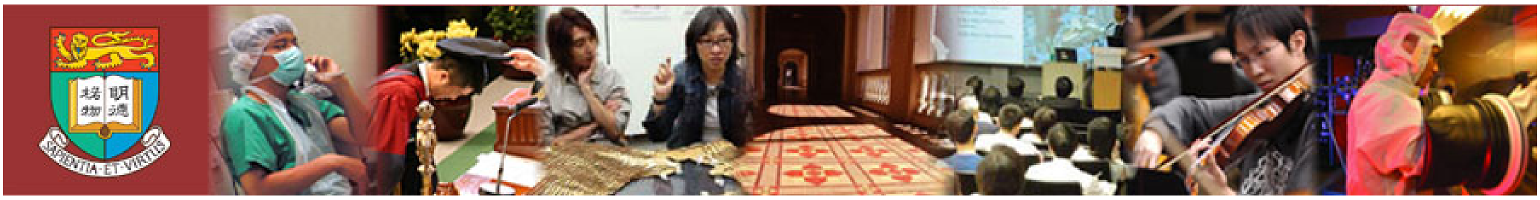

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Person-centred care for demented older adults: a qualitative analysis

VWQ Lou *, GKC Law, XB Zhong

KEY MESSAGES

1. There was a lack of consensus among formal caregivers about the concept of person-centred care (PCC).
2. Formal caregivers associated PCC with positive and empathic feelings, and believed it to be in line with their professional ethics, principles, and organisational vision, mission, and values. However, ambivalent feelings were recorded when formal caregivers encountered difficulties in practising PCC. Formal caregivers reported good practices in providing daily care that aligned with PCC principles, but also admitted practices involving objectification.
3. Family caregivers and older adults with mild cognitive impairment (MCI) were unfamiliar with PCC, linking it to professional intervention. They were ambivalent about PCC, reporting feelings ranging from respect to helplessness. Family caregivers not only demonstrated elevated tendencies to infantilise older adults with MCI, but also proactively communicated with formal caregivers to achieve personalised care.
4. There should be a thorough discussion about quality dementia care standards in Hong Kong. Dementia care practices must be consolidated with reference to evidence-based interventions. Environmental context should be reviewed to identify barriers to quality care for older adults with dementia. Family caregivers and older adults with dementia should engage in the process of developing dementia care policies and practice guidelines.

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Introduction

The prevalence of dementia among older adults in Hong Kong has rapidly increased, with 110 000 cases in 2010 and an estimated 280 000 cases by 2036. Policymakers should adopt a scientific and efficient care model that ensures adequate quality of care for elderly individuals with dementia. Person-centred care (PCC) was developed to meet the need for patient-oriented healthcare services, based on understanding of patient circumstances and needs.[1] When caregivers apply PCC, the use of antipsychotic drugs in people with dementia is reduced as is the agitated behaviours.[2] PCC has been adopted as a standard for dementia care management in the United Kingdom, Canada, and Australia. As such, PCC is considered synonymous with good quality care for dementia patients.

This study aimed to better understand Hong Kong long-term care organisation stakeholders' attitudes towards PCC for older adults with dementia by assessing their (1) perceptions, (2) affection, and (3) practice of PCC for demented older adults, and (4) the implications for quality dementia care standards in Hong Kong.

Theoretical framework

A tripartite model of attitudes was used. This model conceptualises attitudes according to affective, behavioural, and cognitive components.[3] It is a classic theoretical approach of conceptualising attitudes. We also applied Brooker's PCC=V+I+P+S model to examine attitudes towards PCC.[4] The VIPS model has its roots in Kitwood's argument of PCC and comprises four elements: (1) V for valuing people with dementia and those who care for them, (2) I for treating people as individuals, (3) P for looking at the world from the perspective of the person with dementia, and (4) S for a positive social environment in which the person living with dementia can experience relative well-being.[4] The VIPS model has been applied to design training programmes for PCC planning and practice guidelines.[5] The present study integrated the tripartite model of attitudes and the VIPS model to investigate Hong Kong long-term care organisation stakeholders' attitudes towards PCC for older adults with dementia (Fig).

Methods

This study was conducted from October 2011 to September 2012. Qualitative research methods (focus groups and in-depth interviews) were used. Participants were recruited using purposeful sampling methods from non-governmental organisations that provide services for older adults with dementia. After obtaining informed consent, a total of 53 participants were recruited to eight focus groups and eight in-depth interviews among four groups of stakeholders (older adults with mild cognitive impairment [MCI], family caregivers, healthcare workers, and healthcare professionals). After extensive discussion between researchers, guidelines for focus groups and in-depth interviews were developed, and pilot tests were conducted.

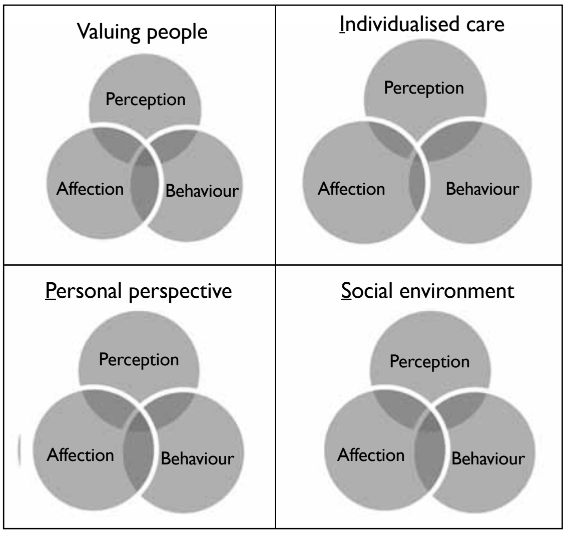

FIG. Theoretical framework

Results

The older adults with MCI (n=13) who participated in a focus group were over 70 years old and mainly female (n=11); most of them widowed (n=11) and living alone (n=7).

The family caregivers (n=16) who participated in a focus group were mainly female (n=10) and the care recipients' spouse (n=10); most had provided care for <10 years (n=14) and approximately 33% relied on the Comprehensive Social Security Assistance Scheme (n=6). The degree of social services usage varied: one carer reported never using them and three reported relying on them for 6 to 10 years; 15 reported that that the current level of social services available for older adults with dementia was insufficient.

The healthcare workers and professional staff (n=24) who participated in a focus group were mainly female (n=20) with a professional background of social work (n=6), nursing (n=3), occupational therapy (n=2), or physiotherapy (n=1).

Those who attended an in-depth interview (n=9) were female and served as unit heads (n=4), supervisors (n=3), or service managers (n=2) in residential and day- and home-care settings.

The Table summarises the major themes of formal caregivers, older adults with MCI, and family caregivers.

Perceptions of PCC

Perceptions of PCC differed between formal

TABLE. Attitudes towards person-centred care (PCC) in formal caregivers and older adults with mild cognitive impairment and family caregivers

VIPS model	**Tripartite model of attitudes (perceptions, affection, and practice of person-centred care**	
	Formal caregivers	**Older adults with mild cognitive impairment and family caregivers**
Valuing people	- Respect dignity is the core (perceptions) - Positive, agreeable and sympathetic (affection) - Showing courtesy and respect vs objectification, disempowerment, and infantilisation (practice)	- Unable to articulate but positive (perceptions) - Unfamiliar (affection) - Tendency to infantilisation, and high expectations of early, targeted interventions from professionals (practice)
Individualised care	- In line with holistic care approach (perceptions) - Positive and useful vs. frustration (affection) - Developing and implementing individual care plan according to comprehensive personal background information and continuous assessment (practice)	- Sensible and flexible to individual needs in cognitive training and self-care competence enhancement (perceptions) - Disappointed, impossible, and helpless (affection) - Higher expectations of cognitive/well-being interventions by professional staff (practice)
Personal perspective	- As a pathway of designing and implementing individual care plan (perceptions) - Empathy vs frustration (affection) - Comprehensive assessment, communication, and continuous observation (practice)	- Dependent on manpower and setting (perceptions) - Proactive is better (affection) - Professional knowledge and skills help (practice)
Social environment	- Help to improve patients' quality of life and as a facilitator to enforce PCC (perceptions) - Encouraging vs powerlessness (affection) - Safe and easy physical environment, positive and supportive social environment, including a variety of dementia intervention projects and activities (practice)	- Continuum of care and affordability are core (perceptions) - Ambivalent (affection) - Opt for subvented services even through it might lack manpower since self-financed services are unaffordable (practice)

caregivers and older adults with dementia and family caregivers. In general, formal caregivers recognised that PCC was concordant with their professional ethics and values, a holistic approach to individualised care that respected the dignity of older adults (by taking a personal perspective), and their principles of service delivery (but hindered by practical barriers). In contrast, older adults with MCI and family caregivers reported that they were largely unfamiliar with PCC; they were unable to articulate PCC values and principles, and only evidenced recognition of individualised care tailored to individual older adults with dementia.

Affection for PCC

Formal caregivers shared positive and affirmative affection for PCC, whereas family caregivers and older adults with MCI expressed ambivalent feelings. In general, formal caregivers affiliated PCC with positive affection; either because the values and principles of PCC were aligned with their personal values or passions, or because they expressed compassion related to the opportunity to take care of such older adults. Nonetheless, formal caregivers did feel frustrated about the environmental constraints associated with the institutional or organisational establishment. In contrast, older adults with MCI and family caregivers were disappointed with current practices of individualised care and ambivalence towards the social environment.

Practice of PCC

Formal caregivers demonstrated practices that aligned with PCC principles and guidelines, whereas family caregivers and older adults with MCI expected professional care to be available to serve this purpose. Good practices of formal caregivers included showing courtesy and respect to older adults with dementia; recognising and facilitating older adults with dementia in order to maximise their freedom; developing individualised care plans according to comprehensive assessments; and considering personal background in the process of developing and implementing care plans. Nonetheless, formal caregivers also reported that they observed instances of objectification, disempowerment, and infantilisation in daily practice, which were mainly attributed to limited resources. Family caregivers intended to infantilise older adults with dementia who deserved 'education' by people outside of family. In addition, family caregivers and older adults with dementia expressed high expectations of professionals' capability to provide targeted and effective interventions to enhance cognitive abilities and well-being (rather than only providing daily care).

Discussion

Hong Kong long-term care organisation stakeholders' attitudes towards PCC for older adults with dementia were diverse in some ways and convergent in others. Hong Kong lacks a framework for dementia care policies and guidelines. Formal caregivers offer care based on professional ethics and guidelines, whereas family caregivers and older adults with MCI lack a reference point from which to evaluate received services. PCC aligns with patient-centred care, holistic care, and person-centred methods in medical and social work professions; formal caregivers are more likely to practice their own forms of care and emphasise different components. Attitudes towards PCC held by family caregivers and older adults with dementia reflect an authority-dependent view.

Four implications can be drawn based on the findings. First, PCC was agreed upon by long-term care organisation stakeholders and can serve as a foundation for further discussion. Second, the empowerment and engagement of family caregivers and older adults with dementia is the only way to decrease the evidenced gap between them and professionals. Third, research is needed to consolidate these practices to achieve better quality of dementia care in Hong Kong. Fourth, further studies are needed to examine these views and break down environmental and contextual barriers at the community, organisational, and family level.

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