Love Stories
The Greek Caring Journeys Project
Summary

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A/Professor Debbie Horsfall, University of Western Sydney
Dr Ilse Blignault, University of New South Wales
Dr Astrid Perry, Multicultural Health Service, SESLHD
Penny Antonopoulos, St. George Migrant Resource Centre
Dr Donna Bridges, University of Western Sydney
Sofia Zogalis, University of Western Sydney
A Migrant Love Story

1959 that was when we came to Australia. On the Patris. Everyone came out on the Patris. There were lots of us Greeks on that ship, all coming looking for work. It was the war with the Germans and then the civil war. Difficult years. We had one pair of shoes each and we’d take care of them so that we could wear them to church. And when they had a hole in them we’d have them repaired over and over again. We did suffer though. On the ship one man said to me ‘why don’t you get some moussaka?’ I took some, and how did they make it? They had two little pieces of eggplant. It seems like they did not have the recipe. We were young. We married in Greece and came here on the ship. We had family here in Australia: my uncle, my aunt, two of my brothers. They had been here a while. In those days whoever wanted to stay in Australia paid ten lire and they could stay. So we stayed with them until we could afford a house of our own. And praise God we paid the house off. We weren’t paying rent. We came for a better life, yes a better life.

I am very happy. All my children are married. They have children. I have grandchildren. Here let me show you something (brings out a photo album). Here I am at 5 years old. Here is George as a soldier. This is at our wedding and this is our son and daughter. There are only the two of us now. We have each other. Our grandchildren come over in the afternoon and we give them little treats to eat. Once a week I cook for my daughter and her children.

I must say as the years pass you become more accustomed to the things that happen. In the beginning you are in shock. You are depressed. You ask why. Why has this happened to me? Then you get used to it and you say ‘that’s life, have patience’. Things change. Nothing’s the same my dear. You are not the same as you were before. You wake. You take your tablets. You sit and then you clean and you cook and eat. It all depends on what life throws at you. But bit by bit we manage. Slowly, slowly. Together we manage. Now the mattress on the bed we turn it over together. I do the washing and George hangs it out. It does tire me. I do continue to try. Sometimes we say ‘this is what we are going to do’ then after five minutes we ask each other ‘what did we agree to do’? We will have forgotten. But we laugh; it’s funny sometimes when you get older. I feel like I am 20 on the inside. Slowly slowly whatever we can do, we do. I am busy. We try to eat lightly as much as we can. We go to Darling Harbour on a Sunday to walk a little bit. To have some coffee. To look at the shops. Our friends visit when they can. They brought that cake over. Have a piece? Take some with you in the car.

Basically we say it’s best for someone to stay in their own home for as long as they can. To stay together. It would be lonely if one went. And if you are an older person and you go to another house, you feel out of place. If we can’t make a decision we fight about it. There isn’t a human that doesn’t argue. It strengthens the love.

Life has got expensive now. We have other tablets as well as those. And the cost of food and everything. And as I’ve said from time to time you get depressed. But then you just continue on. I only need to put out George’s clothes, he can dress himself. Then the tablets, he has to take one before he eats, I put the tablet into water to soften it. The others he finds difficult to swallow them as they are large. I crush those and put honey on them. He calls me his lovely girl.

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1 This story has been written by weaving together the voices of our carer participants from interview transcripts.
Summary

This report documents the findings of a short-term longitudinal study which sought in-depth understandings of the help-seeking behaviours of elderly Greek carers. The research was supported by a partnership grant between the University of Western Sydney, the University of New South Wales, South Eastern Sydney Local Health District (SESLHD) and the St George Migrant Resource Centre (SGMRC). In 2012-2013, we conducted 3 focus groups and 1 follow-up forum with service providers and Greek community leaders in the St George region in southern Sydney (n= 25). Over the intervening 6 months we conducted 2 in home interviews and 2-4 telephone interviews with 13 older Greek carers, all of whom were clients of the St George Migrant Resource Centre. By interviewing carers over a 6-month period, we have been able to document a part of their caring journey, in particular potential turning points in that journey; points at which the carer can decide to seek or accept help or to reject it. Through a deeper understanding of carers’ decisions and decision making we aim to inform service providers about how to develop and promote culturally appropriate services and negotiate them with carers and care recipients in a timely way.

Our motivation for this study was threefold:

1. To understand the caring journey from the carers’ point of view
2. To understand formal (services) and informal (family, friends, neighbours) supports people were already accessing and how they made decisions about seeking and accepting help
3. To provide evidence that would enable service providers to provide information and support that results in a higher uptake of services with the overall aim to encourage people to use services so that they can stay in their own homes and avoid institutional care.

We found that most carers wanted to remain as independent as possible and to avoid institutionalised care of their spouse. They strove to avoid a forced separation and the loss of the one they love. They placed great value on their caring role which, whilst at times was a struggle, gave them a sense of meaning, purpose and belonging. As such we conclude that perhaps the most important question for people providing services is: how can we support people to keep doing what they value, rather than to relieve them of a burden? Assisting carers to continue to love and care for their spouse may be the most helpful orientation and language for service providers to use. Aligned with this we suggest a focus on the caring couple, the dyad, rather than perpetuating the notion of individual intervention.

We also found that the carers had great resourcefulness, strengths and competence. They were all in long term relationships, had negotiated coming to a foreign country and establishing themselves and were now in the process of negotiating old age, increasing frailty and enforced separation either through death or institutionalisation. At the same time they continued to provide care and support to family and friends. They took great pride in their ability to take care of each other and their homes. Most importantly our participants showed that they are people first, carers and carees second. So, a further question for service providers is: how can we support older carers to continue their relationships and further develop mutually supportive caring networks?
Many of the carers we spoke with had poor health literacy\textsuperscript{2}. Our research strongly suggests that services need to be designed so that people are easily able to access them; otherwise they will perpetuate exclusion and poor uptake especially amongst older CALD carers and care recipients. As such, we propose an outreach in-home culturally specific service model with an emphasis on ageing well and staying at home for the dyad. The model of culturally-appropriate service provision is a model of care which emphasises relationships and community and seeks to build social and cultural capital. It is not about service provision in the first instance; rather it is about maintaining and developing mutual support networks. This clearly supports the National Health Priority of ageing well and ageing in place.

Key Findings

Our research findings are organised through the following five main themes. Each theme and sub theme is discussed in detail in the full report.

1. **Caring gives value, meaning and purpose in life**
   a. Caring can be burdensome but is not necessarily so
   b. Juggling multiple roles
   a. Competence in caring is not defined by gender
   b. Slippage between who is caring for who
   c. The dyad is central – moving beyond individual clients
   d. The importance of remaining independent

2. **Decision making is not all it seems**
   a. Decision making patterns remain the same
   b. Role of family
   c. Role of faith/church
   d. Role of health professionals
   e. Planning for the future

3. **Formal and informal supports are used by carers**
   a. Influence of culture on help seeking
   b. The need for culturally specific services
   c. Service provider language can be disempowering and inappropriate

4. **The social isolation paradox**
   a. Can increase during caring
   b. Can increase when caring ceases
   c. Not all carers experience social isolation, but some do

5. **Towards an innovative model of service provision**
   a. Greek speaking research assistant and the impact on knowledge and utilisation of services
   b. Importance of communicating in one’s own language
   c. Building rapport with CALD participants in a research setting
   d. Role of bilingual/bicultural case worker

\textsuperscript{2} Following Nutbeam’s (2008) public health perspective, health literacy is an outcome of health education and communication. People with high levels of health literacy have context specific knowledge and the ability to put that knowledge into practice in ways which enable control over their health and health-related decisions.
Recommendations

1. **Reorient service provision and language used by services to encourage people to use services and avoid institutional care.** This could best be achieved by:

   a. Focussing on the couple, or the dyad, who are embedded in relationships with each other, their families, their neighbourhoods and communities. This could include building a relationship between the service provider network and the dyad that allows for an open dialogue on needs and wants.
   
   b. Supporting carers to continue to love and care for their spouse at home. To achieve this providers must recognise that the services that they offer, presented as relieving people of perceived burden, could take away meaning in carers’ lives.
   
   c. Focussing on providing support progressively which, in the first instance, might be more related to being frail rather than the role of carer, that is, help with gardening and cleaning as opposed to respite care for example.
   
   d. Recognising that duty does not necessarily have negative implications or is a burden. Duty for the participants of this research is bound up with feelings of love, care, mutual respect, and responsibility for a partner, in the context of marriage.

2. **Develop skills to identify and build respect for the decision making/planning processes used by carers and their spouses.** This would include:

   a. Providing the right services at the right time rather than insisting on the acceptance of services at a time that does not meet client needs.
   
   b. Working against general assumptions (stereotypes) about how Greek people make decisions. Focus group discussion suggested that service providers believed that the Greek population make decisions as a family group, often with the son being the primary decision maker. Our data did not support this.
   
   c. Acknowledging existing decision making patterns within the family/dyad as these tend to continue during caring.
   
   d. Most participants in the research placed a great deal of weight on formal health professionals especially people from hospitals and General Practitioners (GPs). There is a great deal of scope for GPs to take a more active role in helping carers seek and accept help.
   
   e. Building cultural competence within mainstream services in terms of working with CALD carers. This includes understanding the caring role in different cultures and what it contributes to people’s lives, and respecting the love stories of couples.
3. Utilise trusted community organisations with a community development orientation to maintain an ongoing relationship with the caring dyad so that service responses can be put in place progressively and health literacy developed as an ongoing process. A linguistically and culturally-appropriate outreach in home service with an emphasis on ageing well and staying at home for the dyad is recommended. The key features of such a service could include:

a. At least 2-3 face to face interviews per year with follow-up phone calls at 6 weekly intervals. The combination of regular contact and an in-depth understanding of specific situations through face to face interviews in the home demonstrably provide opportunities for increasing access to services/support in a timely manner.

b. Contact provided by someone who shares their language and culture and has a good knowledge of regional service provision and support.

c. Interviews aim to develop a relationship and understanding of the carer and care recipient by asking how can we support them to keep doing what they value? Aim of providing support is to enable people to live as independently as possible and maintain self-care.

d. Uses a different type of language. Service provider language can be disempowering, e.g. care recipient, need help, graduate carer/care leavers, burden of care, hidden carers. Carers spoke of love, respect, togetherness and duty. The research assistant in exploring their caring narratives engaged with the dyad using the language used about caring by the dyad, not the service provider.

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This study was approved by: University of Western Sydney Human Research Ethics Committee, the South Eastern Sydney Local Health District – Northern Sector Human Research Ethics Committee and the Calvary Health Care Sydney Research & Ethics Committee.

A full copy of the Report can be obtained by contacting either:

Penny Antonopoulos pennya@sgmrc.org.au
Manager CALD Community Care Program; St George Migrant Resource Centre
P. O. BOX 381, ROCKDALE NSW 2216; T 02 9597 5455 I F 02 95673326

Debbie Horsfall d.horsfall@uws.edu.au School of Social Sciences and Psychology | Penrith (Kingswood campus) | University of Western Sydney Locked Bag 1797 | Penrith NSW 2751

Astrid Perry: Astrid.Perry@SESIAHS.HEALTH.NSW.GOV.AU