

# Pathways to residential respite care in Malta: A qualitative study

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**Abstract.** Although the scope of residential respite is to support and offer caregivers a short break from their responsibilities, caregivers' decision to apply for this service is complex and often involves conflicting perceptions and ambivalent judgements. This article reports on a qualitative study exploring the underlying factors that steer informal caregivers to seek publicly-funded residential respite in Malta. Following in-depth coding and thematic analysis of the emergent data, it resulted that most caregivers who resorted to residential respite were taking care of older persons with relatively high dependence. While some caregivers referred to respite as the only solution to enjoy privacy for a brief period of time in their own home, others perceived respite as filling the gap until their care recipient was admitted permanently to a long-term care site. Most caregivers resorted to residential respite only in times of emergency and when burnt out, but a few made use of the service periodically to take a break from caregiving duties. Lack of co-operation from care recipients, and limited trust in formal care systems, were key factors that hindered the possibility that caregivers use the service more frequently or at all. The crucial policy implication is that the state, as the provider of this residential respite service, should be more sensitive in addressing the consistently changing needs of both caregivers and care recipients. An information campaign about when, how and where, the public service of residential respite care can be accessed is highly warranted if timely access is to be ensured.

**Keywords:** respite, residential respite, older persons, caregiving, informal caregivers.

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## **Background**

As people age, they are more likely to experience chronic health-related issues which might result in a drastic decrease in their level of functional independence (Mortimer & Green, 2015). Consequently, a greater number of older adults rely on family members for care provision, to the extent that informal caregivers play a central role in this background. Although caring for an older family member at home can be exceptionally gratifying, it can be an overwhelming and challenging experience as well. Apart from being a fundamental source of support to the individuals they care for, informal caregivers are key providers in the welfare system as they play a pivotal role in reducing the national health care expenditure (Bauer & Sousa-Poza, 2015).

Significant challenges are anticipated in the coming years as the number of available caregivers is not progressing at the same rate as the growing number of potential care recipients (Bault, 2012; Lund et al., 2014). The complex needs of caregivers for instance; the need for financial sustenance, consistent support from other family members, enough space to focus and address their own personal, physical and emotional needs and sufficient time for socialisation are very often overlooked (Charles, Bremault-Phillips, Parmar, Johnson & Scarey, 2017). Consequently, this often result in increased levels of stress, burn out, emotional and psychological difficulties which ultimately pose a challenge to the cohesiveness of the family, health services and society (Ziemba, 2002). With the passing of time, the caregiving demands tend to increase and informal caregivers often end up providing care without sufficient care support services that address their needs and those of their care recipients (Garces, Carretero, Rodenas & Aleman, 2010; Redfoot, Feinberg & Houser, 2013). Consequently, various researchers accentuate on the importance of implementing effective supportive strategies to assist caregivers in maintaining their challenging roles as well as enhancing the wellbeing of their care recipients. Such strategies are likely to delay admission to long-term care facilities (Nehen & Hermann, 2015; Vandepitte et al., 2016). Although respite care has been found to be one of the most preferred and most commonly requested family support services for informal caregivers, the use of respite is fairly limited even among those who are overwrought. Moreover, it is not always accessible and affordable (Brandao, Ribeiro & Martin, 2016; Phillipson, Jones & Magee, 2014; Reinhard, Levine & Samis, 2012).

The rationale underpinning respite care is to provide relief to informal caregivers from their caring responsibilities so they can restore and boost their energy levels and find time to address facets of their everyday lives that they had been overlooking due to their caring commitments (Greenwood, Habibi & Mackenzie, 2012; Lund et al., 2014). Evans (2013) delineated that respite should be founded on a coalition between the caregiver, the care recipient and the service provider. Chappell, Reid and Dow (2001:212) defined respite as a “pause, a temporary cessation, or an interval of rest” whereas Jeon and colleagues (2005:298) described respite care as “an arrangement to allow caregivers relief or ‘time-out’ from their care commitments, which may be provided on a regular basis or in emergencies”. This definition was considered to be the most suitable for this study as it entails a comprehensive statement of the main points relating to residential respite care for older persons. Respite

encompasses a variety of care services and respite breaks may be publicly-funded, private, offered by voluntary organizations and non-governmental organizations as well. Informal caregivers' break may vary from a couple of hours a day to a number of sequential weeks annually.

Respite care may be availed of at home, in facility-based units such as day centers and night shelters or in residential care settings (Bamford et al., 2009; Denning, 2013; Vandepitte et al., 2016). Residential respite care is at times referred to in the literature as in-patient or institutional respite encompasses the temporary admission of an individual requiring care to a residential care facility (Neville & Byrne, 2007). The utilisation of beds for respite may vary from an overnight stay up to a few days or weeks and services offered vary from one facility to another. This type of respite care may be utilised in cases of emergency or may be booked in advance (Bruen & Howe, 2009; Neville & Byrne, 2007). However, it is noteworthy to mention that most of the studies on respite care tend to amalgamate community and residential respite together in their analysis.

In a study on caregivers' perceptions regarding the use and non-use of residential respite care, Phillipson and Jones (2011) reported that caregivers of persons with dementia who made use of residential respite care perceived utilising this service when they could not cope any longer. It served them as a break when they needed it most. It was also claimed that, when other family members and friends supported their decisions to apply for residential respite they felt more relieved to make use of the service. Other caregivers opted to apply for residential respite care to facilitate the transition to permanent institutional care for their care recipient. They used this period to evaluate the standards and quality of care of certain long-term care facilities and to build a rapport with the staff in case they decided to admit their care recipient for long-term care to a particular facility. Some of the participants considered using respite as a last resort in case of an emergency or when their care recipient's health deteriorated. On the other hand, non-use of residential respite was associated with previous experiences of inadequate quality of care leading to lack of availability when the service was required, preoccupation that the care recipient would not want to leave the house, deterioration in the general function of the care recipient following respite, not satisfying their obligations as caregivers and losing control over their care recipient (*ibid.*).

In line with the above study, it has also been reported that caregivers might refuse to apply for respite because of guilt feelings that they are not fulfilling their role, lack of trust in formal care services and fear that their loved one will not be cared for by others in the same way he or she is cared for by themselves. Moreover, family conflicts often arise due to lack of agreement between family members when considering outside assistance (Mockus-Parks & Novielli, 2000). In a review exploring the factors associated with the non-use of respite services by caregivers of individuals with dementia, barriers to respite use included, lack of knowledge on the type of services being provided, fear of disruption of daily routine, difficulty to settle in a new environment, financial issues, problems to access transport services, lack of confidence in formal systems to understand and manage behavioural issues attributed with dementia (Phillipson et al., 2014).

Stockwell-Smith, Kellett and Moyle (2010) also highlighted that uncertainty about the quality of care and lack of awareness on the formal community care support services discouraged caregivers from making use of the service. Moreover, conflicting advice and rumours from former respite users were found to influence caregivers' decision regarding use of community support services. Caregivers also felt obliged to care for their family members as they wanted to reciprocate previous support provided by their care recipient and they expected the same care if they were in the same situation. Caregivers were unable to trust others with care provision and therefore unable to delegate work accordingly. Despite this, in time of crises they had to rely on formal support for their relatives. Stockwell-Smith and colleagues (2010) referred to the importance of comprehending caregivers' needs and expectations and the challenges they encounter when seeking formal support services.

### **The Context**

The Maltese archipelago is made up of three main islands; Malta, Gozo and Comino. According to the National Statistics Office (2018), by the end of 2017, 18.8 per cent of the total population residing in Malta was at least 65 years old. Moreover, by the year 2055, the Maltese cohort of individuals in the age bracket of 65 years or over is projected to increase up to 27.6% (National Statistics Office, 2016).

Community care for older persons in Malta is provided by the state, the private sector, the Catholic Church and the family (Farrugia-Bonello, 2015). In the past, the government's main agenda regarding the wellbeing of older persons was based on the biomedical model. As a result, older persons were often institutionalised to ensure that they were safely taken care of. Throughout the years, there was a paradigm shift in social policy and the focus is now towards older persons ageing actively in the community while institutionalisation is left as a last route (Formosa, 2017, 2018, 2019). Yet, it is also worth mentioning that a Eurobarometer survey conducted by the European Commission (2012) forwarded intriguing data on the views of Maltese citizenries apropos long-term care. When asked what would be the most suitable choice in the case of an older parent residing alone but requiring assistance due to deterioration in his or her functional performance skills, 60 percent of Maltese participants reported that the best choice would be for the older person to transfer to a nursing home or sheltered housing. Such results manifest that over the past years, the Maltese look as if they more willing to consent the arrangement of one's kin into residential and nursing care. This is challenging, when one takes into account that the population forecasts demonstrate a cumulative future demand and expenditures for long-term care (Formosa, 2015).

A number of non-governmental and voluntary organisations provide ongoing support to caregivers and their care recipients. A variety of community respite care services that include respite at home, facility-based respite, and residential respite care services are provided by the state. At the time of the study, the public residential respite care service was provided at three different facilities in Malta and one in Gozo namely; at a public long-term care facility, in a church-run and a private nursing and residential care home. Residential respite beds and packages are paid for by the state through a public-church and public-

private partnership scheme respectively (Diacono, 2014; Mifsud, 2016). The service in all the sites is completely funded by the state and it may be availed of for a maximum period of three weeks up to three times a year.

In view of the above, this study aimed to explore the underlying factors that steer caregivers taking care of older persons to seek residential respite.

## Methods

This study adopted an interpretative stance and a qualitative approach was employed. This article is based on the findings derived from twelve caregivers who admitted their care recipients for at least once to one of the aforementioned publicly-funded residential care settings during January to December 2016. Participants were recruited using maximum variation sampling. The study was approved by the University of Malta Research Ethics Committee. Prior to embarking on this study, all the necessary permissions to conduct the study were sought from the respective entities. A participant information sheet was sent to all potential participants through the gate keepers in order to prevent coercing anyone into participating and therefore protecting the principles of voluntary participation and autonomy. Prior each interview written informed consent was obtained. Strict confidentiality was adhered to throughout the whole research process and participants were free to withdraw from the study at any time without any repercussions. Semi-structured interviews were carried out in the participants' home at a place and time convenient for them.

Following the interviews data were transcribed verbatim and was analysed through coding and thematic analysis. During the data analysis, the three types of qualitative data coding- open coding, axial coding and selective coding as suggested by Strauss (1987) - were adhered to. Recruitment of all the participants was carried out through gatekeepers. Pseudonyms were used for participants' names to protect confidentiality. The Lincoln and Guba (1985) model of trustworthiness was utilised.

## Results

The following is an overview of the participant's profile, their caregiving experience and level of support. The purpose is to place the reader within the context of the caregivers' situation in order to better understand the findings.

*Profile:* The age of the caregivers (total of eight females and four males) varied from 35 years to 83 years while the age of their care recipients (a total of six females and six males) varied from 69 years to 91 years. All of their care recipients had several co-morbidities including combinations of hypertension, diabetes mellitus, hyperlipidemia, depression, anxiety, Parkinson's disease, dementia, cerebrovascular accident, arthritis, prostate enlargement and/or cardiovascular disease. The participants' level of education varied from a primary level to a tertiary level of education. Two of the caregivers were working on a full-time basis, one stopped from working on a part-time basis to take full care of her care recipient,

two were pensioners, one opted for early retirement and six were homemakers. Whereas eight of the caregivers were co-residing with their care recipients, three lived nearby in the same locality and only one lived in a different locality. Half of the caregivers stated that they had submitted an application for their care recipients to be admitted to a long-term care facility, two were considering the possibility of filling in an application and four had no intention of applying. Most of the caregivers and care recipients were related by consanguinity (lineal generational or collateral bonds) or by affinity whereas only one relationship was based on a long-time friendship.

*The caregiving experience:* The participants' caregiving experience ranged from three to twelve years. Most of them reported that it was not their first experience of providing direct care. They mentioned that caring was always an inner part of their personality and mostly they learnt how to care from previous situations. Two of the male caregivers mentioned that earlier on they took care of their father but their role was not as intense as their current one. Another male caregiver reported that prior to his mother, he had cared for an aunt and two of his neighbours.

*Level of support:* Different levels of informal support from other family members were highlighted by the caregivers. Some felt adequately supported while others felt that they had very limited choice on whom to turn to. Lack of constant and reliable support and limited understanding from other siblings placed considerable pressure on certain caregivers to take full responsibility for their care recipients.

Following data analysis, three themes emerged in relation to the underlying factors which steered caregivers to seek this service. The first theme was 'the push factor to residential respite', the second theme was 'more than just a daily struggle', while the third theme was 'a need for a break before it is too late'.

#### *The push factor to residential respite*

Factors leading caregivers to resort to residential respite varied considerably however the main reason was caregiver burnout. A number of caregivers explained that they only sought residential respite when they had no other alternative and they felt that they could not cope any longer with the increasing needs of their care recipients and their own physical and psychological needs. Some opted to take a break locally and still visit their care recipients regularly to ensure they were being cared for adequately while others preferred to go abroad to detach themselves completely and left their care recipients in the hands of formal caregivers.

Other reasons for using residential respite included: to go abroad to visit family and for work related purposes, to prepare for an important family event including a wedding, to make the necessary arrangements in the caregiver's home to accommodate the care recipient's needs following discharge from hospital, as a trial for long-term care and to recuperate after the caregiver underwent a couple of surgical interventions. Eliza explained that for her residential respite meant,

“A family-oriented place which you can use when you feel you can’t cope any longer, it is more or less like a pit stop. They assess the person needing care and also inquire about the needs of the person providing care. Most important I expect they provide some realistic solutions on how to handle difficult situations”. (Eliza)

The ultimate decision to use residential respite did not depend solely on the caregivers but on their care recipients as well. Lack of co-operation from the care recipients resulted in postponing the use of the service. Some caregivers highlighted that once they had approval from their family and friends they felt better about using residential respite for their care recipients. Most of the caregivers stated that to truly benefit from the service and detach themselves completely, the place and service they were going to leave their care recipients at, had to meet their expectations. Most of the caregivers clarified that they expected good quality standard of care in order for their care recipients to return back home without deteriorating and preferably in better shape. Otherwise, the time they used to restore themselves while their care recipient was at respite would be futile.

Caregivers got to know about the service from a variety of sources at different time points during their caregiving journey. Sources identified included; distant family members and friends who had already used the service for their care recipients, educational programs held on local television stations, the local center catering for older persons’ needs, (caregivers phoned to ask what services they could avail themselves of when they were in a crisis), the Dementia Activity Centre, the Dementia Support Group and from the main acute hospital when their care recipients were hospitalised.

#### *More than just a daily struggle*

Most of the caregivers stated that as years went by, the intensity of their role increased profoundly. They found themselves resorting and embracing more formal care support as they felt the need to balance their own needs and emotions. The community support services that were availing themselves of mainly encompassed; telecare, the pharmacy of your choice scheme, general assistance for bathing and dressing, domiciliary therapeutic sessions, assistance with changing of nappies, homehelp, the incontinence service (diapers free of charge or at a subsidised price), day centres and the dementia activity centre. The latter two services were being used as a form of day respite few days per week. In addition, the Dementia Support Group, the Dementia Helpline and support from a community social worker were other forms of support that were mentioned.

Although the aforementioned formal community support services served to alleviate the strains of caregiving on a daily basis, most of the caregivers confided that to truly pause from their responsibilities they needed to resort to residential respite for their care recipients. Albeit, this choice brought about a number of dilemmas with it, as most felt that it was a moral obligation to take care of their care recipients and they referred to residential respite as a choice out of necessity. Others delved on their hesitancy to give up caregiving even for a short time despite being overwhelmed with their role. Nonetheless, others reported that they booked residential respite for their care recipient at least once a year to

take a well-deserved holiday. Knowing that they had the necessary arrangements sorted for their care recipient while they were abroad was what kept them going.

When considering the number of years the caregivers had been caring for their care recipients and the number of times they utilized residential respite, overall the participants reported minimal use of the service. Some of the caregivers mentioned that they would have considered using residential respite at an earlier stage during their caregiving role if they had known about it before. Some caregivers highlighted that once they had approval from their family and friends they felt better about using residential respite for their care recipients. In contrast, one of the caregivers perceived resorting to residential respite for his spouse as a sign of weakness from his end. He used this service as a last resort upon persistence from his children. He reported that initially he refrained from using respite as he asserted that,

“It is not my style to delegate...not my style at all...I truly believe in doing what I have to do but at one point I couldn't deal with all the strain and I had to try out respite especially since my children insisted...they kept telling me that I needed a break”.  
(Alfred)

Some of those caregivers who were at a cliff's edge in their caregiving journey regarded residential respite as filling the gap until their care recipients were admitted permanently to a residential care home for older persons. Unfortunately, when the caregivers used the service as a last resort they have a lot of unresolved issues and the respite time is often too limited to find a solution for all of these problems.

Moreover, some of the caregivers who were residing in the same dwelling with their care recipients mentioned that for them residential respite meant having some privacy and taking a break in their own home without feeling constantly analysed by the latter. Since some of the care recipients and caregivers were receiving a number of community support services, they reported that different people were coming and going in their own home and they experienced moments where they yearned for some privacy. Residential respite care was the only solution to enjoy privacy in their own home without being constantly interrupted by others.

*Need for a break before it is too late!*

It was rather difficult for the caregivers to quantify the exact number of hours they dedicated directly in caring for their care recipients. However on average, hours of care dedicated directly to the care recipient's needs varied from an average of 20 hours per week to round the clock care with few hours of rest in between. Differences between spousal and filial caregiving were also highlighted. Caregivers who were co-residing with their care recipients especially spouses were more likely to spend more hours with their care recipients than those who were not residing in the same residence. Half of the caregivers reported that they often encountered difficulties (on a daily basis) to deal with their care recipients especially when assisting them with their personal activities of daily living.

Level of care required as reported by the caregivers varied from providing maximal physical assistance in all Activities of Daily Living <sup>1</sup> (ADL's) including hoisting the care recipient out of bed as well as carrying out all the Instrumental Activities of Daily Living <sup>2</sup> (IADL's) to carrying most of the IADL's. All caregivers mentioned different aspects on how their role was affecting their life. Some caregivers confided that they perceived their care recipients from another lens especially those whose care recipient was experiencing cognitive issues or those whom their care recipients required maximal physical assistance. Some caregivers accentuated that as time went by, their relationships went through a transition and some were still dealing with role reversal. One of the caregivers clarified that at times, she perceived her mother as if she was her daughter and she ended up taking the maternal role. One of the spouses mentioned that the way she perceived her relationship with her husband changed completely when compared to what it was before he started experiencing cognitive decline. Although she acknowledged that he was still her husband and she was ready to do anything for him, now their relationship was more as if he was her son and she became his mother. Whereas financial constraints were highlighted by two female caregivers, spending less quality time with other family members including their children, grandchildren and spouses was mentioned by nine of the caregivers.

Caregivers were feeling that they had multiple roles in their life and due to this, they were missing out on important events and bonds with other close family members. Therefore their role had an impact on the whole family not merely on themselves. This is clearly described by Jane, who said,

“I feel that the relationship I have with my daughter is not as it should be...she comes to ask me something and attempts to talk with me and I have to leave her in the middle of a conversation to go and check on my grandma...I worry since this is a very crucial time to strengthen the bond with my daughter and instead I end up giving full attention to my grandma...even with my husband, really it is not that simple...”. (Jane)

A number of caregivers (six of the seven caregivers who were 60 years or older) stated that they had to deal with their own health issues as well apart from those of their care recipients. They claimed that they were on medication for their own health issues and had to attend to their own hospital appointments on a regular basis. Three caregivers reported that they were suffering from severe arthritis, another two stated that they were suffering from severe sciatic pain, one of whom had cardiovascular problems as well. One caregiver claimed that she underwent two operations to repair a recurrent hernia. Five caregivers (three of whom were young caregivers) reported that there were times when they were feeling overwhelmed, stressed and their care recipients were gradually becoming a burden at times as they were feeling that they had too much to cope with.

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<sup>1</sup> Activities of Daily Living (ADL's) may be divided into basic activities, domestic and community activities also known as instrumental activities of daily living. Activities of daily living encompass functional mobility (bed mobility, transfers, ambulation and wheelchair mobility) and personal care (feeding, grooming, oral hygiene, continence and toilet hygiene, bathing and dressing) (Fonti, 2001; Frickle, 2010).

<sup>2</sup> IADL's entail a sequence of life functions which are fundamental to maintain an individual's immediate environment. These include management of one's medication, clothing care, cleaning, shopping, meal preparation, money management, household maintenance and care to others (Foti, 2001; Frickle, 2010).

Most of the caregivers whose care recipients required a substantial amount of physical assistance were primarily concerned with the repercussions resulting from caregiving on their own physical health while those whose care recipients had cognitive impairment complained of both physical and emotional strain but seemed to dwell more on the psychological strains caregiving was inducing on them. As conveyed by Eliza, who said,

“People were telling me I was running downhill but I felt alone and had nowhere to go until my friend told me about respite”. (Eliza)

Ambivalence about caregiving was clearly highlighted through various scenarios depicted by the caregivers when referring to their daily situations. Most of them made reference to the highs and lows they experienced and they compared their fluctuations in their caregiving journey to a rollercoaster ride. Despite the various implications their caregiving role was having on their well-being, on their relation with others and on their quality of life, all caregivers mentioned feelings of contentment and fulfillment at some point in time. They reported that from their end they felt that they were doing everything in their power to ensure that their loved ones were cared for in the most dignified and respectful way possible. This was clearly outlined by Simone who said,

“I do my role out of the love I have for my mother and my brother...I do get tired at times and I do grumble quite often but I wouldn't have it any other way...at the end of the day I feel exhausted but serene as I feel that I am doing the best I can for my loved ones. I am their family, if it was not for me and my husband they have no one else to take care of them...at least once in a while I take them for respite”. (Simone)

## **Discussion**

The characteristics of caregivers seeking residential respite care services for their care recipients in the study were similar to those documented by other researchers (Bauer & Sousa-Poza, 2015; Mack & Thompson, 2004; Lima, Allen, Goldscheider & Intrator, 2008). When the needs of the care recipient surpass the competence of the caregivers, families tend to seek some form of support (Montgomery & Kosloski, 2013). Different kinds of caregiving relationships differ greatly in terms of the extent and quality of support provided. Such relationships are formed by previous experiences and instigated when the older person needs assistance (Cho, 2007). Indeed, the participants' caregiving experiences depict how the type of caregiver-care recipients' past and present relationships play a key role in determining the caregivers' level of satisfaction with the kind of care provided. Likewise, Briathwaite (2000) and Salin and Astedt-Kurki (2007) outlined how previous life situations have an impact on caring roles. Unequal sharing of care responsibilities amid family members was also accentuated by Singh and colleagues (2015). In line with the findings reported by Rigs and Peel (2016) and Van Bruggen et al. (2016), caregivers in our study reported a shift in responsibilities during their caregiving journey. They felt squashed between different roles and somewhat felt guilty that due to their caregiving responsibilities they were not distributing their attention equally on all their loved ones. Moreover, differences in the type and level of caregiving burden amid spousal caregivers and adult children caregivers have been reported (Chappell & Dujela, & Smith, 2014).

Stolz, Uden and William (2004) highlighted caregivers' own health issues as one of the main driving forces that leads caregivers to seek respite care for their care recipients. Similarly, most of the caregivers in our study were providing a high level of assistance with most of the activities of daily living and they had their own held issues to deal with as well. Moreover, Cheung and Hocking (2004) reported that the majority of caregivers of older persons tend to be spouses, who themselves are ageing and require support and assistance. Caregivers in our study reported that at times they felt so overwhelmed and stressed that they felt that their care recipients were becoming a burden. This is in line with the findings of Ziemba (2002) who reported increased levels of stress, burn out, emotional and psychological difficulties resulting from caregiving. Besides, Yin, Zhou and Bashford (2002) highlighted that implications from caregiving were found to influence the type and quality of care the caregiver provided to the care recipient. Hence, the bio-psycho-social needs of the care recipient and the family's adapting and coping competence need to be periodically and thoroughly addressed (Hannum et al., 2007).

Moreover, Beach and colleagues (2005) reported that care recipients who require high levels of assistance from their caregivers are predisposed to a higher risk of abuse especially if their caregiver is suffering from depression, distress and ill health. Likewise, Dunbrack (2003) argued that inadequate respite services are associated with caregiver burnout, neglect, crises and abuse. This draws attention to address the needs of caregivers in a timely manner since decline in their health and social well-being might initiate a cascade of events leading to hospitalization of both the caregiver and care recipient (O'Connell, Hawkins, Ostaskiewicz & Millan, 2012). Furthermore, Kosloski, Montgomery and Youngbauer (2001) and Dal Santo, Scharlach, Nielsen and Fox (2007) illustrated that complex and demanding caregiving situations compelled caregivers to seek respite care. Notwithstanding the feelings of exhaustion and burden arising from the caregiving load, some of the caregivers in our study implied that they were willing to continue with their role since caregiving kindled feelings of achievement and self-worth as well. They stated that as long as they had the physical and psychological strength and adequate forms of support, they were willing to persist despite the negative effects they were experiencing. Positive effects attributed with caregiving were also highlighted by a number of researchers (Boerner, Schulz & Horowitz, 2004; Haley, LaMonde, Han, Burton & Schonwetter, 2003; Harmell, Chatillon, Roepke & Mausbach, 2011).

Some of the caregivers in our study described how they felt stuck in their role and they sought residential respite for their care recipient once they realised that the situation was becoming untenable and they were facing a crisis implying that they left this option as a last resort. This is highlighted in other studies (Reinhard et al., 2012; Phillipson et al., 2014) which reported that respite among caregivers is fairly limited even among those caregivers who are distraught. Conversely some of the caregivers in our study recounted that although initially it was hard to let go of their care recipient for a few weeks, feelings of guilt abated as the whole family gained from the break.

Similar to the findings of Dimech and colleagues (2009), reasons for seeking residential respite varied considerably. For most of the caregivers residential respite meant a secure place and a support mechanism where they could safely leave their care recipients for a brief period of time in order to attend to their needs, recharge their energy and continue caring for their loved ones once discharged back home. Approval from their family and friends made them feel better about using residential respite for their care recipients. This is also in line with the findings of Phillipson and Jones (2011). For some of the caregivers, residential respite was the only way to have some privacy in their own home. Similar findings are outlined by Svensson, Bergh and Jakobsson (2011).

Some of the caregivers mentioned that they would have considered using residential respite at an earlier stage during their caregiving role if they had known about it before. Phillipson and Jones (2011) reported that a number of caregivers associated residential respite with not satisfying their obligations and only resorted to the service when they were completely burnt out. Unfortunately, when the caregivers use the service as a last resort they have a lot of unresolved issues and the respite time is often too limited to find a solution for all of these problems.

## **Conclusion**

Every effort should be made to support and educate caregivers to identify, understand and address their own self-care needs by utilising formal community support care services including residential respite for their care recipients from time to time. While it is vital to target caregivers at risk, it is equally important to increase awareness and educate caregivers and older persons who are in the initial phases of their journey regarding the role of residential respite and its benefits so they can access the service at the right time and prevent crisis. Social workers and health-care professionals have a window of opportunity to delay admissions to long-term care as they should be on the lookout and detect causes for concern at an early stage and refer to the most appropriate service based on the needs of the individual and his or her significant others before issues escalate and become unmanageable. If there is more public awareness, family and friends are more likely to acknowledge the need for caregivers to take a break and counsel them accordingly. In turn, caregivers will feel less stigmatised and keener to utilise more the service.

Although the findings of this study cannot be generalised due to the small sample size, maximum variation sampling was used to produce a heterogeneous sample. Data was collected retrospectively therefore it was subject to recall bias. Although every attempt was made to avoid researchers' bias while carrying out the interviews, the participants were aware of the researcher's professional background and may have tried to answer in a way to please the researcher. Hence, to combat such limitation the researcher made sure to be objective as possible and avoid making any form of judgement and bias that could have resulted in influencing the data collected.

## **Implications for research and practise**

Since lack of co-operation from the care recipients to use residential respite was one of the factors that hindered caregivers from using the service, further in-depth research on the views of older persons' admitted to residential respite will guide and inform better the development of meaningful programs for older persons using residential respite. In an era of patient and family-centred-care, better informing older persons regarding the type of service they are expected to experience is necessary. All professionals working in the primary healthcare sector need to be sensitive to the needs of caregivers and their care recipients and they must ensure that caregivers are informed and provided with timely access to community care support services. Professionals must conduct ongoing evaluations to ensure that the support services provided are addressing the dynamic needs of the caregivers and their care recipients. A stronger bond among all stakeholders is warranted to avoid fragmentation of services and ensure more cohesiveness through teamwork in the best interest of the older person and his or her caregiver. Professional education and support interventions are pivotal in preparing and assisting caregivers to sustain their indispensable role. Hence, caregivers would benefit more if they are trained and offered support on when and how to access services and on managing time more effectively when their care recipient is receiving some form of respite care.

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