

New Horizons in understanding the experience of Chinese people living with dementia: A Positive Psychology approach

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Key points:

- Western research has recently begun applying positive psychology frameworks to understand the wellbeing of people with dementia.
- In contrast, there is a lack of literature on the experience and wellbeing of Chinese people living with dementia.
- Literature on Chinese older adults provide foundations for research on positive psychology among Chinese people with dementia.
- We propose that interpersonal and intrapersonal harmony are culturally-sensitive concepts to consider in this area of research.
- A positive approach may improve understanding of lived experience, and reduce stigma towards Chinese people with dementia.

Abstract

As the global average age increases, the incidence of dementia is also rising. Given improvements in diagnosis and life expectancies, people now live longer with dementia. Thus, the wellbeing and quality of life among people living with dementia are increasingly important areas for research.

Research with Western populations has recently begun to apply positive psychology concepts to understand wellbeing in people with dementia. Positive psychology focuses on positive emotions and traits that allow individuals to flourish and thrive – it highlights the possibility of positive subjective experiences in the face of loss and functional decline, and contrasts the traditional deficit-focused perception of dementia.

Despite being a major driver in the global growth of dementia prevalence, there is a dearth of research using such positive concepts to understand people with dementia in non-Western communities. This review contains discussion of research on positive constructs in Chinese older adults, and parallels between traditional Chinese cultural values and positive psychology. On this basis, we propose the applicability of a positive psychology framework to Chinese people with dementia, and that ‘harmony’ is an important culturally-specific concept to consider in this area of research.

A positive psychology approach acknowledges that strengths and positive experiences can endure after dementia diagnosis. This not only adds to the under-researched area of lived experience of dementia in Chinese people, but highlights areas that could be the focus of interventions or measured as outcomes. By improving understanding, this approach also has potential to reduce carer burden and stigma around dementia.

Introduction

Dementia is a syndrome which involves progressive and chronic deterioration in cognitive function at a faster rate than that expected in normal ageing [1]. It refers to a number of different conditions, including Alzheimer's disease, and vascular, frontotemporal and mixed dementia. As dementia progresses, its impact extends beyond deterioration in thought and memory to other areas of life, including significant impact on social, physical, and functional abilities. It was estimated in 2015 that there were 46.8 million people living with dementia worldwide, and this number was projected to almost double every 20 years thereafter [2].

Historically, a medical model has dominated dementia care, meaning dementia has been understood as an organic, degenerative disease, and responded to with pharmacological treatment to manage symptoms [3]. In line with this model, it was previously believed that people with dementia (PwD) were unable to provide reliable self-reports due to the decline in their functional abilities, and the perspective of PwD has historically been excluded from clinical and academic discourse [4].

However a strictly biomedical approach has been criticised as reductionist. More recent models have instead proposed more person-centred approaches, and incorporate individual and social factors into understanding subjective experience of the disease. Accordingly, prizing lived experience and involving PwD in dementia care, research and policies have gradually increased over time [5]. While it had been long debated whether PwD can report on subjective states such as quality of life, there is now a general consensus that the highly subjective nature of the concept requires the individual's perception wherever possible.

In contrast to the growing body of Western research on the experience of living with dementia, psychosocial dementia research in Chinese populations has very limited coverage of this topic. As the world's most populous country and with the percentage of the population aged 65 and over estimated to be above 35% by 2050 [6], China has an enormous ageing population and is a major driver in the continued global growth of dementia prevalence. However there is scant research on personhood and wellbeing in Chinese PwD, particularly subjective and qualitative reports.

Positive Psychology and Dementia

In more recent years, the study of the wellbeing of PwD has expanded to include the possibility of living well and positively with dementia. In contrast to the narrative of pathology and negativity that has historically dominated psychological science, positive psychology (PP) focuses on human strengths, positive experiences, and wellbeing [7]. A recent review of qualitative research on living well with dementia found that there is evidence for the maintenance of personal strengths such as hope, humour, and continuity of identity and relationships in PwD [8].

Impact

The value of applying a PP approach to dementia can be seen on both individual and systemic levels. On an individual level, there is research to suggest that positive traits are protective in older adults. A recent systematic review and meta-analysis found a negative correlation between resilience – often defined as the ability to “bounce back” from adverse events – and depressive symptoms in older adults [9]. The inverse relationship between

positive character strengths and depression – as well as a positive relationship with wellbeing – has also been demonstrated in PwD [10]. Morlett Paredes and colleagues [11] also found that wisdom (which, as a scientific construct, has been defined as a complex human trait involving emotion regulation, prosocial behaviour and other features [12]) reduces and prevents loneliness in older adults. Furthermore, positive psychology interventions have significant beneficial effects on psychological and subjective wellbeing, including for older adults [13].

On a more systemic level, a PP framework may also help to counter the negative connotations and stereotypes that are associated with dementia. Negative stereotypes such as the perception of PwD as helpless victims potentially limit the care and rehabilitation options provided to PwD, and also the agency that PwD are perceived to have [14]. Furthermore, stigma can be internalised by PwD and potentially lead to excess disability in cognitive and social skills -- that is, dysfunction beyond that directly caused by the disease [15]. As such, stigma and negative stereotypes are inherently linked to the wellbeing of PwD. By providing an alternative discourse for understanding and talking about dementia, the emergence of a positive framework has potential to de-stigmatize dementia [14] and promote dementia-friendly environments.

Cultural sensitivity of the framework for East Asians

Having originated in USA, PP has been criticised as narrow in its Western framework, and researchers have highlighted culturally-specific elements which may differ among East Asians. For instance, while independence and focus on personal goals are considered core values in individualist societies, and constructs such as optimism, hope and self-efficacy are particularly valued [16], collectivist cultures may place more focus on concerns of the group rather than its constituents [17]. In contrast to the emphasis on independence and autonomy of the self, East Asian cultures emphasize the self in relation to others and value connectedness and interdependence. The wellbeing of East Asians thus rests not only on how individuals view themselves, but also on external points of reference, such as how they are perceived by those in their social circles [18].

Furthermore, research suggests that there may be cultural differences in the nature and role of positivity. For example, while individuals from European-American cultures are more likely to see positive and negative emotions as contradictory, East Asians appear to experience positive and negative emotions in a more simultaneous manner [19]. In a multinational study, researchers found a strong negative correlation between negative and positive emotions in a Western sample, but found significantly weaker association between negative and positive emotions in Asian populations [20]. In contrast to the preferential cognitive processing of positive stimuli that has been demonstrated in Western populations, researchers found that Hong Kong older adults look away from happy facial expressions, suggesting that the attentional preference for positive stimuli does not generalise to this population [21]. The results of these studies suggest a more co-existent and dialectical relationship between emotions of opposite valence in East Asian cultures than in Western cultures.

As such, while research on Western populations have suggested that positive emotions may be conducive to outcomes such as mental and physical health [22], caution must be taken in generalising these benefits to East Asian cultures. For instance, while an increase in positive emotion has been found to be linked with a decrease in depressive symptoms among European Americans, this was not found in Asian immigrants and Asian-Americans [23].

Application of PP to Chinese older adults therefore requires culturally-specific enquiry not only into what is considered positive but also its implications on wellbeing.

Trends in Chinese dementia research

In recent reviews of literature on the experience of living with dementia, only one Hong Kong study was identified [24] and, apart from one Iranian study, the remainder of the identified literature was based on Western populations (e.g. [8, 25]). To the best knowledge of the authors, there have not yet been investigations on the wellbeing of Chinese PwD that explicitly adopt a PP framework.

However, there is relevant research on Chinese older adults, which we propose provide empirical foundations for the application of a positive framework for Chinese PwD. For instance, while there is limited research on the subjective experiences of Chinese PwD (apart from quality of life, e.g. [26]), researchers have investigated the quality of life and subjective wellbeing of Chinese older adults (e.g. [27]), with some focusing on specific challenges such as living with chronic illness [28].

Chinese studies on successful ageing have also identified traits that map onto PP constructs. This is reminiscent of findings in Wolverson, Clarke and Moniz-Cook's review [8], which found that very few studies explicitly examined the strengths or resources of PwD, and that themes identified in their meta-synthesis on living positively with dementia closely resembled psychosocial dimensions of successful ageing. For example, a study on Hong Kong centenarians and near-centenarians found that optimism was significantly positively correlated with successful ageing, as measured by physical, psychosocial and economic factors [29]. Another study found that diagnosis of diabetes mellitus had a positive impact on health-related quality of life in Chinese older adults [30]. Researchers proposed that this may be attributable to Chinese culture, which promotes acceptance and adaptation to illness. Lastly, a Singaporean qualitative study on what Chinese older adults with terminal cancer perceive as a 'good death' also identified positive psychology constructs, including hope, control, and social connectedness [31].

Among the PP constructs, resilience appears to have been relatively well studied in Chinese older adults. Resilience has been qualitatively [32] and quantitatively explored, including resilience in older adults living with Human immunodeficiency virus infection and acquired immune deficiency syndrome (HIV/AIDS) [33], and resilience to loneliness among Chinese older adults living on their own [34].

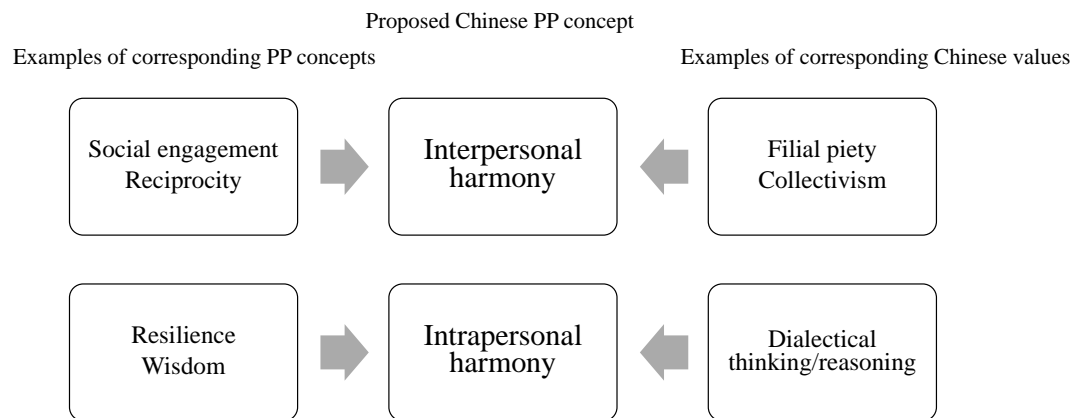
As such, there are beginnings of PP research among various Chinese older adult populations, and opportunity for future research to investigate these concepts among Chinese PwD.

Proposing a PP model for Chinese PwD

However, as discussed previously, cross-cultural application of Western frameworks requires consideration of cultural factors. While the Chinese population is a heterogeneous group, there are common core values which underlie Chinese culture. One such value is harmony, which some have proposed is central to the application of PP to Chinese populations [16]. In Chinese culture, harmony is a framework that involves a dialectical approach to life and a holistic worldview [35]. It is a value that is rooted in Confucian, Taoist and Buddhist doctrine [19] and has implications for a wide variety of life domains for Chinese people, including interpersonal relationships, and managing fluctuations between positive and adverse life

events [35]. We therefore propose that interpersonal and intrapersonal harmony may be helpful ways to understand the manifestation of PP constructs among Chinese PwD. As discussed in further detail below, interpersonal harmony may be associated with Western PP concepts such as social engagement, and intrapersonal harmony with concepts such as resilience and wisdom (Figure 1). This model may also aid future cross-cultural adaptation of Western interventions for Chinese PwD. For instance, a study on Cognitive Stimulation Therapy (CST) similarly identified social harmony as a value that is important to Chinese PwD and suggested adjustments accordingly, in order to improve cultural appropriateness of CST for this population [36].

Figure 1.



Concept map of corresponding Western PP concepts and Chinese cultural values to the proposed Chinese PP concepts

Interpersonal harmony

Maintaining interpersonal harmony is highly valued in Chinese culture and some have proposed that family-oriented determination is the Eastern equivalent of autonomy in Western cultures [37]. An exemplar of the importance of intergenerational relationships is the traditional virtue of filial piety. Filial piety is a virtue with strong connections to Confucianism, whereby individuals are taught from a young age that elders should be respected and obeyed [38, 39]. However, while filial piety has traditionally emphasized parental authority and submission from offspring, studies have shown that social change and modernization have led to greater reciprocity and intergenerational exchange in the modern-day perception and practice of filial piety (see [40]). As opposed to only being on the receiving end of care, Chinese older adults also play a significant role in discussions around providing family caregiving [41]. While the positive impact of maintaining productive roles on wellbeing has been studied in older adults of other cultures (e.g. [42]), filial values perhaps further contribute to the significance of maintaining particular social roles to Chinese older adults. For example, Chinese older adults may consider caring for grandchildren a family obligation, and research has shown that taking on this role has positive effects on the wellbeing of the grandparent [43]. Studies in Hong Kong and Taiwan found that older adults who experience a sense of reward from caring for a grandchild were less likely to experience depressive symptoms [44], and that grandparent caregivers were more likely to report higher life satisfaction and self-rated health than non-caregivers [45]. While there appears to be limited research concerning the positive impact of intergenerational relationships, there are existing studies on Chinese older adults which suggest that loneliness in this population is strongly related to intergenerational relationships. For instance, those without children were significantly lonelier than those with [46].

Beyond the core social network of one's family, non-kin relationships have also been found to promote resilience to loneliness among Chinese older adults living alone [34]. It has been suggested that the collectivist nature of Chinese culture predisposes Chinese older adults to value social connections and adopt relationship-focused coping strategies. This, in turn, may be beneficial and protective in old age. For instance, subjective social support has been found to be negatively associated with depressive symptoms among Chinese older adults who are relatively independent with activities of daily living [47].

In this way, the emphasis on interpersonal harmony in Chinese culture maps onto PP constructs, including promoting prosocial behaviour, reciprocity and social connectedness, and contributing to social role and resilience in later life. Some have also suggested that the prosocial, collectivist nature of Chinese culture promotes compassion and transcendence, in that East Asian culture may promote thinking outside of the self and connecting to others, and that a greater self-understanding may be obtained in this way [16].

Intrapersonal harmony

In Chinese Taoist doctrine, people are encouraged to live in harmony with nature and to not attempt to change the unchangeable [48]. Similarly, Buddhism highlights the inevitability of suffering in human existence, and alleviation from suffering is achieved through Nirvana, a state in which the striving for passions and happiness has been calmed and is no longer the main driving force in one's life [49]. Researchers have proposed that these traditional Chinese values can be applied to understand experiences of adversity in later life such as chronic illness, in that Chinese older adults appear to view ill-health neither as a serious loss nor as an experience leading to a clear sense of transcendence or growth, but as a natural part of life [48].

Liang & Luo [35] have proposed harmonious aging as a way to understand Eastern experiences, which consists of a balanced outlook on both opportunities and challenges in old age. This dual focus on positive and negative has been described as dialectical thinking - a recognition that positive and negative are interchangeable, good things can have bad consequences, and gains can be found in losses [50]. Individuals who adopt this way of thinking may expect and be able to accept greater levels of negativity [51]. This corresponds with cross-cultural research which has found that East Asian older adults may focus on negative information as much as they do positive information, which contrasts the age-related positivity enhancement found in older adults in Western populations [50]. While this suggests that East Asians feel less positive than their Western counterparts, this may not necessarily mean that East Asians have lower emotional wellbeing. In fact, some findings suggest that emotional conflicts and negative self-evaluations may have less of a detrimental impact on mental health for East Asians than for people of other cultures [52, 53]. Similarly, studies on Asian Americans have suggested that positive emotions play a relatively limited role in the mental health of Asians compared to Western populations [23].

Alternatively, the lack of positivity enhancement may suggest that East Asians focus more on emotion regulation [50]. As such, while maximizing positive emotions is ideal in a Western framework, East Asians may focus more on regulating emotions and balancing positive and negative feelings [23]. In addition, dialectical reasoning may contribute to greater tolerance of negative emotion. Within the traditional framework of PP, perhaps this would represent Chinese cultural specificities to the concepts of resilience and wisdom. Within Taoism,

ultimate wisdom and optimal functioning are achieved through understanding and being harmonious with nature, and allowing life processes to take their course [49].

Conclusion

There is a dearth of research on the lived experience of Chinese PwD. Recent Western research with PwD has adopted a positive psychology approach, which has highlighted the possibility of living well with dementia, and that personal strengths can prevail following diagnosis. Research on Chinese older adults contain beginnings of a positive approach, however no studies have investigated the wellbeing and subjective experiences of Chinese PwD using a positive psychology framework.

East Asian populations may include a greater emphasis on the self in relation to others, a more dialectical approach to emotion regulation, and a more harmonious approach to coping with adversity. As such, interpersonal and intrapersonal harmony may be culturally-specific concepts to consider in understanding the experiences of Chinese PwD, and in future research on positive psychology and strengths among this population.

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