

The organisation of dementia care by families in Malta: The experiences of family caregivers

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**Anthea Innes**

University of Stirling, UK

Stephen Abela

Department for the Elderly and Community Care, Malta

Charles Scerri

University of Malta, Malta

Abstract

This paper discusses the experiences of dementia family caregivers in Malta. The study design was essentially exploratory as this is the first funded social research on dementia in the island of Malta. In-depth semi-structured interviews were conducted in October 2008 with 17 caregivers. Identification of caregivers was through their relatives' attendance at a hospital based outpatient memory clinic. Interviews were recorded, transcribed and when required, phrases were translated from Maltese to English. A thematic analysis was guided by the questions; What are the experiences of family caregiving in Malta? And what impact does caregiving have for individual/family life? Three key findings are discussed, namely: the organization of family care in Malta; the use of formal services; and the dislocation of dementia caregiving experiences from wider community life. This paper raises questions about support mechanisms currently available in Malta while presenting cross-national learning opportunities to apply established knowledge to the Maltese context.

Keywords

dementia, family caregiver experiences, Malta, organization of care

Corresponding author:

Anthea Innes, Senior Lecturer in Dementia Studies, Dementia Services Development Centre, Iris Murdoch Building, University of Stirling, Stirling FK9 4LA, Scotland, UK

Email: anthea.innes@stir.ac.uk

Introduction

Demographic changes have led to an increase in the number of people with dementia at a time when there are less people available to provide care. This has come about due to people living longer, alongside a decrease in the availability of the traditional pool of family carers as women undertake paid work. There are an estimated 30 million people in the world who have dementia, projected to increase to over 100 million by 2050 (Alzheimer Disease International, 2008). A number of European countries have developed National Dementia Strategies or Plans, for example France (Alzheimer Europe, 2008a), Norway (Norwegian Ministry of Health and Social Care Services, 2007) and England (Department of Health, 2009), or recently announced the intention to develop a national strategy, for example, Scotland (Scottish Government, 2009). Europe has acknowledge that dementia is a key health challenge and the French Presidency of the European Union pledged attention to this issue, and was later endorsed as a priority area by the Council of the European Union (2008). Malta recently announced its intention to develop a dementia strategy preceded by consultation throughout May–December 2009 (Maltese Department of Elderly and Community Care, 2009). However, much of what is ‘known’ about dementia caregiving is through research undertaken in OECD countries (Moise, Schwarzinger, Um, & the Dementia Experts’ Group, 2004). Important pan-European work has been conducted, led by Alzheimer Europe (2006, 2007, 2008b), providing an overview of the structure of formal care provision and services. However, there is limited information about the day-to-day experiences of people providing family care in other geographical locations.

Other larger Southern European countries have conducted social research on dementia caregiving, published in the English language, for example Greece (Papastavrou, Kalokerinou, Papacostas, Tsangari, & Sourtzi, 2007), Italy (Buono et al., 1999) and Spain (Rivera, Barmejo, Morales-Gonzalez, & Benito-Leon, 2009). There has been comparative work including some Southern European countries, for example Italy has been included in European comparative work (Bond et al., 2005; Vernooij-Dassen et al., 2005). Italian research highlights the changes in the way that Mediterranean cultures organize family care of older people generally (Da Roit, 2007) and Spanish research (Rivera et al., 2009) demonstrates changes in how family dementia care is organized in Spain. Research also shows that intergenerational solidarity is just as strong in Northern and Southern European countries, but the way in which care is organized differs (Daatland and Lowenstein, 2006). Thus different cultures, welfare systems and social expectations will shape how care is organized between countries but that family responsibility remains evident across European countries. Southern Europe comprises a diverse range of countries (some islands) with diverse socio-political and economic contexts. Given the directive on dementia as a priority for Europe (Council of the European Union, 2008), it is important to understand the experiences of different countries shaped by their local social, political, economic and cultural contexts. Malta, the geographical location for this research, is a case in point. In Malta there has been no previous funded research examining dementia caregiving experiences. Unpublished student dissertations, at under graduate and masters level, form the only research evidence to date. A paper on prevalence of dementia in Malta estimated that 1 per cent of the general population lives with dementia

(Abela, Mamo, Aquilina, & Scerri, 2007). Malta has a total population of 410,000 living across a 316 km² geographical area. There are a reported range of services for older people generally in Malta, but very few dementia specific services, notably there is one day centre with twenty places available three days a week for individuals living in the community and the outpatient memory clinic, from where our participants were recruited. There are a number of care homes; however, there is no care home specializing in, or dedicated solely to, dementia care.

This paper begins with an overview of family caregiving literature setting the scene for the presentation of the first data collected in Malta about the experiences of dementia family caregivers. The findings suggest a traditional and largely enduring organization of care that is in a process of flux; this resonates with the situation of disintegrating family care models reported in other Western countries, and also those reported in Southern Europe (Da Roit, 2007; Rivera et al., 2009). This paper adds to the growing evidence that families can no longer be assumed to be available to provide care in countries where there has been a traditional expectation that families will care. This means that traditional assumptions that state provided services are not required need to be challenged.

Drawing on the reported experiences of family carers of people with dementia in Malta this paper demonstrates the limited use of formal services and the relative dislocation of care giving experiences from the social communities where people live. The lack of knowledge, awareness and information available or accessed by participants discussed in this paper reflects a universal concern about how to best support people with dementia and their carers from the point of diagnosis (Woods et al., 2003) onwards (Brodaty, Green, & Koschera, 2003).

This paper adds to the longstanding and ongoing body of work examining the subjective experiences of caregivers (e.g. Andrén and Elmståhl, 2005; Zarit, Todd, & Zarit, 1986), including work on how care is organized differently by ethnic groups in one country (Aranda 2001, Dilworth-Anderson, Williams, & Gibson, 2002). However, most importantly this paper relates experiences to the social organization of care within a particular cultural and geographical context, an aspect that has received limited attention (e.g. Da Riot, 2007; Rivera et al., 2009). This is achieved by examining how family caregivers in Malta organized the informal care and support for their relative with dementia within their specific social and cultural context. This is linked to an analysis of their reported use of formal services and the limited availability of services for people with dementia in this small country. How this contributes to a dislocation from the wider community for both the carer and, in turn the person with dementia, is then discussed.

Background

Although there is a well-established literature on dementia caregiving experiences this has not included the experiences of dementia carers in Malta, with work on dementia limited to unpublished student dissertations, a prevalence study (Abela et al., 2007), and pieces designed to raise the profile of this condition to lay audiences (e.g. Scerri, 2008) and health and social care professional audiences (e.g. Abela, 2004). This study was thus informed by the established international literature on dementia family caregiving.

Family members absorb many of the financial and social costs associated with providing dementia care. It is not surprising, therefore, that one focus of the literature on dementia caregiving has been how to support carers to continue to care at home for longer periods to delay or prevent institutionalization (Etters, Goodall, & Harrison 2008), and thus reduce the financial and social problem for wider society.

However, the organization of family caregiving is to a large extent dependent on the social and cultural norms of society (Dunham & Cannon, 2008), as the expectations about who should provide care as well as what is perceived to be good care will be influenced by policy making and understandings of what it means to have dementia (Innes, 2009). As has been demonstrated in other research exploring the experiences of dementia care in the community, access, availability and awareness of services and support are also likely to influence experiences of dementia (e.g. Brodaty, Thomson, Thompson, & Fine, 2005; Innes, Blackstock, Mason, Smith, & Cox, 2005; Morgan, Semchuk, Stewart, & D'Arcy, 2002; Toseland, McCallion, Gerber, & Banks, 2002), for the care recipient and the care receiver. Uptake of services has been found to be related to social and psychological factors rather than objective or subjective caregiver burden (Roelands, Van Oest, & Depoorter, 2008). However, using a service is dependent on its availability, accessibility and cost, as well as awareness of the service by the family or person with dementia. In a study examining spousal dementia, care givers help-seeking behaviour, gender, role expectations, past coping and family relationships all contributed to use of services (Brown & Chen, 2008).

The discourse of caregiving shapes the power relationship as it influences who is expected to provide the care and the type of care that is given (Dunham & Cannon, 2008). Knowledge about dementia and what care should be provided is communicated by professionals (Dunham & Cannon, 2008) who have accepted the biomedicalization of dementia (Bond, 1992; Lyman 1989) that does not consider the broader psycho-social, cultural, political and economic contexts caregiving is located (Innes, 2009). Carers may embrace the help that medical knowledge can provide but reject the depersonalization that can accompany medical definitions of care (Dunham & Cannon, 2008). Thus, reflecting the challenge to the standard paradigm of dementia posed by Kitwood (1997) when he championed a more individualized approach to the person with dementia.

There are thus two particular strands to the wealth of literature on family caregiving that are relevant to this study. First the expectations surrounding family caregiving in societies where there has and continues to be an expectation of filial piety and family duty and gendered assumptions made about caregiving, and second, the satisfactions and burdens of providing care to a family member with dementia. These areas will be briefly considered before moving on to discuss the design and findings from our study in Malta.

Expectations about family dementia care

Expectations about who will provide care to people with dementia arise within unique cultural, social, political and economic contexts.

A study in the Philippines, where filial responsibility is a reported cultural norm (Natividad, 2000), found that social support networks acted as a buffer for the

burden and strain experienced by adult-child caregivers (Varona, Saito, Takahashi, & Kai, 2007), highlighting the need to provide formal support services for caregivers to help them maintain their role.

In Korea, daughters and daughter-in-laws are most like to provide care (Kim, 2001), due to pervading traditional social values of familism and filial piety. However as the eldest adult son has responsibility for the care of aging parents this has meant in practice that his wife will provide the care. Due to cultural shifts within society these daughter-in-laws are less able to provide care as more women go to work. Indifference of family members (especially husbands) creates tension between their own emotions and the expectations placed on them (Kim, 2001). The hidden or invisible caregivers in families adopting a shared approach to the care of ill relatives has been raised (Lingler, Sherwood, Crighton, Song, & Happ, 2008), highlighting the importance for care providers to know and recognize the complexity in the care giving situation and relationships between several family members, as it is often assumed that there is one primary care giver. For example daughters report conflicts with their brothers who are not caring as expected, due to the cultural expectation where the eldest male child is expected to assume responsibility (Kim, 2001).

The paradox of power in dementia caregiving has been acknowledged (Dunham & Cannon, 2008), highlighting the difficulties that caregivers experience when they are aware of the gender expectations that they will care and thus the power they can exert over the care situation; however the difficulty in managing prior relationships is not acknowledged in this model. This may be particularly true for daughter-in-laws who have no established bond with the person they are expected to care for.

Hong and Kim (2008), also reporting from Korean experiences draw attention to the tradition of the majority of care being delivered by the daughter-in-law (who report high levels of burden) evolving to situations where other family members are now providing care to those with dementia. Daughters-in-law continue to provide the majority of the care and do so to those with higher levels of behavioural difficulties and higher levels of need. Spouse caregivers in this Korean study (Hong & Kim, 2008) reported higher levels of burden than the daughter-in-laws, perhaps reflecting their own frailty and discontent with a role that traditionally would have been carried out by their daughters-in-law. This study highlights the heterogeneity amongst caregivers and the different perceptions they have about their role.

Obligation is often accompanied by ambivalent feelings about caregiving as individuals seek to deal with the contradictions of duty and guilt for resenting the obligation and duty that has befallen them, this is aptly described as, 'The feelings of powerlessness result from the inadequacies of the medical understandings and community supports that caregivers receive' (Dunham & Cannon, 2008, p. 53).

Causes of cohabitation arrangements in Spain for the person with dementia have been described as linking to feelings of love (being cared for by the person with dementia in the past) and obligation imposed by social rules and tradition (Rivera et al., 2009).

Love and commitment as a motivation to care giving has been described by others (Dunham & Cannon, 2008), yet an enduring theme in the literature is that of a sense of duty and obligation driving much family caregiving. Problems of the system of rotating care in Spain were acknowledged by the women adopting this system of 'shared care and obligation' (Rivera et al., 2009, pp. 145–146), but this was seen as the only fair

way to meet their responsibilities. These problems have also been acknowledged by Spanish caregivers who adopt this approach (Rivera et al., 2009) but was seen as a preferable alternative to institutional care. Rivera et al. (2009) concluded that the rotational model of dementia care provision in Spain is a result of societal changes coupled with a rejection of the only alternative form of care provision, long stay institutions.

Differences in the outcomes for people with dementia being institutionalized have been observed in relation to the previous use of day care services. Wives who place their spouse in day care were likely to decide on an earlier placement to long term care than daughters who were more likely to delay placement to long stay care if day care was used. Therefore differences in coping abilities and decision making depending on the relationship to the person with dementia have been observed (Cho, Zarit, & Chiriboga, 2009).

Thus organizing care for the person with dementia within the family network in some way is a common preference to the alternative of institutionalization. This is due, in part, to the lack of availability of community based services across countries, and even in countries with relatively high levels of community support, the services on offer are often not seen as appropriate to individuals' needs (Innes et al., 2005; Morgan et al., 2002, Toseland et al., 2002).

Experiences of dementia caregivers

Reviews of the caregiving literature have demonstrated that there has been a huge increase in the attention of researchers on the experiences of both the person with dementia (Steeman, Godderis, Grypdonck, Bal, & Casterle, 2007), family carers (Rigaux, 2009), and both people with dementia and their families (Fortinsky, 2001). Of particular interest to this work is the focus on family carers. In her review of the focus of researchers on the burden or strain experienced by care givers, Rigaux (2009) has highlighted the shift in focus since the 1980s on examining the satisfactions in providing care and the political importance of this shift in helping to identify what can be done to support families to continue to provide care to those with dementia to either prevent or delay institutionalization and place a further financial and social care burden on the state. Yet, a review of studies focusing on outcome measures for family carers have established the burden (financial, social and physical) that carers experience (Brodsky, 2007).

It is important to remember that caregiving often involves professionals and, of course, the person with dementia. The complexity of the relationship between family caregivers, the person with dementia and health professionals has been acknowledged (Fortinsky, 2001) and remains an area requiring further work to ascertain to maximize the potential of such health care triads to promote positive experiences of the person with dementia and their caregivers.

Often the family member and the person with dementia are not given full information about the diagnosis or what to expect. Perry (2002) reports different approaches adopted by carers who are not given information and therefore resort to interpreting what is going on. These approaches are: taking over, drawing new inferences, rewriting identities, seeing the signs, picking up the slack. Four types of stories about caring – ideal, ordinary, ambiguous, compromised – were found in

Ayres' (2000) work examining the narratives of family caregivers about their role. As such these provide an example of a typology of care giving where an interpretive process of role in action is described (Perry, 2002).

The positive and negative emotions that can be experienced by caregivers have been examined, with four affect pattern groups identified: well adjusted, ambiguous, intense (high positive and negative emotions) and distressed (Robertson, Zarit, Duncan, Rovine, & Femia, 2007). Working out what interventions would be appropriate for caregivers depends to a large extent on how they are coping prior to providing an intervention, and as such the success of caregiver interventions will be influenced by how caregivers are coping at the baseline data collection period (Zarit & Femia, 2008). This is similar to the conclusion of other reviews of dementia caregiver burden, advocating multi-component interventions that can be individually tailored to enable carers to continue to care at home for longer periods prior to institutionalization (Etters, Goodall, & Harrison, 2008). Related to this is the importance of preventing or minimizing abusive behaviour towards the person with dementia. Recent research has found that abusive behaviour towards those with dementia is common (Cooper et al., 2009) and therefore developing initiatives to help caregivers cope more positively are required.

Schulz et al. (2008) have demonstrated that perceived suffering in the person with dementia by the caregiver has a direct bearing on the burden and depression caregivers' experience. Thus the suffering of those with dementia needs to be addressed, not only to promote well-being in those with dementia, but for those providing care. The presence of behavioural and emotional difficulties in the person with dementia has also been shown to link to perceived caregiver burden (Bruce, McQuiggan, Williams, Westervelt, & Tremont, 2008). Research also demonstrates the resentment family caregivers report when they feel that they have put their lives on hold to be able to care (Dunham & Cannon, 2008).

The need to adapt personal lifestyles, and in effect reorganize the family nucleus to accommodate the needs of the person with dementia, has been reported as a problem in Italian research (Ferrara et al., 2008). Related to the difficulties of rearranging lifestyles are key problems reported by French caregivers was the lack of time to themselves and the need for information about the diagnosis, care structures and day care facilities (Thomas et al., 2002).

The guilt adult daughters feel when caring and the association this has with stress has been discussed by Gonyea, Paris and Zerden (2008), with different levels of guilt experienced by daughters relating to previous relationships with their parent. However the type of coping strategy adopted by family members has been found to relate to their feelings of anxiety and depression (Cooper, Katona, Orrell, & Livingston, 2008). A difference in tendency to adopt an emotional or practical response suggests that the key need is for caregivers to be able to adjust emotionally to their caregiving roles (Cooper et al., 2008) to reduce reported anxiety and depression.

In their review of studies of caregiving relationships (Quinn, Clare & Woods, 2009) found that stronger pre-diagnosis relationships helps maintain well-being when caregiving. Caregiving can change the relationship between family members; however, the ability of the person with dementia to persist with activities of daily living have been found to have an impact on perceptions of the quality of the relationship (Quinn, Clare, & Woods, 2009).

Study design

Fieldwork was carried out in Malta in October 2008. Seventeen family caregivers were interviewed comprising four spouse carers (two husbands and two wives), nine children (eight daughters and one son) and three daughters-in-law. The sample of potential caregivers was derived from the memory clinic patient list. All participants had to be caring for a relative who had a formal diagnosis of dementia, who was attending the memory clinic, who continued to live in the community and who was over 65 years of age.

Ethical approval was obtained from three sources prior to conducting the fieldwork, two university ethics committees and the Malta Health Department. All participants received a written information sheet prior to consenting to participate and this was also discussed verbally prior to obtaining written consent.

Each semi-structured interview was audio recorded and fully transcribed and translated when required by a bi-lingual transcriber. All data was entered into the computer program NVivo8 to assist with data management. A fieldwork diary was maintained and used to identify initial themes. Nodes were created to begin coding each transcript with further levels of coding devised during an ongoing, across case thematic analysis where links were explored, exceptions identified and differences examined to determine the overall themes and findings.

Findings and discussion

We now move on to discuss three key findings from our research, first the family organization of care in Malta, second, the use of services and finally the dislocation of caregiving from wider community life.

Family organization of care

The selection criterion for this study meant that all caregivers were providing care to a relative who continued to live in the community rather than in an institutional form of care. Initially attempts were made to identify the primary carer but it became apparent from requests for family interviews (rather than 1–1 interview) that caring was very much a family affair for some carers who were approached and who showed interest in participating. Thirty per cent of interviews were conducted with the family members who shared the care between them. Two other interviews with the principal family carer revealed significant involvement from other family members. Therefore, half of those interviewed were caring via a shared care arrangement. This emerged in part due to notions of shared filial responsibility, and also to accommodate caring while juggling family responsibilities to children and grandchildren as well as paid work. Another notable feature of how care was organized by carers in Malta relates to gendered expectations about who should provide care. Spousal and child carers both reported individual responsibility to provide care based on the relationship they had to the person with dementia as well as the lack of alternative formal care or the physical distance of another family member who could share the caring responsibility.

These three features of shared filial responsibility, individual responsibility and gendered expectations often overlapped in the way family members then organized the caregiving for their relative.

Gendered expectations

The following examples illustrate the gendered expectations to provide care imposed on daughters and daughters-in-law.

Daughter (D) caring for her mother with no input from her three brothers:

D: I want that we all look after her, but it is not going to happen because my brothers don't want to...they are saying that I am obliged to do it because I am the girl, and this is the 'illness' of the family that says that the girl (cares) and the boys follow this understanding [tradition].

Three daughters-in-law (DL) expected to care for their mother by their husbands (mother-in-law spends a week in each house on a rotating basis). They wish to change the care arrangements:

DL1: Don't you know how they are? Three professors, am I going to speak to them?

DL2: I tell him 'go and watch you, see what she is saying'.

DL3: We will tell them what is happening and there will be a lot of mmm and as usual we will get nowhere.

The findings here reflect previous discussions where women express their disappointment in the lack of support from other family members and resentment that men make the decisions but do not participate in the hands-on delivery of care (Dunham & Cannon, 2008).

Psycho-physical distance from other family members and thus the lack of social support available to and offered to the principal carer has been reported elsewhere (Upton & Reed, 2006) and was reported by daughters in this study where their brothers no longer live in Malta and therefore are unable to help physically and have been psychologically distanced from their families for many years.

Shared filial obligation

Daughters and sons reported sharing the care of their parent based on a sense of shared filial responsibility and obligation.

Three daughters (D) rotating care of their mother in their homes on a week-by-week basis:

...and the thing is, we are her family we are the ones who should be taking care of her...she brought us up...we share.

Three daughters and son (S) sharing the care of their mother on a day-by-day basis:

D1:...and we share.

D2: We share.

D3:...and we share.

S: I am the driver.

Rotating care among family members by having the person with dementia live with several family members on a rolling basis has been reported as a mechanism for Spanish families to cope with the demands and obligation to provide care to a relative with dementia while maintaining public and private lives (Rivera et al., 2009). The absence of formal care services and support has contributed to a way of organizing family care to accommodate expectations of family obligation (particularly filial duty) that are engrained in Maltese cultural and social norms at a time of social change where women are working and expect to be able to engage in public, social and working lives rather than remain in the private sphere of the home.

Notions of individual responsibility

Individual responsibility based on the previous relationship was reported by husbands and wives, and echoes findings from previous spousal caregiver research (Quinn, Clare, & Woods, 2009; Zarit, Todd, & Zarit, 1986) where feeling of duty and responsibility underpin views of the caregiving role.

Husband: It is my cross and I have to carry it.

Wife: We are sort of devoting ourselves to one another really. You did it for me... Now it's my turn, isn't it?

Adult children caring also reported feelings of obligation and responsibility but did not perceive this as a positive experience:

Daughter: I feel obliged. I feel so guilty. I can't get away from that. It's terrible. I can't even live my own life.... I really wish I can run away but I can't. I can't even leave. She has trapped me really.

The need to adapt personal lifestyles, and in effect reorganize the family nucleus to accommodate the needs of the person with dementia, has been reported as a problem in Italian research (Ferrara et al., 2008). The need for caregivers to rapidly adapt their own lifestyles to accommodate the needs of the person with dementia contributes to perceived stress and burden in the caregiving role. This is evident in this study of Maltese caregivers who reported frustration in the way they shared the care and in the process created a reorganization of family life for their partners, children and grandchildren.

The tensions between assuming a responsibility to provide care for the person with dementia while continuing to provide for the family could result in grandchildren being asked to help provide care:

Daughter: That is the problem I am having. I am giving pressure to my children [relative's grandchildren] to stay with her [so the daughter can shop and take care of bills]. Jaħasra [poor things] It is not good hu [you know]. It is like I am punishing them hu [you know]. And one of them, you are going to stay here with her. And for them it is a punish[ment] to stay with her.

Having the grandmother staying in the house could also result in difficulties for grandchildren who had to adapt to having a person with dementia live with them who did not appear to recognize their need to use family living space for their

activities, for example:

Daughter 1: Listen, her daughter is a teacher. She give private lessons in her house. She tell her 'Sh, sh there is the lesson upstairs'. No no. Even with her daughter she has got trouble.

Daughter 3: No respect at all! Le? [No?] I stopped her. Even my son has the exams. I tell her 'don't speak to him'. Even when once she sees you on the telephone she talks to you she talks to you, talks to you.

Thus, the changes to family life experienced by relatives who made the decision to have the person with dementia live with them (for some or, part of the time) was a difficult situation for adult children (or in-law) caregivers to manage.

Service use

Caregivers reported that the frustrations around reorganizing family life to accommodate their caregiving responsibilities occurred due to the limited availability of services suitable for their circumstances and/or for their relatives needs.

The lack of respite care in particular, available to family members to enable them to continue with their working or personal lives was discussed:

Daughter: In Malta unfortunately there is a severe lack of any help of any sort whatsoever and I have suggested many years ago, to see whether the government could ehm, start some kind of pooling, a service, like a pooling services, where they can have a group of people who they can send out as carers. Because as I said, we don't need hospitals, you don't need walkers, you don't need that, you don't need the pills, you need someone to replace you.
Interviewer: Some respite care.

Daughter: Yes, and respite care that comes to you, over here it is sending them to an old people's home, chucking them with all these people who are gaga which for me I feel... I didn't do it... it's crazy not what we have in mind, not what I had in mind at all. I want someone who can come to the house and stay there, for example.

The difficulty in finding someone to provide personal care was also raised:

Daughter: Honestly I don't know what we need. If you ask me, what, what, what, what can help? I don't know. Because she definitely won't trust any outsiders. And there were times when we helped her even in the bathroom but I don't think she would expect any outsider to do it. What can you do, so what can you ask what more?

Thomas et al. (2002) argue that the key requirement for caregivers was the provision of support (home helps, day care) to give them relief from caregiving. Salin and Astedt-Kurki (2007) have argued that the challenge for respite care providers is to take into account the dynamic between the caregiver and care recipient and how to ensure that the care offered meets the expectations and standards of the caregiver as well as the care recipient. Yet the situation described by these caregivers does not reflect the type of care advocated through previous research. Individual family caregivers did organize paid help to assist them in the home, for example maids were employed privately to help with cleaning the floors and other household chores, and one example was provided where a daughter paid for a nurse to come in and help give out medication when she was unable to do so herself. Respite care had been set up (but not yet tried) by two carers to give them a break from caregiving, although they were

apprehensive about using the respite care options available to them, beds in the 1000+ bed long stay care hospital.

The outpatient hospital, housing the memory clinic where all relatives of caregivers attended, had offered a range of services as part of their assessment, and this had been viewed positively. The difficulty arose when the services offered were stopped and no alternative service provision was made available.

Daughter 1: Heq [you know], Not much because I mean in the beginning when we were taking the occupational therapy sessions they were quite ok because ehm they were asking her a lot of things and you realise where she's can do something and what she can't. Otherwise when we come, I mean like this morning she did the memory score test once again because practically we asked for it.

Daughter 2: We asked for it.

Daughter 1: Because we wanted to know at least what level she's in and when she started off 27 over 30 the last time we did it, it was 20 now it is 17.

Interviewer: So you are saying...

Daughter 1: At least we know that we are not going crazy ourselves. There is regression but heq [you know] otherwise.

Daughter 2: There is nothing I think that they can do.

Daughter 1: We know that this is not something that you can heal. I mean, it is not like going in for an operation...

Daughter 1: What we what we might do is I think we have to go to the Social Securities at Valletta where there's the Ministry for the Elderly. I think there is a respite centre at St Vincent de Paul where you can leave them. But obviously you have to go through a lot of applications and things like that because my brother's friend she said that there are people who are carers and if you want to have a break or something.

Thus, although services at the day hospital, accessed via the memory clinic were valued, they were time limited and when the relative was discharged this felt to be a loss by caregivers who had limited knowledge about alternative services and how these could be accessed.

The limited services available contribute directly to limited usage reported by carers in this study. Relatives also reported a limited knowledge of dementia and what they should do in their situations.

Wife: The doctor gave me a leaflet, but I haven't followed it up, I don't know how useful it was at this point.

And:

Daughter:...the thing you need is support...like from social workers, because you don't know how to deal with the situation when it happens...you have to deal with it and sometimes I am sure there are better ways...but it is one thing being a nurse or a doctor, and another thing when this is your mother.

Where to get information was problematic:

Daughter: I went a couple of times through the Internet imma [but] that's it. I mean, sometimes our lives are so hectic. [laughter] The thing is you go to meetings and you hear what's happening and you say well this is what I am going through. But then it's your individual case that makes the difference.

During three interviews and after the audio recorder was turned off another four caregivers asked the interviewer about her opinion and whether she knew where they could find information about aspects of their relatives care they were finding difficult or where they could find more information about dementia generally. The interviewer was also asked about whether they should be considering care home placement at this point in time based on what they had shared during the interview. This provides further evidence that caregivers who participated in the study did not generally feel well supported or fully informed about their role or their relatives' dementia. Perry (2002) has demonstrated that when little information is available caregivers report adopting a process of trying to interpret what was happening. A limited understanding of dementia has also been found to compound the difficulties carers were facing as they adjusted to a caregiving role (Quinn, Clare, Pearce, & Van Dijkhuizen, 2008). Given the limited information and the lack of services available to help caregivers in Malta undertake their role in an informed way it is not surprising perhaps that participants in this study reported difficulties.

Family caregivers have reported a need for medical information and information about the structures of care provision available (Thomas et al., 2002), as well as dissatisfaction in services that are available but not meeting their needs (Innes et al., 2005). In a Belgian study, the use of services was linked to confidence in the service model used and personal strategies of care givers who adopted a problem-solving approach to help them cope with the challenges of caring for a person with dementia (Roelands et al., 2008). Thus to call on formal services requires established services that are highly regarded by the community they serve. In this Maltese research it is evident that services were perceived as not meeting the needs of carers or the person with dementia, resulting in low usage compounded by low levels of availability.

Previous research demonstrates the underutilization of community resources and services when such services are available (Brodaty et al., 2005; Toseland et al., 2002,) with various reasons given for low uptake, such as accessibility and lack of awareness of services, costs, and the family relationships (Brodaty et al., 2005; Innes et al., 2005; Toseland et al., 2002.). These reasons were also reported by Maltese carers, services they wanted were not available and to pay privately was personally difficult.

Toseland et al.'s (2002) findings suggest that caregivers who perceived caregiving having a negative impact on their own health are more likely to use services. In Malta the option of using more services is curtailed by the absence of many services appropriate to those with dementia or their caregivers.

The support and understanding of immediate neighbours was also found to be lacking:

Wife: I can't have breaks. The neighbours noticed [when she went to a church meeting] that and you know, they told me 'You abandoned him'...I was so hurt because I never did.

The lack of tolerance caregivers reported experiencing from friends, other family members and neighbours reflects a situation where there is a low level of awareness of dementia contributing to the perpetuation of stigma associated with dementia and

isolation experienced by caregivers (and the person with dementia) that has been reported in other European countries (e.g. De Mendoca Lima, Levav, Jacobsson, & Rutz, 2003; Devlin, MacAskil, & Stead, 2007).

The stigma that continues to surround dementia in Malta compounds difficulties accessing services, as to access services one has to acknowledge the problem. The lack of support experienced by families from their communities and the lack of formal service provision available led to their experiences of caregiving being distinct and separate from community life, resulting in a dislocation of caregiving from other experiences and community involvement.

A further burden of caregivers reported in this study was the financial costs involved in accessing services that they felt would be appropriate. The majority reported a burden due to the financial costs involved in the purchase of the anti-dementia drugs. In Europe the majority of countries have a reimbursement system for anti-dementia drugs. Malta is however one of the few European exceptions, along with Latvia and Bulgaria (Alzheimer Europe, 2006).

A common report from participants related to the financial burden of caregiving:

Husband...the problem about the pills [is that they] are much too expensive...I take the lowest part of the pension you know.

And:

Wife:...about one third of my pension goes to the chemist you know...If I have a little bit of interest from the bank, because I had some money in the bank, I spend all the interest on medicine

Relatives were ambivalent as to the effectiveness of the drugs they struggled to pay for but were unwilling to discontinue the treatment in case it made the general caregiving role more difficult. For example,

Daughter:...it keeps, still to be getting worse. I don't know if we stop, it will get worse, and that's why we don't stop, because we don't know what will happen.

Participants in this study reported creative solutions to providing care for their relative to help them remain in the community alongside the financial burden of drug treatments and family burden of juggling multiple roles and obligations, and doing so with limited formal service support. However the situation of rotating the care of the person with dementia by their moving from one relative to another, or being cared for by unwilling relatives contributes to a situation where dementia caregiving is marginalized and dislocated from wider social and community life. It is to this issue that we now turn.

Dislocation of dementia caregiving from and in the community

The way dementia caregiving was organized by families helped to preserve a social front of family coping, while allowing individual family members to maintain their own family and working/social lives. In essence, the organization of dementia care by the families presents a way of containing both the caregiving role and the social world of the person with dementia.

The lack of tolerance of neighbours, exemplified by the example above of the wife who was told she by her neighbour that she was 'abandoning' her husband while she attended church and church related activities, demonstrates the notion that caregiving dislocated the caregiver from an important aspect of community life in Maltese villages.

The separation of caregiving days or weeks from normal family and work life through families rotating the care amongst different members presents a clear example of dislocating the caregiving role from the caregivers' regular life. Families recognized they were approaching care with this idea in mind, as they discussed their desire to meet the needs of other family members and preserve social and working lives.

Daughter 1: She [D2] use to look after her most of the time because I used to work...she would come for the day only and go back in the evening [to D2's home].

And in another caregiving family:

Daughter 1: I work part-time, we have a family business and I have a part-time job as well which is not very regular, but I manage to, either I don't or else my sisters help out...or I take her with me.

For caregivers who did not have the benefit of co-caregivers, caregiving led to their dislocation from previous pursuits and roles. For example, the demands of caregiving resulted in one daughter giving up her work resulting in a much diminished social circle and her life revolving around maintaining the home, meeting the demands of her roles as wife and mother and doing so while acting as the sole caregiver to her mother.

Daughter: It doesn't matter where...if it is your mother and you love her, you come from anywhere, I was working...but everything she is saying to me...she is making my life too hard [when working too]...but it is hard on the children...And my husband he works more...is out more.

Husbands were the exception to this in our research, as they maintained previous interests and dislocated their caregiving role from their desire and need to maintain social lives.

Husband: I go dancing every Saturday...She used to come with me, but she used to tell me 'I don't like it anymore'...So do I have to stay at home?...when I dance I don't feel anything, anything....

Studies focusing on outcome measures for family carers have established the burden (financial, social and physical) carers experience (Brodaty, 2007) and interviews with carers in Malta reflect these patterns. However financial costs are perhaps greater due to having to pay for medications.

The strategy of trying to interpret what is happening to the person with dementia reported by Perry (2002) can be seen to be happening with carers in this study, particularly when little information available leads to a process of trying to interpret what was happening using this kind of 'common sense' approach to understanding what was going on.

Thus the information (mainly from medical sources about the condition) given to families and people with dementia had a limited impact as it did not help with

day-to-day care situations or provide a way of helping to understand the changes observed in or experienced by the person with dementia. This contributes to caregivers in particular trying to interpret the situation using a common sense approach relating current situations to previous character traits of the person with dementia.

Daughter-in-Law 3: Trouble, trouble. She tells us, she tell these that I tell him to make him trouble. ...so that I am fed up with her and it is not true. She tells them that I encourage my son to do things.... To make trouble.

Generally caregivers felt that they would benefit from help, but they were ambivalent about the type of help they would need, or that the person with dementia would accept. They also wanted information (clearly demonstrated in their requests for the interviewer to advise them discussed above) but were not sure what kind of advice they required.

The general lack of services available and perception that what is available is not appropriate, results in caregiving being dislocated from general health and social care provision. Caregiving remains in the family and leads to a cycle where caregiving is organized in a way to accommodate the multiple roles of different family members, or where individual family members feel isolated and very much reliant on their own individual ability to provide any care required.

Future directions and conclusions

The findings from this small exploratory study highlight the difficulties caregivers in Malta face in providing care to their relative with dementia. Families have developed innovative rotating care patterns to accommodate individual family member's social and working lives while maintaining their responsibility, whether this be from a sense of shared filial obligation or the wider families gendered expectations about who will care. Family caregivers who do not have a shared care arrangement within their family rely on themselves to provide the care required with very small inputs of help, for example, from paid home helps or maids, rather than through formal service provision. Caregivers' views on formal services were dismissive and scathing as to their lack of suitability for their, or their relatives', needs. This suggests that there is the opportunity for both private and state providers to respond to the gap in the market for specialized dementia care services for people with dementia and their caregivers living in Malta.

This research highlights the need to expand support services for people with dementia and their caregivers. The memory clinic used to find our participants provides not only medical assessment, but a route to disseminate information on dementia and for a multi-disciplinary team evaluation. It is anticipated that the clinic should receive requests for clinical reviews to help respond quickly to future caregivers' concerns.

There is much international research about family caregiving experiences, however how to address difficulties that caregivers face must be considered within a country's social and cultural framework. Similar traditional societies such as Spain, who have a reliance on families rather than formal service provision, also report a rotating

pattern of caregiving rather than resort to institutionalization of the person with dementia (Rivera et al., 2009).

Following the French Presidency meeting on dementia in Paris in October 2008, where European countries were urged to put dementia at the top of their national health priorities, the Maltese Health Department, through the Ministry for the Elderly and Community Care, formed a working group with the brief of providing a set of recommendations aimed at increasing high-quality dementia care in Malta. The working group has adopted a three part strategy, namely the evaluation of the local situation *vis-à-vis* availability of care, consultation with various stakeholders including the general public and finally a report containing a series of recommendations that should form the backbone of a future national dementia policy. An online questionnaire has been made available to the public on a government-sponsored website addressing various aspects of care. The responses received together with discussions with all the identified stakeholders will provide an important tool in obtaining an inclusive view, from a range of stakeholders, to guide any strategy. Other countries, England (Department of Health, 2009) and Norway (Norwegian Ministry of Health and Social Care Services, 2007) have adopted similar strategies where a bird's eye view of the situation was taken in the development of their national dementia plan. Thus Malta is beginning to seriously consider how best to plan for dementia care in the future. The challenge is how to do this and meet the varied needs of caregivers.

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Anthea Innes, PhD, MSc, BA(Hons) is Senior Lecturer in Dementia Studies, Dementia Services Development Centre, Iris Murdoch Building, University of Stirling, Stirling FK9 4LA, Scotland, UK. [email: anthea.innes@stir.ac.uk]

Stephen Abela, MD, MRCP(UK), M Phil, MHSc, HSM, is Head of Clinical Services Rehabilitation Hospital Department for the Elderly and Community Care, Malta. [email: stephen.abela@gov.mt]

Charles Scerri is Lecturer in Pathology, Department of Pathology, Faculty of Medicine and Surgery, University of Malta, Msida MSD 2080, Malta. [email: charles.scerri@um.edu.mt]