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Care-givers' perspectives of occupational engagement of persons with dementia

MEGUMI TSUNAKA* and JENNY C. C. CHUNG†

ABSTRACT

Meaningful engagement in activity is associated with the maintenance of health and wellbeing, but reduced activity participation is common among persons with dementia. Family care-givers play an important role in engaging their relatives with dementia in activities but little is known about their perception of occupational engagement. This study aimed to examine care-givers' perception of occupational performance of their relatives from three aspects: person, occupation and environment. Adopting a qualitative methodology, semi-structured and in-depth interviews were conducted with 14 family care-givers. Care-givers were also asked to document the activity patterns of their relative, using the Activity Card Sort Hong Kong version (ACS-HK). The ACS-HK findings suggested that high-demand leisure activities were mostly retained (61%) while instrumental activities of daily living were the least retained (37%). Qualitative analysis revealed that care-givers' perception of activity participation was intertwined with their motives and behaviours to get their relatives engaged in activities. Care-givers acknowledged occupational engagement as a means of maintaining wellness and used various strategies to encourage their relative's activity participation. Apathy and passivity, however, are difficult to deal with. Also, activity decisions appear to depend on the availability of support resources and a balance between safety concern and risk-taking. Clinical practitioners could assist care-givers by suggesting activity strategies and providing support resources for continued engagement of their relative in activities.

KEY WORDS—care-givers, persons with dementia, engagement, activity pattern, qualitative method.

Introduction

As in many parts of the world, Hong Kong and Singapore have witnessed a growing population of older people suffering from dementia. Recent studies have reported that over 10 per cent of community-dwelling older people

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suffer from very mild to mild dementia in Hong Kong (Lam *et al.* 2008), and between 2.5 and 4 per cent of the elderly population of Singapore have dementia (Ministry of Health Singapore 2002). Alzheimer's disease, the most common form of dementia, is characterised by a gradual loss of cognitive function, reduced ability in performing daily activities, personality changes, and behavioural disturbances (Potkin 2002).

Engagement in occupation, which is broadly defined as activities that are related to one's life roles, plays a significant role in the maintenance of health and wellbeing (Baum 1995). Older people have articulated that being able to retain a role in society and/or family and to perform activities relevant to the life roles are central to quality of life (Gabriel and Bowling 2004). Studies have reported that even for individuals at the more advanced stages of dementia, they still have an innate need for activity participation (Chung 2004; Perrin 1997). Nonetheless, the escalating levels of cognitive and functional impairments experienced by persons with dementia greatly restrict their optimal and meaningful engagement in activities. They need to rely more on care-givers for the performance of many activities including day-to-day functional activities and socially related activities (Lee *et al.* 2006; Nygard and Ohman 2002).

Informal care-giving, mostly provided by family members, has continued to be a key pattern of care-giving in many Asian countries including China, Korea, Japan and the ethnic Chinese groups of Singapore. These countries share a common Confucian thinking and consider filial piety as one of the greatest virtues (Lee and Kwok 2005; Yap, Thang and Traphagan 2006). In present days, filial piety has been broadly defined as showing respect to elderly family members and taking care of them whenever in need (Zhan 2004). Despite the fact that Confucian thinking has been weakened due to economic growth, modernisation and the influence of Western culture, filial piety has remained a value observed by many Asian families (Chan 2005; Mehta 2005).

In the context of dementia care, family care-givers play a key role. While occupational engagement has the potential to maintain the identity of and to provide a sense of usefulness to persons with dementia (Action *et al.* 1999), it is essential that care-givers encourage and promote pleasurable and meaningful activity participation of their relative with dementia (Vikstrom *et al.* 2005). Nonetheless, previous studies have reported that care-givers restrict the participation in activities of their relative and/or take over their tasks for safety reasons (Hasselkus and Murray 2007; Lach and Chang 2007). It appears that care-givers experience the tension between risk-taking and safety concern and have to make a trade-off between encouraging participation and restricting participation from time to time (Egan, Hobson and Fearing 2006).

The Person–Environment–Occupation (PEO) framework (Law *et al.* 1996) was adopted as the conceptual model of this study. It is comprised of three core components. The person (P) is a unique being who assumes a variety of roles and is seen holistically as a composite of mind, body and spiritual qualities, and constantly interacting with the environment. The environment (E) is defined as encompassing the cultural, socio-economic, institutional, physical and social dimensions. The occupation (O) refers to activities and tasks performed by the person in relation to his life roles (Baum, Perlmutter and Edwards 2000; Law *et al.* 1996). According to the PEO framework, occupational performance – the doing of occupation (activities) to satisfy one’s needs – emerges from the interaction of the person with his occupations and with the environments in which he lives, works, and plays (Law and Baum 2005; Law *et al.* 1996). Its three components interact continually in ways that increase or diminish their congruence. Occupational performance is maximised when there is optimal fit between the components (Law *et al.* 1996). With disease progression, increasing cognitive difficulties deter engagement in previous activities (Perrin and May 2000; Reisberg *et al.* 1999). Hence, the PEO framework provides a systematic approach to analyse the person’s function and dysfunction and how his social and living environments and occupational activities can be adapted to promote optimal and safe occupational performance (Cooper and Day 2003; Strong *et al.* 1999).

Undeniably, family care-givers play a significant role in assisting and supporting their relatives with dementia to take part in various activities. However, little is known about care-givers’ perception of occupational engagement as related to their relatives with dementia. The purpose of this study was to examine the activity patterns of persons with dementia and care-givers’ perception of occupational engagement of their relatives with dementia. In addition, the interaction of the person, environment and occupation of persons with dementia from care-givers’ perspectives was explored.

In this study, occupations are defined as groups of activities and tasks in which an individual engages so as to meet his/her intrinsic needs for self-maintenance, expression and fulfilment (Law *et al.* 1996). Beyond the occupational therapy profession, the term ‘activity’ is often used to illustrate this concept (Rudman, Cook and Polatajko 1997).

Method

Design and study participants

Adopting the PEO framework as the conceptual model of the study, a qualitative methodology was used to gain a deeper understanding of

care-givers' meaning and perceptions of occupational performance of their relatives with dementia (Yerxa 1991). A quantitative methodology was also used to document the patterns and levels of activity participation of individuals with dementia.

Using the convenience and snowballing sampling methods, 14 family care-givers and their relatives with dementia were recruited from dementia-specific day centres and community hospitals in Hong Kong and in Singapore. The reason for the subject recruitment being conducted in the two sites was one of convenience. The first author had worked in Singapore and at the time when this study was conducted she was enrolled in a post-graduate programme in Hong Kong. The connections that both authors had with the potential recruitment sites prompted the subject recruitment to be carried out in both Hong Kong and Singapore. To a certain extent, the two cities are similar in many ways, including a post-colonial history, a large Chinese population, sharing of Confucian thoughts, and a long life expectancy (Asher and Newman 2001; Census and Statistics Department 2006; Singapore Department of Statistics 2009; Soontiens 2007).

The inclusion criteria for family care-givers were: (1) having a family member who had received a diagnosis of dementia, (2) assuming the primary role of taking care of and making decisions for a family member suffering from dementia, and (3) having looked after the family member with dementia for more than one year. Potential family care-givers were excluded from the study if their relatives did not live at home but in long-term care settings. Individuals with dementia who did not have a formal medical diagnosis were also excluded from the study.

The Human Ethics Committee of the Hong Kong Polytechnic University approved the study protocol. Prior to the study implementation, written informed consent was obtained from the family care-givers.

Data collection

In-depth, semi-structured and face-to-face interviews were used to understand care-givers' perceptions towards occupational engagement of their relatives with dementia. The interview questions were developed based on the PEO framework and the past literature. Examples of the interview questions were:

- Person: How are the abilities (*e.g.* cognitive, behavioural, psychological) of your relative with dementia before and after the onset of dementia?

- Environment: How do you interact with your relative with dementia? Tell me whether you would encourage your relative with dementia to take part in activities.
- Occupation: Are there any meanings attached to the activities your relative with dementia continues to perform? Tell me whether there are any changes in activity participation pattern after the onset of dementia.

The interviews were conducted by the first author at the study participants' homes. On average, the interview lasted for about an hour, ranging from 45 to 90 minutes. All interviews were audio-recorded and transcribed verbatim. Field notes were written during and/or immediately following each interview session.

To document the patterns and level of activity participation of the participants with dementia, the Activity Card Sort Hong Kong version (ACS-HK) (Chan, Chung and Packer 2006) was used. It is comprised of 65 picture cards showing four categories of activities, including instrumental activities of daily living (IADL) (*e.g.* grocery shopping, dish washing), high-demand leisure (*e.g.* morning exercise, Tai-Chi playing), low-demand leisure (*e.g.* newspaper reading, chess/card games) and social (*e.g.* family gathering, travelling), typically performed by older Chinese adults. For the purpose of this study, the 'recovery version' of the ACS-HK was adopted to record changes in the activity patterns prior to and after the onset of dementia on five sorting categories – 'not done prior to illness', 'continued to do during illness', 'given up due to illness', 'beginning to do again' and 'new activity since illness' (Chung, Chan and Packer 2007: 6). The retained level of activity engagement (as a percentage) is computed by dividing the previous activity level from the current activity level and multiplying by 100. The current activity level is the sum value of 'continued to do during illness', 'beginning to do again' and 'new activity since illness'. The previous activity level is the sum value of 'continued to do during illness', 'given up due to illness' and 'beginning to do again'.

The ACS-HK was used for the study participants in Hong Kong and Singapore because the ACS-Singapore version was in the process of validation. As the Chinese people of Hong Kong and Singapore share similar cultural values and lifestyle patterns (Soontiens 2007), the use of the ACS-HK with the Singaporean participants was considered appropriate. During data collection, the Singaporean study participants were asked to report any activities that their relatives with dementia engaged in but that were not shown in the ACS-HK to reflect the cultural differences. Satisfactory psychometric properties including content validity, test-retest reliability and construct validity have been established for the ACS-HK (Chan, Chung and Packer 2006).

Data analysis

Descriptive statistics were performed to summarise the demographic characteristics of the care-giver participants and the participants with dementia, and to compute the patterns and level of activity participation of the participants with dementia.

The qualitative data obtained from the interviews were analysed based on the PEO framework. First, the interviews were read several times to obtain a sense of the whole. Then, the texts were divided into units that represented similar contexts and/or meaning. The meaningfully related categories were collapsed into the three core themes of the PEO framework. To ensure credibility of the data, the codes and themes were compared to the original data through a peer examination. Data obtained from interviews were also compared to the field notes taken during each interview (Patton 2002). Member checking was also conducted with eight participants (57%), who reviewed the data analysis performed by the researchers and checked for accuracy (Holloway and Wheeler 1996). Additionally, the researchers kept reflective journals so that the research process and materials could be audited (Shenton 2004).

Results

Table 1 shows the demographic characteristics of the care-giver respondents and their relatives with dementia. Among the 14 care-givers, nine were recruited from Singapore and five from Hong Kong. The care-givers' mean age was 50 years old. All except one were adult children, most lived with their relatives with dementia, and all were educated at the secondary level and/or above. As for the persons with dementia, the mean age was 81 years old and mean years of the dementia diagnosis was four. Two-thirds of them were females and classified as having mild to moderate severity of cognitive impairment.

Patterns of activity participation of persons with dementia

At the time of the study, nine participants with dementia (64%) were attending day centres four to five times a week. The overall retained level of activity participation, as measured by the ACS-HK, among all participants with dementia was 47 per cent. Of the four activity areas, 'high-demand leisure' was found having the highest retained level (61%), followed by 'social-related activities' (57%) and 'low-demand leisure' (47%), and 'IADL' had the lowest level (37%).

TABLE 1. *Demographics of the care-givers and persons with dementia*

	N (SD)
Care-givers (N=14):	
Mean age	50 (7.8)
Gender:	
Female	12
Male	2
Education:	
Secondary	7
Undergraduate	5
Postgraduate	2
Racial group:	
Chinese	11
Indian	2
Other	1
Kin relationship:	
Adult children	13
Spouse	1
Living with persons with dementia	12
Persons with dementia (N=14):	
Mean age	81 (6.0)
Gender:	
Female	10
Male	4
Mean years of dementia diagnosis	4 (3.3)

Note: SD: standard deviation.

For high-demand leisure activities (activities demanding higher levels of energy consumption such as swimming), about three-quarters of the participants with dementia performed physical exercises either with the care-givers or when attending day centres (71%). Yet, two participants showed very different activity patterns. One participant had never engaged in any high-demand leisure activities before the onset of dementia and this pattern remained unchanged after the disease onset. In contrast, another participant recently took up two new physical activities (walking in the park and watering pot plants) under the encouragement and facilitation of her care-giver.

In terms of social activities, most participants with dementia continued taking part in family functions such as weekly gathering (86%) and having meals at home or in restaurant with family (64%) after the disease onset. Similar to high-demand leisure activities, most participants continued engaging in low-demand leisure activities, of which watching television was the most popular one (86%) and playing mah-jong (a popular activity among Chinese people) ranked second (43%). As for IADLs, taking

medication and having a rest were mostly engaged in by the participants with dementia. In contrast, the more complex forms of IADL such as cooking and laundry were no longer performed by most participants.

Care-givers' perception of occupational engagement of persons with dementia

Occupational performance is the outcome of the interaction of the person, environment and occupation (Law *et al.* 1996). In this study, the PEO framework (Law *et al.* 1996) was used to analyse care-giver respondents' perception of their demented relatives' occupational engagement. Four primary themes resulted from the analyses: (a) increased impairment for activity participation (person), (b) use of self as a tool to promote occupational engagement (environment), (c) devising adaptations and strategies to optimise participation (environment), and (d) using activity participation as a means of maintaining health and wellbeing (occupation).

Person

Increased impairment for activity participation

All care-givers acknowledged that their relatives with dementia experienced increasing difficulty in performing activities because of the deteriorating cognitive, emotional and physical competence. Care-givers had to offer assistance and used caring strategies such as verbal prompts to support their relative for task performance and to encourage activity participation. Some care-givers, however, expressed the difficulty they experienced when their relatives showed little interest in activities. As one care-giver said:

My mother has become increasingly passive, inactive and rigid... it seems that nothing can arouse her interest and motivate her for participation. During the day, she just sits there and falls asleep most of the time. I have tried different strategies to engage her in activities that she previously enjoyed. She just did it for a very short while and soon lost the interest in it. Even for the Chinese New Year, she looked as if she did not recognise this important festival of the year at all... she appeared apathetic and did not show any interest in most of the celebration events. At times, we are frustrated by not knowing how to deal with her passive and apathetic behaviour.

Interestingly although the ACS-HK results suggested the participants with dementia had a high level of participation in social activities, a closer examination of the findings revealed that the social activities that most participants with dementia engaged in were with family. In contrast, there was a substantial reduction in social activities with friends. Care-givers

postulated a few reasons for these observations. First, when the participants with dementia started to experience challenges in making meaningful social exchanges with friends or having difficulty in recognising friends, they gradually disengage themselves from attending these social functions. Another possible reason is that the challenging behaviours manifested by the participants with dementia might have made them 'strange' and not welcomed in social situations with friends. In contrast, the declining language abilities, impaired communication skills and challenging behaviours manifested by the participants with dementia were more readily accepted and/or tolerated by their family members. As a result, they were more likely to have a higher level of participation in family-based activities as compared to other forms of social activities.

Even though the care-givers were fully aware that dementia is a degenerative disease, they still hoped that their relatives with dementia could remain 'well' for as long as possible and that their cognitive and functional deterioration could be slow and insidious. As a daughter care-giver shared:

At one stage my mother had been very ill, and fortunately she has mostly recovered. I feel so much relief that her health condition has been stabilised. Now, she can eat by herself and has started to show interest in her surroundings. Besides, she is more responsive when we talk and interact with her.

Environment

Family care-givers are considered as part of the social and cultural environments that interact and facilitate occupational engagement of persons with dementia. All care-givers of this study reported that they gained a fundamental understanding of dementia from courses and workshops and most of them were members of care-giver support groups.

Use of self as a tool to promote occupational engagement

Care-givers emphasised the importance of patience, understanding, respect and love when caring for their relative with dementia. To encourage activity participation, the care-givers learned to be observant and sensitive to the body gestures and non-verbal cues shown by their relative. As one daughter care-giver illustrated:

My mother is no longer able to express herself using verbal languages. We try to understand her non-verbal gestures and actions and then to make an interpretation or a guess of what she wants to express. For instance, when she looks uneasy and moves around in the chair, we will take her to the toilet. If there is a sign of relief in her face, we know that we have made a correct guess of her discomfort. . . . These are

moments of satisfaction when we are able to understand her needs and to make her feel comfortable and pleasurable.

Devising adaptations and strategies to promote participation

Several care-givers said they made adaptations to the activities and the living environment so as to support their relative's activity participation. Care-givers also devised, tried and used a variety of strategies – prompting, demonstration, consistent daily routine and caring approach and environmental orientation cues – to engage their relative in daily functional activities. Most care-givers encouraged their relatives to perform activities they were familiar with and related to their life roles (*e.g.* housewife) and interests (*e.g.* mah-jong playing). As one daughter care-giver shared:

Sometimes I sit with my mother and encourage her to pluck bean sprouts or vegetables, together with me. This is what she did when she was a housewife. She looks like she is enjoying herself when doing the tasks that she performed in the past, and the tasks that she is 'still' capable of doing.

Nonetheless, several care-givers pointed out that they sometimes would wonder whether the strategies or the activities they used were appropriate and safe enough for their relative. Yet, less than one-third of the care-givers sought professional advice such as from occupational therapists regarding the design and choice of activities for their relative with dementia.

Occupation

Using activity participation as a means of maintaining health and wellbeing

Care-givers generally acknowledged activity participation as a means of maintaining physical and cognitive functioning of their relative with dementia. Some also pointed out the potential psychological benefits associated with activity participation such as the provision of a sense of fulfilment, connectedness, and meaning in life for both care-givers and persons with dementia. One son care-giver shared his feeling when being able to engage his father in activities he enjoyed doing:

I have always encouraged my father to do whatever activities he enjoys doing. I enjoy spending time with him to make him happy, to make him feel that we are with him, and to let him know that he is important to the family. To me, these are precious moments. I regain the feeling of connectedness and closeness when doing activities together with him. I hope that he also feels the same.

Nevertheless, one son care-giver said occupational engagement was not the only means of maintaining his mother's wellbeing, but respecting her wish and choice was of equal importance. Thus, he seldom insisted his mother

doing activities she was not interested in. Instead, he let her do whatever she enjoyed:

In cases when she wants the domestic helper to help with dressing or eating a meal, I do not insist that she has to do it by herself. I respect her wish and believe she feels happier this way. I do not bother to find out whether she cannot do the task or she does not want to do it.

As for another care-giver, she acknowledged the activity need of her mother but she had been under great stress and resource constraint that she could only attend to her mother's basic self-care needs. She was upset and distressed because she received hardly any support from other family members and could not afford to employ a domestic helper to assist the care-giving duties. As a result, her mother was left idling most of the time, and probably because of the lack of stimulation, she displayed temper outbursts at times. However, she hardly had any time and energy to address her mother's occupational deprivation and to deal with her temper outbursts and challenging behaviours. Even more, she said she did not want her mother to perform activities other than the basic self-care activities because of safety:

None of my siblings share the care-giving duties. I am all by myself to look after my mother. So my goals are how to survive, how to make the ends meet, and how to cope. . . . Frankly speaking, I don't want her to do anything at all. What happens if she falls? I don't have the time to watch her every minute, so it is safer if she just sits or lies down there.

Discussion

Participation in meaningful occupation plays an important role in our lives and is considered a significant aspect of the human experience (Christiansen and Baum 2005). For persons with dementia, being able to attain an optimal level of activity engagement is essential for the maintenance of health and wellbeing (Everard *et al.* 2000; Perrin 2000). Consistent with previous studies, family care-givers of this study recognised that continued activity participation is a representation of 'wellness' for persons with dementia (Everard *et al.* 2000; Hasselkus and Murray 2007). The study findings also concur with previous research that care-givers feel satisfied and less burdened when their relative can remain 'well' for as long as possible and 'still' be able to carry out simple everyday tasks (Hasselkus 1998; Pruchno, Burant and Peters 1997).

The use of the PEO framework for analysis has shed light on the transactional relationship of the occupational engagement of persons with dementia with family care-givers and with the level of functioning

(or impairment) of persons with dementia. To accommodate for the progressive deterioration of the functioning of individuals with dementia (the person), family care-givers (the social environment) devise and use strategies and make adaptation and simplification to activities and/or living environment (the physical environment) to support the occupational performance of their relative (Cooper and Day 2003). Essentially, family care-givers assume a pivotal role in shaping the occupational lives of their relatives with dementia. The patterns of occupational engagement of persons with dementia have been closely intertwined with those of their care-givers.

Given the patterns of activity, participation of persons with dementia are mostly dependent on the planning and support of their family care-givers (Persson and Zingmark 2006; Voelkl 1998), it is therefore not an unexpected observation that persons with dementia mostly have higher levels of engagement in activities that are accompanied by care-givers such as family gathering, morning exercise and simple household chores. Being part of the 'social' environment, family care-givers use 'self' as a tool to encourage their relative to stay active in some kinds of activity (Chung, Ellis-Hill and Coleman 2008). Although family care-givers do not always have the best knowledge to determine whether the activities they choose or the strategies they use are the most appropriate for their relative, they continue developing activity strategies through a 'trial and error' approach (Chung 1997; Chung, Ellis-Hill and Coleman 2008; Nolan, Ingram and Watson 2002). Hasselkus and Murray (2007) contended that for family care-givers, being able to engage persons with dementia in activities provides them with a major source of satisfaction. For instance, arranging tasks that are familiar and related to the past life roles of persons with dementia has been reported to be an effective activity strategy, as the performance of familiar tasks is capitalised on the relatively sparse abilities of persons with dementia and is considered a means of maintaining a sense of identity (Chung, Ellis-Hill and Coleman 2008; Phinney 2006).

Nonetheless, there are moments when care-givers find themselves not competent and losing confidence to engage their relatives in activity, particularly after repeated failures and unsuccessful attempts. In this study, several care-givers regarded apathy and disengagement from passivity difficult and troublesome to deal with. According to a recent population-based prevalence study on behavioural and psychological symptoms of dementia, apathy is the most prevalent non-cognitive symptom of dementia (Savva *et al.* 2009). Not knowing how to arouse the relative's activity interest, how to motivate him/her to get involved in even basic self-care activities, and how to cope with his/her passivity and over-dependence are challenges faced by many care-givers (Kaufer *et al.* 1998). Excess disability has been

reported as one of the undesirable consequences among persons with dementia who are apathetic and inactive (Rogers *et al.* 2000). When not properly managed, excess disability leads to increased dependence, deconditioning and manifestation of maladaptive behaviours, making care-giving even more difficult. There is a need that care-givers are provided with the knowledge, skills and activity strategies to address passivity and apathetic behaviours of persons with dementia (Graff *et al.* 2006; Josephsson *et al.* 2000).

The provision of security and the prevention from being harmed have always been a priority of family care-givers when planning activities for their relative with dementia (Chung, Ellis-Hill and Coleman 2008; Hasselkus 1998). Consistent with previous research, some care-givers in this study restricted their relative from activities that may be unsafe and risky (Egan, Hobson and Fearing 2006). The activity decision between safety concern and risk-taking becomes even more apparent when support and resources are less available. Under these circumstances, care-givers choose not to take a risk by restricting their relatives from performing activities that are considered non-essential. Nonetheless, such caring arrangements may elicit undesirable consequences such as maladaptive behaviours and excess disability. Clearly, it is crucial that care-givers with limited informal/family support and their relatives with dementia are provided with formal services and resources such as day centre, home-based service or respite care. Clinical practitioners such as occupational therapists may be able to assist care-givers by providing suggestions regarding ways to choose appropriate activities and to modify them or the environment to maximise function in meaningful occupations. At the same time, they must appreciate the safety concerns of care-givers (Egan, Hobson and Fearing 2006).

In this study, the majority of care-givers were Chinese and adult children. Hence, the intertwining relationship between care-givers and their relatives on occupational engagement may reflect a cultural bearing. Despite economic development and modernisation, close family ties and filial piety have remained the core values of many Chinese and Asian families (Chao 1983; Lam 2007). Caring for elderly parents is seen as a reciprocal return of care and love care-givers received when they were children (Holroyd 2001; Lam 2007). According to previous research, the connectedness and the intertwining relationship between care-givers and their relative with dementia is further strengthened when the former finds themselves capable of engaging their elderly parents in doing activities they feel pleasurable and fulfilling (Lewinter 2003). Indeed, such reciprocity and connectedness have served as important motives for care-givers' continual involvement in the occupational engagement of their relative with dementia (Chung, Ellis-Hill and Coleman 2008).

Limitations of the study

There were some limitations inherent in this study. The first limitation was a biased study sample. All care-giver participants had a secondary school education and/or above, all except one were adult children care-givers, and about half of them had prior knowledge of health care and dementia. Thus, the generalisation of the findings was limited because of a non-representative sample. Second, the data of the ACS-HK were obtained from family care-givers who provided a proxy report for their relative with dementia. Although excellent test–retest reliability among proxy respondents (care-givers) was reported in the original ACS version (Baum, Perlmutter and Edwards 2000), such reliability has not yet been established for the ACS-HK. Third, the level and patterns of activity participation of persons with dementia could not be fully analysed because of the unavailability of the functional status and the cognitive performance of the participants with dementia.

Conclusion

Declining cognitive and physical abilities of persons with dementia are barriers limiting an optimal level of activity participation. The study findings suggest that family care-givers, being the social environment, play a central role in shaping the occupational lives of their relatives with dementia. Care-givers' perception of occupation and activity participation are intertwined with their motives and behaviours to get their relatives engaged in activities. Care-givers also perceive activity participation as a means of maintaining health and wellness of their relative with dementia, and therefore they actively develop and use various strategies to engage their relative in activities. Yet, care-givers' activity decision may be dependent on the availability of support resources as well as a trade-off between personal safety and risk-taking. Hence, there is a need to provide care-givers with the resources (*e.g.* formal services) and suggestions regarding activity strategies to support their relative's continued activity engagement.

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