

Italian-speaking family caregivers of
people with dementia

Report on focus groups with the Italian community

Prepared by Desiree Boughtwood and Silvana Gava

With input from Jon Adams, Yvonne Santalucia, Chris Shanley and Helena
Kyriazopoulos

Aged Care Research Unit, Liverpool Hospital

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Foreword

This report outlines the major issues for Italian family caregivers of people with dementia who participated in focus groups as part of a research project. The caregivers were predominantly from south west Sydney and discussed all aspects of dementia care giving.

The report contents also formed the basis of a presentation which was delivered to the Italian community (research participants, community members and others). The intention of both the report and presentation is to generate awareness of issues that Italian carers face.

Interested parties should consult articles published by the authors in dementia, ageing and multicultural journals for more detail on and other aspects of the research not contained in this report.

While there are some difficulties in addressing all of the participants’ concerns, the recommendations section outlines some ways in which dementia policy and service provision could be improved for Italian carers.

Glossary

CALD	Culturally and linguistically diverse
FG	Focus group/s
NHMRC	National Health and Medical Research Council
PLWD	Person living with dementia
ESG	English-speaking groups
ISG	Italian-speaking group

Introduction and background to project

Approximately one in eight Australians do not speak English at home. This culturally and linguistically diverse (CALD) population is ageing at a much greater rate than Anglo communities (Access Economics, 2006). There are many knowledge gaps pertaining to dementia in CALD communities, including types of dementia, factors influencing use of services and medical interventions for dementia and related symptoms (Cheng et al., 2009).

This project is funded by the NHMRC Dementia Research Program and is titled: *Family care-giving for culturally and linguistically diverse (CALD) people living with dementia: the perspectives of family carers and health service providers.*

Four CALD communities living predominately in south west Sydney (Liverpool, Fairfield and Bankstown Local Government Areas) are the focus of this project: Arabic, Chinese, Italian and Spanish-speaking. They were chosen because they are some of the larger groups in the local area and differ significantly from each other (in terms of culture, migration history, etc). To gain a broad and varied perspective on these issues, four different groups were invited to participate in the research: family caregivers, ethno-specific and multicultural workers (meaning those who worked specifically with one community or CALD communities generally) bilingual general practitioners and geriatricians. Four focus groups per community were conducted with family caregivers and one-to-one interviews were conducted with the multicultural workers, GPs and geriatricians.

This report concentrates on the focus groups with Italian family caregivers. A total of 40 participants of Italian background participated across four focus groups. Detailed demographic information was not collected but of these 40, 29 were female, 11 male and the age range was mid 20s to mid 70s. Although a bilingual fieldworker (Silvana Gava) was engaged to recruit to and facilitate the focus groups in Italian, three of the groups were conducted in English as participants indicated this was their preference. While there was some variation between participants, differences were particularly marked between the English and Italian-speaking groups.

Major issues raised by the community

The major issues that participants were concerned about and impacted caring for their relative are summarised in this section.

Knowledge of and reactions to dementia

The majority of participants suggested there was limited knowledge of dementia within the community. It was behavioural changes, in particular, that community members found hard to comprehend. According to participants, this lack of knowledge persisted unless people were confronted by dementia – meaning that a member of their family had dementia. Participants spoke about the reaction of people who had previously been close to the person living with dementia (PLWD) prior to the development of dementia

Um friends of the person concerned don't call anymore because they can't have a conversation with them (FG 2)

When the community offered interpretations of dementia, participants suggested, one common misconception was that dementia was old age

Like through my experience I found that a lot of people, friends, they consider dementia just a part of getting old and that's it (FG 1)

Participants across all four groups recounted how their families became more isolated than at other stages of their lives due to dementia. As the community didn't understand and reacted negatively to the PLWD, participants noted that it was really down to the individual family to cope

I think the outside will just say...lock em up and that's it (FG 3)

Dementia means changes to family's lives

Having a family member with dementia resulted in significant changes to families' lives. Some of these changes were small, but had significant meaning. For example, some older male participants mentioned they were now doing the cooking – which was something they had not done before. That their wives were no longer cooking or cleaning was a clear signal that they were unwell

I think it's good for her to continue cooking, cleaning, with my supervision, of course, otherwise she feels sad, useless. I try my best to encourage her to do everything. Sometime she would go somewhere, for example to the fridge; she would open it and say "what am I doing here?" (FG 4)

Most participants were grieving and attributed their grief to a range of things, such as feeling helpless, seeing their parents remember past experiences (war, loss of a child) and loss of the person, both their personality and skills

up until then Mum's always had the gift of being able to speak English because Dad said as soon as he got out here "that's your job" you know, so Mum had to learn and she was a-okay with it, now sometimes she will talk in English sometimes she just won't even understand a normal discussion (FG 3).

Participants were also concerned about their own physical and mental health. With some exceptions, participants in the Italian-speaking group (ISG) were more worried about their physical health and participants of the English-speaking groups (ESG) more concerned about the psychological and emotional aspects of health

I nearly had a breakdown (FG 1).

Carers, particularly those that provided all the care alone stated that *you basically give up your life (FG 3)* but felt that they were unable to do anything else. Participants, particularly the ISG were worried about the implications for the PLWD if something happened to them

I am the oldest one and if I died my wife can't live by herself (FG 4).

A few adult children mentioned they were concerned about the impact of care-giving on the older members of their family.

Information about dementia

Participants drew on a range of resources to assist them in finding out about dementia. The three most frequently used included GP's (both bilingual and mainstream), hospital staff (Aged Care and Assessment Teams (ACAT's), geriatricians, neurologists and social workers) and friends whose family members had experienced dementia. A smaller number of participants had used Alzheimer's Australia (two) and three used the Internet (two were assisted by their

children). Carers mentioned that despite the long wait for them, ACATs and geriatricians were very helpful once they became involved with families, both in terms of supplying information about dementia, informing of services and addressing carer's needs. However, the ESG who had some knowledge of the aged care services, as opposed to the ISG, mentioned that the aged care system is very disorganised, there seems to be no links between different services and there are too many acronyms which made it difficult to negotiate the system.

Participants mentioned that sometimes both the PLWD and carers, particularly older family members, denied there was a problem

Can I also just say I think some of them are in denial, the older people they like you were saying, they don't think that there's anything wrong with them. If like they're telling a story they think they're telling it for the first time again (FG 2)

Whilst some carers felt they should educate their parents and tried to explain, for example, that they were not going to get better, others played along and agreed with their parents that there was nothing wrong until the dementia progressed to a point that it had to be confronted. Some participants were concerned when (well) older family denied there was a problem, or that the PLWD would get better, because this meant the PLWD was sometimes not supervised appropriately. Furthermore, legal, financial and decisions were delayed or not made because the family could not reach a consensus

the hardest part is in all our families there's always been one at least not willing to accept that there is a health problem ok and that's the hardest thing to overcome (FG 3)

Medicine and doctors

Italian families used both Italian-speaking and mainstream doctors. They mentioned that the PLWD and their spouse preferred to see Italian-speaking doctors as it was easier to communicate. Carers, particularly younger/English-speaking people suggested they were not terribly bothered whether the doctor spoke Italian or not, and they were happy to translate if need be. Their main concern was that the PLWD received appropriate medical treatment

It's a matter of finding a good doctor it's not the language (FG 1)

Carers across all groups reported significant concerns with the GP's management of dementia, which they attributed to doctors having limited time and/or knowledge of dementia. Carers concerns were dismissed or attributed to their parent's age. Participants felt medications were over prescribed, people were on too many medications that seemed to be for a similar purpose and some suggested numerous medications had a negative effect on the PLWD. The cost of many medications was also a concern to pensioners. Carers in the ESG felt able to challenge

GP's on a particular issue or ask more questions of specialists, however the older generation (mainly ISG) did not do this as openly, as discussed in the groups, although they recognised when care and information provision was below par. Some mentioned how relieved they felt when they found a good GP.

A significant number of carers had questions about the progression of dementia and all but three participants felt unprepared to deal with the next stage of the illness. Their concerns pertained to the physical and psychological changes and the safety of the PLWD and in the group, participants asked each other about the stage of their relative's illness and what measures they had put in place.

Participants from all four groups felt strongly that the PLWD was not as unwell and sometimes not showing any symptoms of dementia prior to hospitalisation. Participants across all four groups noted a significant decline in the person within and post hospital. Carers mentioned they felt like they needed to stay in hospital to make sure that appropriate care was provided and the PLWD was able to communicate their needs to the staff. Short staffing was a problem in hospitals, as was staff's lack of awareness that people may have limited English and/or forgotten it completely with dementia

[hospital] reduced her to a statue, they were horrible (FG 1).

Family arrangements regarding care-giving

There was much variation in family set-ups for care-giving. The four most common set ups were: spouse provided all the care; one adult daughter or son provided the majority of care, sometimes with the help of their spouse; immediate families provided all the care (children and grandchildren of the PLWD were involved); and the PLWD was in residential care and one or two carer went regularly to the nursing home/hostel. There tended to be two, rather than one primary carer

with Mum we look after her 24 hours a day, we have a [paid] carer that comes in only four hours a day that the government provides, yip, like the rest of the time, night and day its my sister and myself, we've got a younger brother, he'll help with his wife for a few hours, so you kind of, like for us to come here like we had to get two of my daughters to go and stay with Mum until like I got this other lady to go and take over at 5 o'clock (FG 3)

Some participants had young children (under 15) who lived with or had much contact with their grandparents who had dementia. Participants mentioned that their children treated the PLWD with much love and respect although the groups wondered whether this would continue once the children were older and whether there would be any impact on the children from

witnessing (in particular) the behavioural symptoms of dementia. Several participants from the ESG suggested their children would provide similar care for them once they were old/had dementia – namely keep them at home. Participants suggested this was the Italian tradition and children would adhere to it. In contrast, the ISG acknowledged home care was the tradition but did not think it would happen

Youth is different today. When we were young nursing homes didn't exist. Parents used to stay home till the end. Today, sometimes they end in a nursing home even if they are not that sick or that old (FG 4)

Services

Participants who provided care at home, which included about half of all carers, with the exception of a few, used home based services. However they deemed services inadequate for reasons of safety /privacy (having a stranger in your home), the dishonesty of some of the workers and also culturally (different standards of cleanliness)

I used to do that job and its true, from the company you're not allowed to do this, this and this and what you're meant to do, like you're only meant to do certain rooms and certain things but because I was Italian and I was basically going to the Italians I cheated and did a little bit more only because I wanted to (FG 3)

In the Italian-speaking group no participant had placed the PLWD in residential care and suggested they disagreed with the concept of residential care

They said I should start to look for a place in a nursing home but I have everything I need at home. Until I can make it (...) I remember my mother, she died two years ago. She was in a nursing home (...) I can't believe that now it's my husband's turn. He's just 70 years old (FG 4)

In contrast, in the three other groups, slightly less than half had their relatives in nursing homes or hostels. Yet all participants acknowledged placement was and continued to be a difficult decision. Individuals had to weigh up safety, other commitments of various family members and the levels of care offered by residential facilities – at home the carer has no life but in the nursing home the individual needs and preferences are not always catered to. Participants using nursing homes still took much responsibility for their parents, including consulting doctors, coming in to shower the PLWD and providing extras like food and massage services. The ISG suggested the only positive of nursing home was that the PLWD received care during the night time.

People deliberately chose ethno-specific facilities because of language, cultural traditions like Mass and food. However they were dismayed that many staff were unable to speak Italian

and sometimes not even English very well, which meant they could not communicate with their family member. This sometimes resulted in limited care and even neglect.

When the residents can't communicate to the nurse it's a big problem they will start to become agitated and ah they become uncomfortable and they can become angry and aggressive, especially when they need to go to the toilet, that's number one (FG 2)

What compounded this problem, families suggested, was that there were not enough staff in nursing homes.

Self care for carer

Many carers suggested they were struggling with a multitude of roles, e.g. wife, mother, daughter and carer for PLWD. Some also worked or volunteered. While juggling a number of different roles caused carers difficulty it was also losing aspects of their relationship with the PLWD that people found distressing.

Most carers had been told to practice self-care to maintain their own health, both for themselves and for the person with dementia. While they agreed with this concept, they noted it was difficult to do and some of others suggestions were inappropriate

I think it depends on what frame of mind when you're at that boiling point when someone says "oh go do your nails," you just want to punch them in the face (FG 1)

The other form of self-help that was suggested by doctors was to place the PLWD in a nursing home for a period of time. Some participants, again particularly the ISG, mentioned both they and the PLWD found this suggestion unacceptable. All groups suggested they needed some emotional support.

Conclusion

With some exceptions, the ISG were less knowledgeable about dementia and services, were more unlikely to use nursing homes but equally concerned their children would not provide care, had more financial worries, struggled to speak to service providers and did not understand the group was research. Some of the participants in the ESG, as told to the facilitator, were not the primary carer of the PLWD and mentioned that older members of their families would be unwilling to participate because of having limited English, were unwilling to speak about their problems in public and concern they may have to write.

In the ESG, participants provided more detail and emotion when relating their experiences, including grief about their parent's situations, encounters with doctors and discussions with other family members. Despite being more knowledgeable about services, including those for carers,

they found it much harder to practice any self-care because they were often juggling a large number of responsibilities.

Participants' questions about dementia

This section summarises the questions participants raised about dementia in the focus groups. Most questions were raised by a number of groups. Answers to these questions were provided at the feedback session that was held for Italian focus group participants and other members of the community.

- How is dementia different from Alzheimer's disease? [Raised by two groups]
- Is dementia hereditary? [Raised by two groups]
- Is dementia caused by environmental factors? [Raised by two groups]
- Is dementia a mental illness? [Raised by three groups]
- What is the relationship between dementia and depression? [Raised by three groups]
- Why do older people become more unwell or get dementia post-hospitalisation? [Raised by four groups]
- How much of what's occurring around them do PLWD understand? Does this differ in specific situations/with particular people? [Raised by two groups]
- How should families respond when the PLWD doesn't recognise them? [Raised by three groups]
- How families should respond when PLWD thought they were living in another time? [Raised by three groups]
- What is the packages system? How do you access packages? What are the other services? [Raised by three groups]

Recommendations

These recommendations relate to suggestions for improving family caregiver's situations.

Recommendation 1: Improve information provision

There is a need for information at diagnosis in clear, simple language with no medical jargon. Participants also suggested that information provision should be ongoing and tailored specifically to the PLWD. As the specific manifestations of dementia and disease progression differ for each person, participants suggested health professionals should periodically re-assess the PLWD and provide carers with relevant information.

Recommendation 2: Improve GPs service

As GPs were often the first person consulted about dementia it would be helpful if GP's were knowledgeable about the condition, could provide information including what specific symptoms the medications they prescribed were intending to treat.

Recommendation 3: Educate the general community

Participants suggested the Italian community required education about dementia. This may result in others treating the PLWD and their family with more compassion.

Recommendation 4: Hospitals to provide better care for older Italians

Participants suggested hospital services need to respond more quickly when older people are unwell. It was also noted that often hospital staff could not communicate with older Italians, nor did they understand there was a need to offer a culturally appropriate service.

Recommendation 5: Clarification of practices and services

Carers required information on power of attorney and how to implement this, clarification of the specific types of community services and what Alzheimer's Australia provides, including the helpline. Participants also suggested services should be easier to access – a central intake point as opposed to having to make multiple phone calls.

Recommendation 6: More Italian-speaking care staff in residential facilities

Italian specific facilities were chosen because of language and cultural issues and participants suggested this needed to be reflected in the care provided, either by training existing staff in Italian language and culture or employing Italian staff.

Recommendation 7: Take measures to ease financial burden

Many carers suffered financially. Carers felt they should be informed early in the process about the carers pension (as opposed to finding out accidentally) and they should be allowed other sources of income as they were struggling to meet costs for essentials like medication.

Recommendation 8: Support for carers

Carers stated they needed emotional/psychological support, perhaps an Italian-speaking support group or community visitors who were knowledgeable about dementia and able to come to the home. Participants mentioned they would also appreciate some appropriate and practical suggestions for self-care.

Recommendation 9: Italian welfare worker

Participants suggested they wanted a worker who understood about the Italian culture and who could support carers, explain dementia and services.

What is the next step in the study?

In relation to the outcomes of this project, the findings will be disseminated by the investigators to individuals and organisations including Alzheimer's Australia, the Department of Health and Ageing and NSW Health.

Once information is passed on, the recommendations may be considered by relevant organisations, decisions made, programs developed and reviewed. So while the team will work hard to inform governments and advocate for CALD communities, there are no guarantees for specific changes or timelines.

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