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Ethnographic Study of Living Alone Elderly with Mild Cognitive Impairment in Hong Kong: A Pilot Study

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ABSTRACT

According to a published research report by the World Health Organization, more than 30 million people suffer from dementia throughout the world, and that figure is expected to increase twofold by 2030. When older people lack social networks, neighbours or friends, they experience a certain level of social loneliness. In this study, three people, aged 75 to 85, who were living alone in public housing and who suffered from mild cognitive impairment were invited to participate in a research project. Six months of participant observations were conducted in a natural setting, to gain better understanding of their latent needs in living to be fulfilled through the application of universal design and several themes of concern were suggested.

Keywords: Mild cognitive impairment, Dementia, Universal design, Participant observation , Day-to-day activity, Ethnography

INTRODUCTION

A report by the United Nations has revealed the number of older adults in the world is projected to reach 1.4 billion by 2030, and this number is expected to increase to 2.1 billion by 2050. This development will place enormous pressure on current healthcare and social protection systems (United Nations, 2015). If life expectancy continues to rise while fertility constantly declines over many years, the ageing of the population will continue to throughout the world. The gigantic numbers of elderly people will place significant pressure on current systems of social protection and global health care. By 2024, it is expected to have nearly 400,000 people over the age of 80 in Hong Kong —a 24.8% increase over the figure recorded in 2014 (Census and Statistics Department, 2016). This ageing trend will continue for the coming decades, owning to the ageing of ‘baby boomers’ who were born between 1940s and 1960s.

PROBLEM STATEMENT

Like in other Asian cities, the population of Hong Kong exhibits a continuous ageing trend. The change in the population structure will need an

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improved housing policy and health care system and infrastructure in order to tackle these resulting social problems. The more older adults are living in the city, the greater the numbers of people who are living with dementia. In United States, The Aging, Demographics and Memory Study reported that nearly 14% of people aged 71 and over suffered with dementia (Plassman, et al, 2007). No doubt, the prevalence of this disease will continue to grow alongside the increases in the population of older people among major countries. Dementia-friendly residential homes and product designs could serve as tactics as remediation. Universal Design (UD could offer a more inclusive approach to meeting these people's needs in ways that are more intuitive and flexible and that require less physical effort as intelligent solutions.

OLDER ADULTS LIVING WITH MILD COGNITIVE IMPAIRMENT

Dementia is characterized by the loss of mental abilities and by further degeneration over time. This condition is not inevitable, as the hallmark symptoms of cognitive deterioration are not considered to be a normal part of ageing. It is a typical biomedical disease that might appear when the brain is affected by some specific diseases, such as a series of small strokes damage the brain and cause confusion, speech problems and progressive loss of memory and cognition (Alzheimer's Society, 2006). This gradual decline in cognitive functions causes people to need extra support for daily living. Sufferers may experience mood swings that might be directly affected by their living environments. A person who is having slightly problems with planning, reasoning and also remembering may be classified as having mild cognitive impairment (MCI). On average, approximately 10 to 15% of people living with MCI will develop progressive dementia each year, however, the declining rate in cognitive function varies from different person. The term 'MCI' is mainly used among medical practitioners and social workers to describe people who are experiencing declines in cognitive functioning, but are otherwise non-demented persons. Numerous subtypes of MCI have been identified, such as amnestic MCI, in which impairment due to memory loss and related symptoms is presumed be progressing towards dementia (Petersen, 2004). According to previous studies, the rate of conversion from MCI to dementia varies drastically, ranging from 9.6% within 22 years to 100% within 4.5 years (Elias et al, 2001). Again, people living with MCI show variable capabilities for recovering over time, and such rates of recovery are too different to be predictably quantified. In normal practice, it remains difficult to distinguish between cognitive loss due to ageing, MCI and the early stages of dementia (Graham & Ritchie, 2006).

UNIVERSAL DESIGN

UD (universal design) is classified as the practice of making things in ways that involve almost no extra cost, but offer attractive yet functional styles that are fulfilling all people, regardless of each individual's ability or disability (Mace, 1985). UD addresses the complete span of functionality through making each element and space accessible to its deepest extent by careful

planning at all different stages of a project. UD requires deep consideration of the wide range of changing human abilities in one's lifespan (Mace, 1990). UD plays a major role in improving each individual's potential for achieving a preferred and better quality of living (Russell, 1999). Moreover, UD seeks to reduce the social stigma of human disabilities by giving equal consideration to people with physical disabilities and those who are able-bodied, thereby benefiting the entire society as a whole (Danford & Maurer, 2005). UD reduces the economic burdens of providing services and products, and supports one's effort to be socially engaged. Seeking UD solutions to health concerns is already considered not just as a social responsibility, but also a financial necessity because of the rising costs of healthcare. The seven principles of UD are (1) equitable use, (2) flexibility in use, (3) simple and intuitive use, (4) perceptible information, (5) tolerance for error, (6) low physical effort, (7) size, and space for approach and use (Mace, 1990).

PARTICIPANT OBSERVATION AND DATA COLLECTION

This study is an ethnographic investigation of older adult living alone with MCI in Hong Kong. Rather than quantitative research, an observational study could help investigators learn more about what happens in real life situation through data collection. An interpretive approach is adopted as a research paradigm for understanding the meanings that human beings attach to their experiences (Schutt, 2006). For this study, a centre manager of the well-established Yan Oi Tong Elderly Community Centre recruited three older adults to participate for nine months. These people were living with MCI in a rural district. Prior to this study, these three elders engaged in a participative design workshop that was organized by the same researcher. The workshop had two sessions, and explored the participants' latent needs concerning home decoration and product design for public housing. Observational visits were conducted with each participant every two weeks for a nine-month period. The participants are referred to as CH, CP and SK, and they were aged between 79 and 85 years old. A few other participants agreed to join in this project, but they withdrew after the first meeting, as they felt that the study could be done through talking on the phone.

CH (aged 78) wore a typical uniform of a local domestic maid, which was clean and white. She lived alone and had never married. CH had served as a school janitor at a local primary school near the western district hospital for 38 years. At the age of 62, she had her first retirement, and then she started a new job working with a local teacher, finding a job in her 60s was difficult, especially for people who had little education. When the researcher first met CH in her 280 square foot public housing unit, she asked him to change a florescent tube in her living room that had not functioned for several weeks. She had bought a replacement at a local mini store, and wanted the researcher to install it even before he had a chance to officially introduce himself. Regrettably, the size of tube was not correct, and CH asked the researcher if he could buy a replacement for her on his next visit. She had cancelled a lunch gathering with her close friend to participate the first day of observational research with the re-searcher. CH had two younger brothers, but these

family members did not trust each other due to a dispute over the ownership of property in their hometown. A single tear ran down CH's cheek when she mentioned this situation. She explained that she had successfully applied to live in a subvented elderly care home with the support of YOT, which is one of the largest non-governmental organisations for helping older persons to live in inclusive communities. She had suffered from muscle pain for years, but did not receive good medical treatment in the public sector. After CH had consulted other medical professionals in her hometown, a doctor in the public clinic refused to offer medical advice, as her medical records could not be easily retrieved. Recently, she was diagnosed with a benign tumour, and a few tiny red spots appeared on her abdomen. Her family doctor suggested that she should start medical treatment as soon as possible, as otherwise the disease might spread to other major organs. CH explained that for the last year she had been unable to twist a towel properly, because of periodic shaking in her hands.

CP (aged 85), had been living in a typical public housing unit in Tuen Mun (a rural area in Hong Kong) for the past 35 years, alone. In the 1980s when she moved there, only one bus stop connected the downtown and Tuen Mun district. CP described the housing estate she lived in as designated for poor people, and many older people could be seen there on a typical day. She did not have much education – only one year of general schooling when she was eight years old. She indicated that she no longer had a good memory, and during the past few years the situation had become worse. Quite often, she could not remember the dialogue we had had the day before. She experienced difficulty finding her front door key, even though it was placed on top of the dining table next to her. CP had experienced great difficulties in her life, as her husband had left her in the 1980s. Before she retired, she served as a worker in the garment industry, which was a popular occupation for women during the 1980s. She insisted that her whole life was a tragedy. A few weeks before her first interview with the researcher, a social worker paid her a visit to see if any repairs to her walls and basic facilities were required. CP mentioned that she could not move the loose furniture by herself for the wall repair. Even if she realized that there was a crack in the wall, she had to accept it. She understood that when she died, her flat would immediately return to the Hong Kong Housing Authority. When the researcher asked her to share her happiest moment in life, her immediate response was unexpected - no regular visits from her daughters and sons. In addition, she did not have a religious back-ground, and therefore she had no religious gatherings to attend on typical weekends. No social workers came to visit her unless she asked for assistance through the YOT. CP said that she stayed at home all the time and felt bored. She noticed that her health was getting worse, and her immune system had grown weaker over the past few years. Sometimes she felt sudden dizziness, and it seemed that her legs could not support her body. She was worried about herself, and thought that the nearest community centre could offer her help, as she had been a member of this organization in the past. She attempted to buy a lunch box at the YOT, which cost only eighteen Hong Kong dollars, compared to the usual price of fifty dollars. She explained that when each day was over, another brand-new day came again, and nothing

special happened. Her younger son had died a few years previously, which made her extremely upset, as he was the one who treated her the best in her life. She mentioned again that her life was a tragedy—she was nothing, and she was like a stupid pig! She had learned things in the past, but could not make use of them. She had totally forgotten what she knew before, and described herself as useless. When she forgot to bring along a door key to go downstairs for raw food in the nearby wet market, she had to find her close neighbor, who kept a spare key in case of emergency. One day when she started cooking, she found her key inside the fridge, where she had put it for no reason.

SK (aged 79), was still living with her husband, but her husband had been diagnosed with mania. He had suffered four strokes, and at this point could only lie on a single bed in the living room.SK felt that she had lost her freedom due to taking care of him. She had five children, and was now living in housing under the Home Ownership Scheme –a subsidized sale programme for public housing. SK felt 'grateful' to be entitled to become a player in a YOT-sponsored training group, so that she had a chance to 'play' for free to spend time in the afternoon. She was satisfied with the arrangement, and saw it as an opportunity to mingle with new members. This training series was supported by the Hong Kong Jockey Club, which was a sponsoring organization that had helped co-organize many significant year-long programmes for the elderly, along with the YOT. SK said that several of the game sets offered in this training programme were too simple, yet she still wanted to have a set to play at home. She mentioned that her daughter could not afford to pay her visits on a daily, or even a weekly basis, due to the nature of her work. When she was asked to describe the happiest moment in her life, SK could not come up an answer. She had been a member of the YOT since 2005, and was actively participating in the past, before the situation of her husband's condition got worse. SK did not want to spend the rest of her life just being a care giver for her husband. She re-joined YOT as a member to learn more about the new programmes that she could participate in. The centre manager recommended that she should participate in a mild cognitive training session, which consisted of a variety of games. At the end of the event, a physiotherapist examined her, and diagnosed her as having MCI. Therefore, she began participating in other sponsored training programmes.

DISCUSSION

This investigation identified several themes in the challenges that elderly experienced. Theme 1: Fear of being alone. The participants described their experiences of facing loneliness. Although they felt that their memories were getting worse, they could still express how loneliness was one of the most difficult challenges that they had to face day-by-day. SK said that 'I want to do my preferred activities, and don't want to stay at home all the time!' She remembered that she was a member of the YOT in the 2000s, where she found happiness in group activities and sharing. CP explained that she could 'feel myself getting worse than before and I need to find a way out!' Older people living with MCI require extra support from society. However,

only a very few of them can have regular visits from volunteers. UD principles suggest the need for a novel product device that could help older adults with MCI who live alone. Such a device could help them to remember and to find the motivation to participate social activities on a regular basis. As a good design should communicate necessary information to the end users regardless of their sensory abilities, it should be compatible with a wide variety of techniques for use, and should maximize the legibility of 'perceptible information' for helping people to connect with the outside world.

Theme 2: Recognition of incompetence. The older persons suffering from MCI be-lieved that they were, to varying degrees, incompetent in dealing with day-to-day activities. As CP explained, 'I have become useless and cannot remember things recently…' CH had spent over a thousand Hong Kong dollars to have her door gate opened each time she forgot to bring a key with her. She could not explain why this scenario happened twice, but she had to accept it. When she asked the researcher to change a broken florescent tube, he found that the new tube she had bought a few weeks previously was the wrong size. She felt hapless, as she had to pay for another tube because the package had been opened. Even then, she did not know the exact size she needed until the researcher examined the old tube. UD applications could be adopted in the product development stage so that the specification and the method of operation could involve 'simple and intuitive use', and require only 'low physical effort'. As the majority of older adults do not possess good education, repairing home decorations, appliances and utensils is difficult for them if the instructions are not clearly designed.

Theme 3: Lack of neighbourhood spirit. For older people living alone in public housing, neighbours become the most reliable people after their families. Older participants reported that they commonly displaced their house keys due to their gradual memory loss. They had to make duplicate front door keys, and gave them to neighbours who they trusted. To deal with such problems, a product design or system could be pre-installed in housing facilities that would enable better communication or connection between neighbours, and allow older residents to become closer to others. Close relationships must be built on trust, which takes time to develop. The UD principle of 'flexibility in use' could be widely adopted, as the health conditions of older persons can vary a lot. CP was suffering from glaucoma, andwas waiting for surgery to help her. She was increasingly less capable of carrying heavy things due to a loss of muscle mass. CH had a benign tumour around her abdomen that made her feet less able to function. If better design could provide a new experience for such older persons with cognitive impairment and physical limitations, and help them to build a supported living environment, then the burgeoning costs of healthcare for older people could be reduced. To this end, 'flexibility in use' could serve as a guiding principle for offering a range of methods for use, and to provide adaptability in meeting every user's capabilities. The basic needs of older persons could be met by offering a secured yet port-able networking device that minimizes repetitive action and allows operation with 'low physical effort'.

CONCLUSION

This ethnographic study has investigated the latent, unfulfilled needs of older persons living with MCI. Building rapport with these older participants was an important step at the beginning of the study. This finding of "Fear of being alone", "Lack of neighbourhood spirit" also revealed that regular visits by community centre staff and-local social workers should be organised to provide older community members and stakeholders with more attention regarding their day-to-day activities and their relations to society as a whole in order to eliminate "Recognition of incompetence".

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