

Background

(1) Ageing population in Hong Kong

- The number of people who are 65 years old or above is around 1,099,200 in 2014 which take 14.9% of total population.
- Rapid ageing population will occur due to the baby boom in 1950-60s. It estimates from 13.7% in 2012 to 30.2% in 2041 of the total population (Census and Statistic Department, 2014).

(2) Prevalence of dementia

- Dementia is strongly related to the increasing of age 
- The prevalence of dementia is increased from 6.1% in 1998 to 9.3% in 2008 of the elderly with 70 years old or above. Estimated 10% of older adults' population (110,000 people), regarding 1.2% among those aged 60 to 64 to 32.1% among those aged 85 and above
- (Chiu et al., 1998; Lam et al., 2008; Woo, Ho, Lau, & Yuen, 1994).

Background

(3) High institutional rate in Hong Kong

- One of the **most high institutionalization rate** countries.

Hong Kong	United Kingdom	United States	Japan	Singapore
6.8%	4.2%	3.9%	3.0%	2.3%

- Dementia is **one of the most common reasons** for applying residential care homes (Van Rensbergen & Nawrot, 2010) and **more than half of the residents** are living with dementia in local residential care homes (Corcoran, Hui, & Woo, 2003; Lee, Hui, Kng, & Auyeung, 2013; Leung et al., 2013).

(4) The predicament of caring people with dementia

- Looking after the residents with dementia are treated as **emotionally and physically draining** (Morgan, Stewart, D'arcy, Forbes, & Lawson, 2005; Zimmerman et al., 2005).
- Aggressive behavior and behavioral and psychological symptoms of dementia the complication of care  (Brodaty, Draper, & Low, 2003).

Background

(5) Negative stereotyping

- Latin as “De” and “Ment” “Without” and “Mind” or “madness”
(Trachtenberg & Trojanowski, 2008). Chinese translation very negative connotation

	Hong Kong	Singapore, Macau & Taiwan	China	Japan	South Korea
Old translation	Chi Dai Zheng (癡呆症)	Chi Dai Zheng (癡呆症)	Chi Dai Zheng (癡呆症)	Chiho (癡呆)	Chi-Mae (癡呆症)
New translation	“Ren Zhi Zhang Ai Zheng” (認知障礙症)	Shi Zhi Zheng (失智症)	Chi Dai Zheng (癡呆症)	Ninchi-Sho (認知症)	Chi-Mae (癡呆症)

- The above term leads to the perception of people with dementia as “total loss of self” or “living death” and “social death” (Chiu & Li, 2012; Chiu et al., 2014).

(6) Medical dominance

- Psychiatric illness/abnormality focuses on signs and symptoms.
- Known as “the confused” and “dementia suffers” through the medical knowledge of interpretations (Cheston & Bender, 1999; Jacques, 1992; Meacher, 1972).

Background

(7) Ignorance of subjective views

- The **professional-driven of care** somehow ignore the voice and subjective views of people with dementia (Brooker, 2007 ; Chiu & Li, 2012; Chiu et al., 2014; Dewing, 2008; Kitwood, 1997).
- **Very limited researches** of the subjective views of people with dementia and the interpretation of self in HK (Chung, 2000; 2006).

(8) The significant of humanistic care

- Subjective views promotes humanistic care and addresses the **person-centered based** concerns.
- To preserve the basic **human rights and dignity** of people with dementia. Taking their considerations into the clinical practice.

(Brooker, 2004; Caddell & Clare, 2010; Clare, 2003; Dewing, 2008; Kelly, 2007, 2010; Kitwood, 1997; Naue, 2008; Naue & Kroll, 2009; Phinney, 2008; Sabat and Harre, 1992)

Purpose of this research

- Adopting a **humanistic approach** and to **go beyond the dominance of medical approaches** to enlarge the perspective of professions.
- To explore the **self-perception** of people with dementia who live in the residential care home and their **subjective interpretations of self**.

Interest on:

- 1) How people with dementia perceive themselves;
- 2) How the caring staff perceive people with dementia;
- 3) How the interactions between people with dementia and the caring staff in the residential care homes co-constructed the interpretations;
- 4) The self-perception of people with dementia and
- 5) The impact of caring staff after being informed the self-perception of residents

Significance of this research

- ✓ To find out the process of self-perception and the interpretations of “self” among the interactions, with **an aim to bring humanity and humanistic care to people with dementia in the residential care homes** (Brooker, 2004; Blumer, 1969; Clare, 2003; Dewing, 2008; Kelly, 2007; Kitwood, 1997).

Knowledge

- ✓ **To enrich the caring perspectives and multi-dimensional understanding of people with dementia.**

(Leung et al., 2013; Lai & Chung, 2007; Woo, Mak, Cheng & Choy, 2011; Yan, Ho, Kwok, & Tang, 2007)

Clinical practice

- ✓ **To bring another angle to design and review the services benefit to both people with dementia and the caring staff.**

(Cohen-Mansfield, Parpura-Gill, & Golander, 2006; Head, Portnoy, & Woods, 1990; Romero & Wenz, 2001)

Research development

- ✓ **To support and fill up the research gap among the existing quantitative studies in dementia care**
- ✓ **To encourage the active involvement and participation of people with dementia in the researches**

(Ikels, 2002; Mok et al., 2007; Chung & Man, 2009)

(Clare, 2002; 2003; Clare, Marková, Verhey, & Kenny, 2005; Hughes, 2011; Pearce, Clare, & Pistrang, 2002; Roberts, & Clare, 2013)

Reviews of key concept

Self-perception

- “The individual experiences himself as such, not directly, but only indirectly . . . from the generalized standpoint of the social group as a whole to which he belongs” (Mead, 1934, p. 138)
- Self-perception understanding the perceptions of others & the perceptions of self (Bem, 1967; Cooley 1902; Lewis & Brooks-Gunn, 1979; Mead, 1934).
- According to Bem’s (1972) self-perception theory, the individuals come to “know” their own attitude, emotions and other internal states partially by inferring them from observations of their own overt behavior and/or the circumstance in which their behavior occurs.
- It is the way we perceive ourselves should correspond closely with the way we are perceived by others (John & Robins, 1994).

How self-perception of people with dementia is formed and how understanding the self-perception of people with dementia can bring impacts to the caring staff in the residential care homes in Hong Kong?

Research Design

In this research, it contains three main parts and tasks.

Part I

- **Observations and interviews in the residential care homes**
- People with dementia (8-10 interviewees)
- The caring staff (8-10 interviewees)

Total: 16-20
participants

Part II

- **One sharing session (Sharing about the self-perception of people with dementia)**
- 15 or above participants mainly Personal Care Workers or Health Care Workers (Each C&A home)

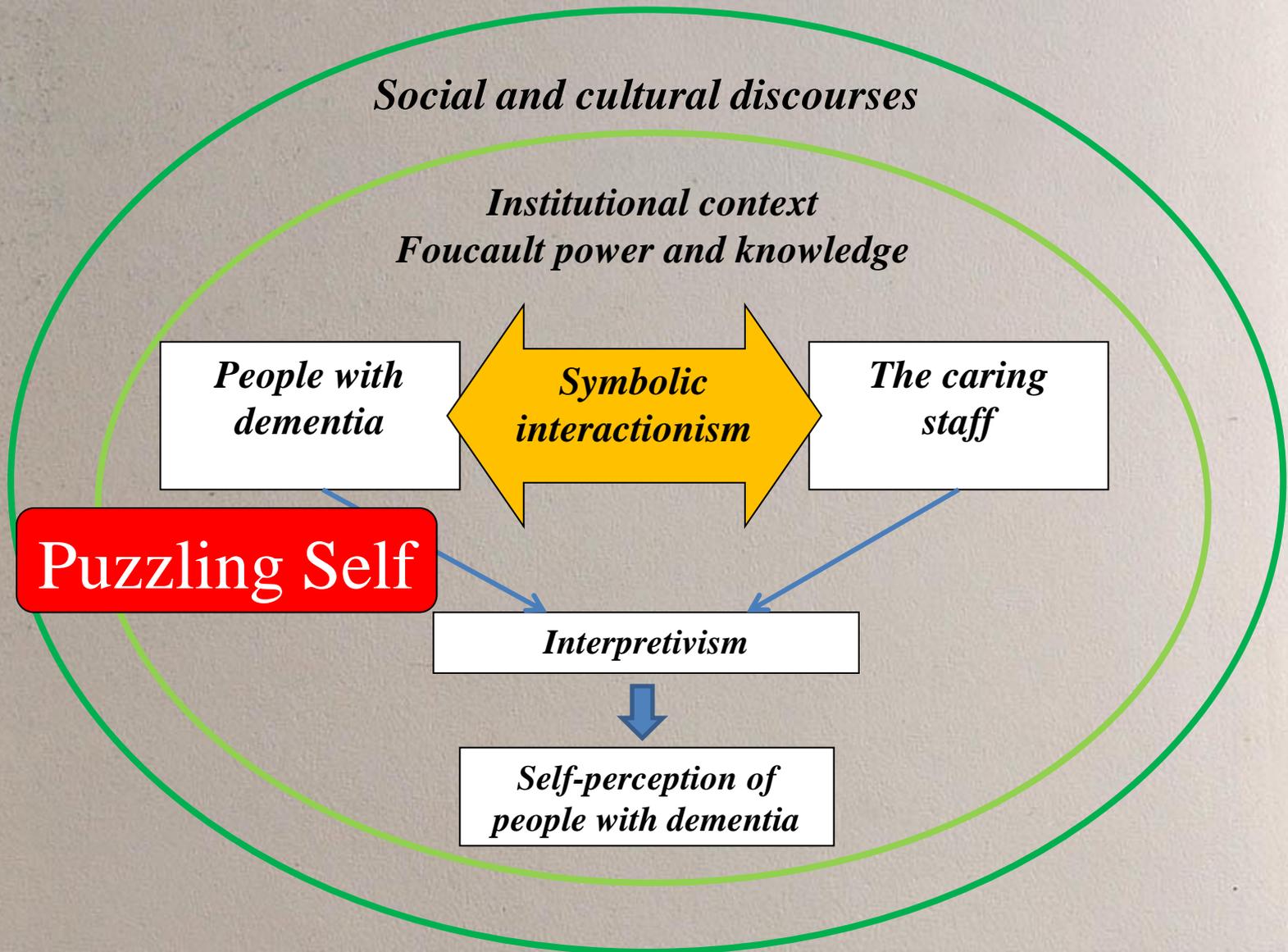
Total: 30
participants

Part III

- **One focus group (Collect feedback and explore impact)**
- 6-8 participants who had taken part in the sharing session and all of them should be PCWs or HCWs (Each C&A home)

Total: 12-16
participants

Graph of theoretical foundations

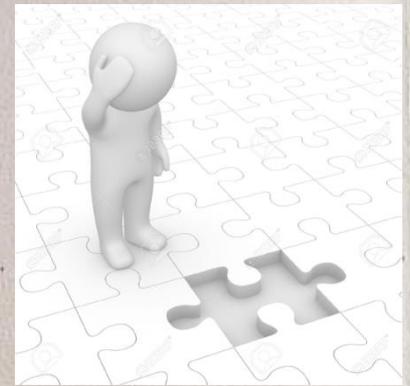


Highlighted Findings

➤ Missing pieces

- Some of the parts are omitted due to the memory loss and hence, to find it difficult to figure out the whole picture.

" I do not know why I am here and how to be arranged to the residential care home....I just cannot remember the recent events.....However, I can sure that there is something happened to me so that I am living here now... Where am I? why my family members leave me here and where they are now???"

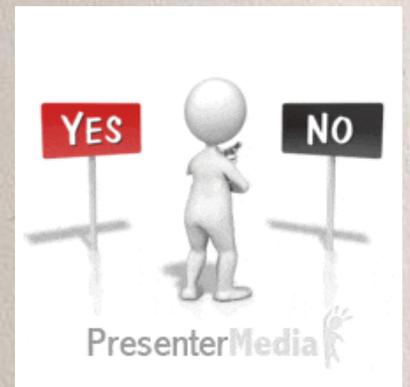


➤ Contradiction of information

- The inconsistency of present and past (Error of verification)
- Historical VS Existing memory (Achievement and failure)

" My son bought this unit to me and I just come back to here... I am just living here for several months but they said that I have lived for several years.....I just feel strange to them...."

" My company arrange me to come for working but I do not know why nothing is arranged for me to do and I feel loss...."



Highlighted Findings

➤ Discrepancy of abilities, capability or mood

- Other perceived reality VS Self-perceived reality
- The different understanding towards the matters

" You can see that I am physically health and I can take care of myself. It is impossible for me to have dementia... The staff keep saying that I cannot do the caring tasks, I do not agree with them and I refuse letting them help..."



➤ Uncertainty and suspect to the others

- Unpredictable experience and no regular engagement
- Telling lies to the people with dementia with their own purposes

" No one will tell me what to do and what I can do here.... Suddenly tell me to go there and suddenly will ask me to do that....I am in choas (mo cha cha) and I am not ready....."

" The staff warn me that I have to eat faster and there will be a wedding party to launch here....but it is not....Indeed, they would like to tidy up earlier and make some time to take a break..."



Highlighted Findings

➤ Referencing with the other residents

- Comparing with the other residents in the residential home in order to perceive their own conditions and self.

" I know that I do not have dementia. As you can see there is a lady walking around here and she always take care of the baby doll, she must be dementia. The baby is fake and she just treated it as real.....I will not do so.....She is typically dementia which I know that I am not....."

➤ No connection to the environment and lack of choice

➤ Not being respect and ignorance of my needs

➤ Disengagement of relationship and trust

Puzzling Self

External elements/ factors



Internal elements/ factors

Coming up and ongoing work

- The perception of caring staff to people with dementia in the residential care home
- How do the interaction and communication affect the change of self-perception of people with dementia
- Training package of non-professional staff related to self-perception
- The impact of the training

