved in the group studied but strongly desired by the communities. While these issues are not new, the barriers created by the digital delivery of information and services is a new item requiring attention. Innovations need to be encouraged to deal with this.

Goal 3 – Older people from CALD backgrounds are able and have the confidence to access and use the full range of ageing and aged care services:

This is yet to be achieved in the group studied but strongly desired by the communities. It is conditional on better achievement of Goal 2.

Goal 4 – Monitor and evaluate the delivery of ageing and aged care services to ensure that they meet the care needs of older people from CALD backgrounds, their families and carers:

This report provides evidence for this monitoring but more widespread and consistent monitoring is needed, particularly for NEC groups in other areas.

Goal 5 – Enhance the CALD sector's capacity to provide ageing and aged care services:

While more support for these groups is needed, the combination of the local council, National Unity CALD Alliance, and the leadership of committed community leaders is making good progress with this goal in Brimbank.

Goal 6 – Achieve better practice through improving research and data collection mechanisms that are inclusive of cultural and linguistic diversity in the ageing population:

With the consistency of themes in research on CALD services across 18 years, research now needs more practical direction towards improving information sources and sound trialling of innovations to deal with issues more effectively. In summary, this goal is reasonably done with descriptive evidence, but now needs more applied work.

While National Seniors is a membership organisation, its research and advocacy is undertaken for the benefit of all Australians over 50, including those from diverse backgrounds. The Office of the United Nations High Commissioner for Human Rights (OHCHR) estimates that approximately 3% of the world's population live outside their country of origin:

(A)n increasing number of migrants are forced to leave their homes for a complex combination of reasons, including poverty, lack of access to healthcare, education, water, food, housing, and the consequences of environmental degradation and climate change, as well as the more 'traditional' drivers of forced displacement such as persecution and conflict (OHCHR, 2018).

The OHCHR “promotes a human rights-based approach to migration”, and says it is essential that migrants themselves should be included in all relevant national strategies that seek to ensure migrants have equal access to the services they need.

According to the International Organization for Migration:

While the core motivation for migration is usually the pursuit of a better life, migrants often experience profound, systemic challenges to their physical, mental, and social well-being. They often face separation from their families, unfamiliar social and cultural norms, language barriers, appalling living standards, exploitative working conditions, as well as discriminatory access to health-related services (IOM, 2009).

The pursuit of fair access to services, including aged care, health, translation services, and digital literacy, accords with the ‘United Nations Principles for Older Persons’, that they have access to health care, community support, social services, institutional care, and educational and recreational resources (IOM, 2009). These values are clearly appreciated by the CALD participants in this study in their references to “this beautiful country” (p.14, 1.3), and they express surprise about the reality of delays in receiving services (p.20, 2.9), but with a strong reference to family responsibilities and intercultural self-reliance (p.15, 2.2).

National Seniors regularly receives comments from members on the responsibility of government to its citizens, and they have the last word here with their support for a ‘fair go’ in regards to diversity of all kinds:

Every society is judged by how it takes care of those members who are disadvantaged (F, 71).

A measure of a civilised, wealthy society must be the opportunity given to those on the lowest socio-economic scale to live productive and fulfilling lives (M, 72).

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