Review Article

Utilizing Principles of Universal Design to Support the Development of Rehabilitation Games for People with Dementia Living Alone: A Qualitative Study

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Abstract

The population of Hong Kong will continue to age as life expectancy increases and is projected to rise from 1,065,900 in 2014 to 2,582,300 by 2064 for the population aged sixty-five and over. In 2011, 12.7% of elderly aged sixty-five and above lived alone, constitute a 9.5% increase from 2006.

Dementia is a biomedical disease that involves degeneration and increase in prevalence as the population ages. In 2014, there were about 70,000 elderly living with dementia aged seventy or over in Hong Kong. By 2036, it is estimated that one in three families will have member aged eighty-five or above with dementia. The Principle Investigator (PI) conducted participant observation with two elderly individuals living alone with dementia. They were invited to participate in four games facilitated by trainers in a natural setting. The PI conducted semi-structured interviews to reveal the participants' own interpretation of the games and clustered these observations into categories. A qualitative analysis of behaviours and emotional responses will be conducted as a foundation for future participatory design with care takers, designers and occupational therapists in order to propose a series of experience-based rehabilitation tool for dementia care day centres.

Introduction

A recent report from United Nations (UN) indicated that by 2030, the number of older persons around the world will reach 1.4 billion, and expected to double by 2100, putting pressure on current social protection and health care systems [1]. As the global population aged 60 years and over is growing, population ageing is more pronounced in Hong Kong than in other major Asian cities. By 2024 Hong Kong will be home to 397,000 people over the age of 80, a 24.8% increase from 2014 [2]. 12.7% of people aged 65 and above live alone, constitute a 9.5% increase from 2006 [3]. People living with dementia often feel alone and socially isolated as they are unable to communicate with friends or lose them entirely [4]. People can experience loneliness in various ways that may feel lonely even they have regular contact with family members. Research indicates that 17% of older people have contact with family and neighbours less than once a week. For 11% of older people, contact occurs less than once a month [5]. When people lack social networks, they will experience different levels of social loneliness.

Dementia and the Loneliness

Dementia occurs when the human brain is affected by specific diseases such as Alzheimer Disease (AD) or a series of strokes that cause speech problems, confusion and progressive memory and cognitive loss [6]. It is a degenerative disease that involves loss of abilities over time. This deterioration in cognitive function is not considered as a part of normal ageing. These cognitive impairments are often preceded by a decline in emotional control, motivation and social behaviour. As a result, the gradual decline in function eventually creates the need for extra support in daily life. People living with dementia can experience mood changes that can be influenced by surroundings. About 10-15% of people will gradually develop dementia each year at a different rate of cognitive decline that varies from each person. People with dementia who are living alone are at a greater risk of loneliness than those who are living in residential care homes or with family members. Reports from the government of Hong Kong have shown that the proportion of elderly living alone increased from 11.3% (2001) to 12.7% (2011) [3]. Social engagement tools such as cognitive game sets can foster more tangible contact to overcome social isolation, and to improve the quality of life of dementia sufferers. There is a clear societal need for serious game designers to seek to stimulate social interaction through participant observation and make use of probes in natural settings with different stakeholders [7]. Meaningful activities and games can help them improve the sense of accomplishment and self-expression to reduce boredom and loneliness.

No doubt, the prevalence of dementia will continue to rise as the global population ages. The Aging, Demographics and Memory Study in the United States reported that 13.9% of people aged 71 and over had been living with dementia [8]. A research report conducted by the World Health Organization (2012) [9] revealed that 35.6 million people suffer from dementia globally. This figure is expected to double by 2030 and triple by 2050. People living with dementia tend to be lonelier than the rest of the population. A British survey stated that more than half of people living with dementia feel lonely some of the time [4]. They may have received few support services and social contacts. Another study suggested that people with Alzheimer's disease experience at least twice the level of loneliness than the rest of the elderly population [10]. People living with dementia might have visits from friends, relatives and family members, but they might not remember their faces as well as recognize them. Hence, social contact is not effectively established at all. The needs for social researchers to explore potential product designs, interiors and training games that can effectively lower the rate of cognitive decline become crucial. A public survey in UK shown that 35% of people do not feel comfortable conversing with dementia sufferer [11]. The situation needs to be addressed by raising public awareness of dementia and the ways to communicate with dementia sufferers through day-to-day activities. When dementia sufferers lose confidence, their motivation is affected and thus reduces their possible interactions further. They may feel confused and worry about getting lost, affecting their abilities to fully participate in the community. More than 50% of respondents to the UK study indicated that there is a lack of appropriate activities designed for people with dementia to enhance their social inclusion [11]. Possible ways to alleviate loneliness include regular conversation with people, meeting visitors including friends and relatives, and attending dementia-friendly day centres in a regular basis. In this case, a series of game sets designed as a rehabilitation tool for people living with dementia who are living alone could provide social interaction, and reduce social stigma. Lacking social support can prevent dementia sufferers from taking part in regular activities that can affect the rate of cognitive decline.

The Problem

Cognitive rehabilitation tools such as game sets are rare in domestic market. They have either designed in relatively poor quality due to printing cost or are too general, lacking a progressive training focus. They are not readily available in local department stores or entertainment centres. Rather, they are often found as custom-designed training tools in dementia-friendly elderly centres by social workers and occupational therapists. Today, there is a proliferation of cognitive training and those related exercises for people living with dementia, but serious games in this field are still yet to be developed. If the game sets are not sufficiently legible and the force required to operate them is beyond the ability of dementia sufferers, they can be classified as less effective. Cognitive game sets do lower the rate of cognitive decline. The best game sets offer a corresponding training focus on visual and spatial reasoning, language ability, calculation and memory. The design of games that fail to deliver benefits in these training areas can make players feel confused and antipathetic to play.

Universal Design

Universal Design (UD) addresses the full scope of functionality by making all spaces and elements accessible to the greatest extent through thorough planning and design at all different project stages. In addition, it requires a deeper consideration and understanding of an extensive range of human abilities throughout one's lifespan [12]. UD involves building at little or no extra cost while maintaining a functional, yet attractive style satisfying all kind of people, regardless of ability or disability [13]. UD plays a key role in enhancing the potential to develop a better quality of life for a wide range of individuals [14]. It shapes different products, places and systems to reduce the need for additional accommodations and many expensive assistive devices so as to improve users' overall well-being. Apart from that, it also reduces stigma by putting people with disabilities on an equal playing field with the able-bodied population, benefiting society as a whole [15]. UD is a concept that emphasises accessibility, adaptability, aesthetics and affordability [16]. It supports people's efforts to be self-reliant and socially engaged. It also lowers the economic burden created by services and products that must be specially designed to assist individuals, and helps to solve social problems in which usability; health and social participation play a major role in design response. The successful integration of universally usable features into products and environments has the potential to render the elderly indistinguishable from their younger counterparts [17]. UD is less about style and more a method of design that focuses on different ages, sizes, mental and physical abilities. Seeking UD solutions to health issues is already become both a social responsibility and a financial necessity due to burgeoning cost of healthcare. The seven principles of UD adopted during the design process in the later stages of research are as follows: (1) equitable use, (2) flexibility in use, (3) simple and intuitive use, (4) perceptible information, (5) tolerance of error, (6) low physical effort, (7) size and space for approach and use [18].

The present study is a qualitative examination of the dementia-suffering elderly who live alone in Hong Kong. It uses an interpretive approach as a research paradigm to understand the meanings that humans attach to their experiences [19]. The research paradigm involves an empathetic understanding of participants' daily lives, routines and problematic events in a natural setting. An inductive reasoning approach is used to observe the behaviour of people living alone with dementia in Hong Kong under a cross-sectional rather than longitudinal timeframe. The highly informative transcribed data were anonymised to protect the privacy of each patient. In this study, a local visual communication design agency commissioned the redevelopment and proposal of a new design direction to enhance the current cognitive game sets for local dementia patients at the Christian Family Service Centre (CFSC) in Hong Kong. This involved purposive sampling, as the participants were referred by the CFSC, which had been participating in the training centre for more than one month.

Participant Observation

The research paradigm of the present study involves an empathetic understanding of participants' daily routine lives and problematic events in a natural setting under a cross-sectional timeframe. It is a qualitative examination of the dementia-suffering elderly who live alone in Hong Kong by using an interpretive approach to understand the meanings that humans attach to their experiences [19]. The highly informative transcribed data were anonymised to protect the privacy of each single patient. In this study, a local graphic design agency commissioned the redevelopment and proposal of a new

design direction to enhance the current cognitive game sets for local dementia patients at Christian Family Service Centre (CFSC) in Hong Kong. All participants were referred by the CFSC, which had been participating in the training centre for more than one month.

The first subject, LY (aged 82), retired in 1996 and had been living alone in Hong Kong since his family moved to the United States several years ago. According to Danny, the CFSC's manager, LY's Mini-Mental State Exam (MMSE) score was 23, below the normal cognitive function of 27-30. First, LY was asked to match geometrical graphics (shown on paper) with multi-coloured plastic pieces to test visual and spatial reasoning and attention span. On his first attempt, he tried and failed to grasp a single piece. The material's thickness made it difficult for LY. After a few attempts, he switched to other methods by moving the targeted piece to the edge of the long table using his right middle finger or sweeping it with two fingers to his left palm, attempting to match it again with the outline (shown on paper). It took LY a few minutes to grasp two tangram pieces. The research team recorded each of his gestures and movements, including his shaking hands during the research. Turning a single piece of triangular tangram was particularly difficult for LY, and became a major barrier for him even when he was assisted by a facilitator. The facilitator introduced the guidelines at the beginning of the game, and then verbally encouraged LY to try different directions, ultimately physically guiding his hand to finish the task after a few failed attempts. He chose the correct colour quite frequently, but still struggled with the directions to match the appropriate location. Unfortunately, he could not complete the game on his own within the allowed time given (Figure 1).

The second game entitled 'Putting Things Back Where They Belong' was recommended by the centre manager who had been caring for LY for almost two months. He would propose the most effective and appropriate games to train each patient. The rehabilitation game mentioned is designed to let players locate daily objects such as cooking oil, utensils and kitchenware and return them to their corresponding areas in a logical fashion. The main objectives of the game are to test the participant's speech and ability to identify day-to-day objects. While relatively straightforward for a person with normal cognitive ability, the game required plenty of effort for LY to complete. The centre manager proposed this serious game for LY to build his corresponding abilities because he did not

obtain satisfactory results in MMSE. He was asked to select a photo of an object, for instance a teapot and put it on top of the laminated photo of the environment in large landscape format. Each photo was approximately half the thickness of a typical business card but not rigid. Unfortunately, the flat surface of the photos proved difficult for him to pick up, and it took him two and sometimes three attempts to complete each match (Figure 2).

The readability of the environment photo was also poor because the laminated surface caused reflection, obscuring visibility. Attempts to navigate using a finger on top of the laminated photo was unsuccessful, as the photo were predominantly designed to be fixed with four coin-shaped magnets arranged at four corners. LY reported that he could not recognize a few of the photos due to their low resolution and unrealistic size. More importantly, the inconsistencies in the perspectives applied in both of the photo groups complicated the gameplay. LY struggled to match the exact locations, and the design did not provide him with a clear explanation. No doubt, it was not a suitable game set for people with dementia live alone. Gameplay should be well-defined and speak for itself. Due to the improper visual presentation, LY put the photo of the 'cooking pan' on the correct 'environment', but incorrectly placed the 'kettle' right below the 'cooking pan'. Direct observation did not reveal whether LY intended to put the paper 'kettle' back to the base cabinet, or whether the placement was the result of the cooking area shown in the photo being fully 'occupied'.

LH, an 86-year-old woman with dementia who lives alone, is usually visited by her daughter two to three times a week after work. The facilitator tried to engage LH using a game-based rehabilitation tool and made use of the hierarchy of the animal kingdom: 'Lion' killed 'Tiger', 'Tiger' killed 'Leopard' and 'Leopard' killed 'Cat' and so on. The series game was designed to train the memory and language skills of dementia patient who was not good at these cognitive areas. First, the facilitator spent a few minutes repeatedly explaining the game rules to LH, including the different levels of play. She admitted to the facilitator that she only partially understood the rules. The facilitator began the first level of play by telling a story about a local zoo in Hong Kong to build rapport (Figure 3). He then selected a picture of a 'lion' with the Chinese title in the upper right corner and asked LH to choose a picture from the pool to match it. LH noted that the pictures were quite similar, and she was able to correctly identify

Figure 1: Participant observation during regular training with LY and the centre staff.

Figure 2: LY engaged in the existing serious game set 'Putting Back Where They Belong'.

Figure 3: LY engaged in the given game set without fully understood the rules.

matches only because she understood the Chinese titles imprinted on the playing cards. To LH, the animals' colours and sizes were similar because the printed graphics were not to scale. The next animal card chosen by the facilitator depicted a 'cat', and LH successfully found a match because she was familiar with the animal. The third one was a 'leopard', which LH had never seen before. Thus she did not understand or recognize the complicated Chinese title. The facilitator tried to describe the animal's size and even the sound it made, but LY could not find a match at all. During the second level of play, LH was told to place the animals in sequential order based on size ('Rat', 'Cat', 'Fox' and 'Lion'), assisted by the facilitator. Before LY made her choice, the facilitator deliberately distracted her with conversation. Unfortunately, LH failed to complete the game independently; instead, she had to rely on the facilitator's verbal cues to complete her task.

Semi-Structured Interview

The semi-structured interviews were conducted during breaks from the games, to understand the human experiences in a natural setting which lasted 20 minutes. Each interview was recorded and transcribed, supplemented by field notes. In-depth interviews with the CSFC manager and care-givers will be included in the second stage of research to be reported separately.

I : *Nice to meet you, Lung-Yum. How do you find the tangram game?*

LY : *Good… I feel good… a bit difficult… quite good… I'm tired.*

I : *Is it fun?*

LY : *Yes… um…*

I : *Do you still remember how to play the game 'Putting Things Back Where They Belong'?*

LY : *Not sure…*

I : *Do you want to play again?*

LY : *Um… no… I'm tired (he drinks water).*

I : *How old are you, Lung-Yum?*

LY : *I'm 82… I worked in San Francisco… 40 years ago… many years… do you know San Francisco? United States…*

San Francisco in United States… My family is living there…   (right hand is shaking) San Francisco… I worked in San Francisco… in San Francisco… for years… do you want some water?

I : *Will someone bring you home after training today?*

LY : *Yes… sometimes (I have seen a Filipino caretaker sitting outside).*

I : *Thank you LY, I will meet you again next month. Good day, LH?*

LH : *Yes, how are you, sir?*

I : *I'm good. Thank you. Do you enjoy playing the card game 'Animal Kingdom' with the centre staff?*

LH : *Yes! I like to play games! I like to play card games!*

I : *Will you play card games with your friends?*

LH : *No… they sometimes called me idiot… I feel sad. I am idiot! They are not kind! What time is it now?*

I : *4:30 pm. We are now having a tea break after playing the games. During the break, you are being interviewed by me.*

LH : *My daughter… my daughter will prepare a dinner with me tonight… it will be a late dinner. She is in Hong Kong now…*

I : *How often will your daughter come to see you?*

LH : *When she does not need to work overtime, she will come… she will call me.*

I : *How do you find 'Animal Kingdom'? Is it easy to play and understand?*

LH : *I cannot read it clearly… I am useless… I am not educated… like an idiot!*

I : *You have just finished two games, one is 'Animal Kingdom' and the other is 'Matching Game'. Which one is better?*

LH : *They are all good! I want to play again! What time is it now?*

I : *We are about to finish and thank you for your time and see you next month.*

Discussion

The findings of this study were recorded to discuss whether the developers should utilize principles of universal design to support the development of rehabilitation games for people with dementia living alone. First, there was a general lack of concern about 'physical effort' in the existing product design. LY repeatedly tried and failed to grasp the single piece of triangular tangram and eventually, chose another triangular piece next to it. This might have affected his preference, influencing the effectiveness of entire rehabilitation game. After several attempts, he tried to guide the target piece with his right middle finger to the corner edge near himself and use his left hand to finish the task, taking additional time to finish a simple step. He lost the desire to play with the facilitator and ultimately became frustrated. The Principal Investigator (PI) has suggested that the tangram pieces should be made thicker to satisfy these ergonomic considerations, leaving the player free to experience the game in terms of cognitive

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focus thanks to the benefits of universal design. The combination of current designs in the training kit seemingly failed in this regard.

Second, the game sets did not satisfy the concept of 'perceptible information'. 'Putting Things Back Where They Belong' could potentially be substantially redeveloped into a meaningful game set free from the existing drawbacks, such as the unrealistic sizes of the detachable pieces (for instance a classic 'kettle' appears larger than two pieces of 'watermelon'). LY also did not recognize the differences between a bottle of 'cooking oil' and a one-litre bottle of 'orange juice'. This confusion seriously affected LY's decisions when choosing and placing items. The game set was also made with inferior paper. Creases were visible all over the surface that further affecting the effectiveness. High gloss surface lamination created reflection that made reading difficult. Product design that can achieve the concept of perceptible information should provide enough correct information so that users can make effective and efficient use of the products. Even when users have low sensory abilities, they should be able to understand and perform tasks appropriate for their cognitive abilities. Finally, one of the game sets did not fulfill the 'simple and intuitive use' requirement. A game should be easy to understand, regardless of player's education level, language skills or knowledge. Even if one has had no experience with the product, he or she should still be able to intuitively use it correctly. 'Animal Kingdom' failed to achieve this requirement because its rules violated common sense. Why does the 'fox' kill the 'cat' instead of the 'dog'? What about the 'elephant'? It is the biggest animal, but can be killed by the 'lion' – why? The facilitator did not provide a detailed explanation, and thus the game's rules were vague, which may have reduced its appropriateness. Many existing game sets found in dementia-friendly elderly centres are designed for play between a group of patients, usually facilitated by a staff member, but dementia sufferers who live alone need to be able to play alone, although they can play the games with visitors. Every detail should be considered: (1) the size of the playing board, (2) the number of pieces, (3) the design of the storage case and (4) the time spent to repack all the pieces. Game sets should ideally fulfill the seven principles of universal design to the greatest degree possible. Simple with clear instructions would help dementia sufferers to play alone in the early stages of cognitive impairment.

Conclusion

This study revealed that many of the game sets used in traditional elderly day-care dementia-friendly centres in Hong Kong do not satisfy the needs for cognitive training because they have not considered universal design during the development process. Gameplay should be well developed and facilitated by a trained staff. Even though there is proliferation of cognitive training games developed by occupational therapists, there is a lack of qualitative studies on whether elderly dementia sufferers who live alone can play effectively with those game sets. Because the study was conducted in one elderly centre with a dementia focus, its findings may not be representative of other local elderly centres. Participant observation and semi-structured interviews were used to enhance the accuracy of the results. Further semi-structured interviews will be conducted with the CSFC's manager and one care-giver to reveal concerns about caring for elderly dementia sufferers during day-to-day activities. The findings will appear in a future paper. It is necessary to raise public awareness of the importance of applying universal design principles to cognitive gameplay as a rehabilitation tool for elderly with dementia live alone. The findings of this research will help to improve their participation in gameplay by improving the design of current play tools. The PI intends to promote dementia-friendly products and environments that enhance the meaningfulness of daily life and reduce social stigma.

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