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# Filial Piety and Dignity in End-of-Life Caregiving: Lived Experience of Chinese Families facing Terminal Cancer and receiving LTC Services in Hong Kong

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# Ageing & End-of-Life Care Policies in Hong Kong



- One of the most confounding challenges of health care providers today is to optimize quality of life and promote death with dignity
  - Hong Kong government has based its elderly policy on the **Confucian value of Filial Piety**, which requires adult children to take care of their aging parents
  - **'Filial Responsibility'** and the principles of **'Aging in Place'** has become the impetus that drives the coordination of elderly services in Hong Kong
- Such policy agenda essential places family, and especially adult-children, at the forefront of caregiving for older terminal patients

# Ethics of Traditional Filial Piety

- **The virtue of filial piety defines duties and obligations:**
  - Maintenance of hierarchy within the family system
  - Governs authority and power structure
  - Regulates intergenerational interactions
  - Serves as the foundation of social cohesion
  
- **Filial attitudes and behaviors:**
  - Minimizing parents' worries
  - Repaying parents' sacrifices
  - Treating parents with respectful propriety
  - Staying close to serve parents
  - Complete obedience and non-resistance



# Social Change and Filial Practice

- **Modernization have led to the decay of filial piety**
  - Filial piety do not protect against caregiver burden
  - A declining adherence to filial commitments among younger generations
  - Financial subsistence becomes a primary expression of filial obligation
  - 7% of Hong Kong elders aged 65+ are living in nursing homes
  
- **Vast dissonance between government policies that are based upon traditional values and the social realities of family practices**
  - An imperative need to examine the evolving concept of filial piety in family caregiving so as to ensure that individual and family dignities are preserved at life's most vulnerable moments

# Current Study: Constructivist Paradigm

- Meaning-oriented Interviews with 15 Chinese Family Caregivers of terminal cancer patients to elicit the narratives of the EoL caregiving
  - **Introspection and articulation of experience to generate renewed meaning:** recalling all significant events leading up to the cancer diagnosis, the immediate aftermath, the eventual coping and adjustment processes, as well as reflections on family caregiving
- Clinical observations, field notes and researcher reflexivity
  - **Understanding Meaning via Context:** eliciting the temporal orientations of experience to include retrospective assessment and pre-reflective, real-time unfolding of social life
- Data collection & analysis
  - All interviews were conducted between November 2009 and February 2011
  - **Investigator Triangulation:** interviews were recorded, transcribed verbatim, edited for accuracy and coded independently by 3 researchers using ground theory analysis
  - **Theory Triangulation:** Analysis involved revisiting the literature to identify conceptual tools that elucidate emergent themes

# Characteristics of Chinese Family Caregivers (N=15)

| Name <sup>a</sup> | Age | Gender | Education   | Employment   | Relationship with Patient          | Type of Care Provided <sup>d</sup> |
|-------------------|-----|--------|-------------|--------------|------------------------------------|------------------------------------|
| <b>Andrew</b>     | 30  | Male   | College     | FT Caregiver | Father-Son (only)                  | Home Care                          |
| <b>Ming</b>       | 38  | Male   | High School | FT Caregiver | Father-Son (eldest)                | Home Care                          |
| <b>Penny</b>      | 42  | Female | High School | FT Caregiver | Mother-Daughter (eldest)           | Home Care                          |
| <b>Yuki</b>       | 44  | Female | High School | FT Caregiver | Mother-Goddaughter                 | Home Care                          |
| <b>Suzu</b>       | 45  | Female | College     | FT Caregiver | Mother-Daughter (eldest)           | Home Care                          |
| <b>Ling</b>       | 58  | Female | High School | FT Caregiver | Mother-Daughter (eldest)           | Home Care                          |
| <b>Bonnie</b>     | 59  | Female | High School | FT Caregiver | Mother-Daughter (eldest)           | Home Care                          |
| <b>Sammy</b>      | 60  | Female | High School | FT Caregiver | Mother-Daughter (2 <sup>nd</sup> ) | Home Care                          |
| <b>Janet</b>      | 40  | Female | College     | FT Employed  | Mother-Daughter (2 <sup>nd</sup> ) | Nursing Home Support               |
| <b>Lee</b>        | 50  | Female | High School | FT Employed  | Father-Daughter (2 <sup>nd</sup> ) | Nursing Home Support               |
| <b>Ping</b>       | 57  | Male   | High School | FT Employed  | Mother-Son (eldest)                | Nursing Home Support               |
| <b>Kary</b>       | 58  | Female | High School | FT Employed  | Mother-Daughter (eldest)           | Nursing Home Support               |
| <b>Karen</b>      | 58  | Female | High School | FT Employed  | Mother-Daughter (eldest)           | Nursing Home Support               |
| <b>Mary</b>       | 58  | Female | High School | FT Employed  | Father-Daughter (eldest)           | Nursing Home Support               |
| <b>Susan</b>      | 62  | Female | High School | FT Employed  | Mother-Daughter (eldest)           | Nursing Home Support               |

<sup>a</sup> Names have been changed to protect confidentiality.

3 men and 12 women; ages ranged from 30 to 62 years, mean age 50.6 years; 3 eldest/only son, 8 eldest daughter; 10 pairs of mother and daughters, 3 fathers and sons, 1 pair of mother and son, 1 pair of father and daughter; 8 provided intensive home care, 7 relied on nursing home and provided financial support.

# Themes Emerged from Family Caregivers' Narratives

In all of the narratives, participants expressed their subjective experiences of EoL caregiving in relation to their filial attitudes and behaviors. 5 contemporary themes of filial piety for the promotion of dignity at the end-of-life have emerged:

1. Reciprocal Relationship
2. Mutual Support
3. Compassionate Duty
4. Emotional Connection
5. Appreciation and Forgiveness



# Reciprocal Relationship

In contrary to the notion of authority in filial piety, all adult-children caregivers expressed the importance of reciprocal relationships in the care of their dying parents.

*“I feel that it is my duty to look after him (father)... we talked about me taking a long leave of absence from work to care for him at home, and together worked out a plan to support the family financially... He was very appreciative and grateful, and I believe we grew stronger as a family because of that.”*

*(Andrew, 30 Son, Home Care)*

Being able to discuss and share needs and concerns between parents and adult-children in end-of life caregiving were of paramount importance for sustaining filial conviction and behaviours.

# Mutual Support

Apart from reciprocity and understanding, mutual support between parents, adult-children and the larger family was another important theme of filial piety identified in the current study that overshadowed the traditional notion of complete obedience.

*“Having the support of my brother and his wife is so important, our two families take turns to go see her (mother) every day so she won’t feel lonely or abandoned.”*

*(Ping, 57 Son, Nursing Home Support)*

While the majority of caregivers were eldest sons and daughters, it is obviously that the weight of filial responsibilities did not befall on them alone but the entire family where the elderly-patients may also play a supporting role.

# Compassionate Duty

Whilst most literature on filial piety has contended that caring of elderly parents is an obligatory duty, caregivers in this study believed that the traditional idea of repaying parents' scarifies is not enough to sustain family caregiving.

*“Caring for my father during his final days is the most meaningful thing I have ever done in my life. I am not doing this because I feel like owing him for the things that he has done for me, but rather, as a true token of my love and appreciation ... Yes, it is my duty to care for him as a son, however it is not because I am obliged to, but because I want to.”*

*(Ming, 38 Son, Home Care)*

In order to sustain filial caregiving and to preserve dignity at the end-of-life, adult-children must understand the pain and suffering of their parents so as to care for them wholeheartedly with love and compassion.

# Emotional Connection

Despite the transformation in filial attitudes, the act of caregiving among most participants is still heavily based on the physical and the practical.

*“I want to connect with her (mother) on a deeper level... But I don’t know what to say or how to connect with her... Every time that I visit her there are a lot of silent moments... It feels like I have not fulfilled my duty as caring and loving daughter.”*

*(Sammy, 44, Daughter, Nursing Home Support)*

The inability to spiritually bond with their dying parents has caused great sorrows and regrets for most caregivers, underlining the vital significance of emotional connection in the contemporary experience of filial piety and dignity at the end-of-life.

# Appreciation and Forgiveness

As the ethnics of filial piety is founded upon a culture that warrant self-evaluation of one's moral conduct, caregivers who lacked the resources to provide home care for their ailing parents had expressed great shame and immense guilt.

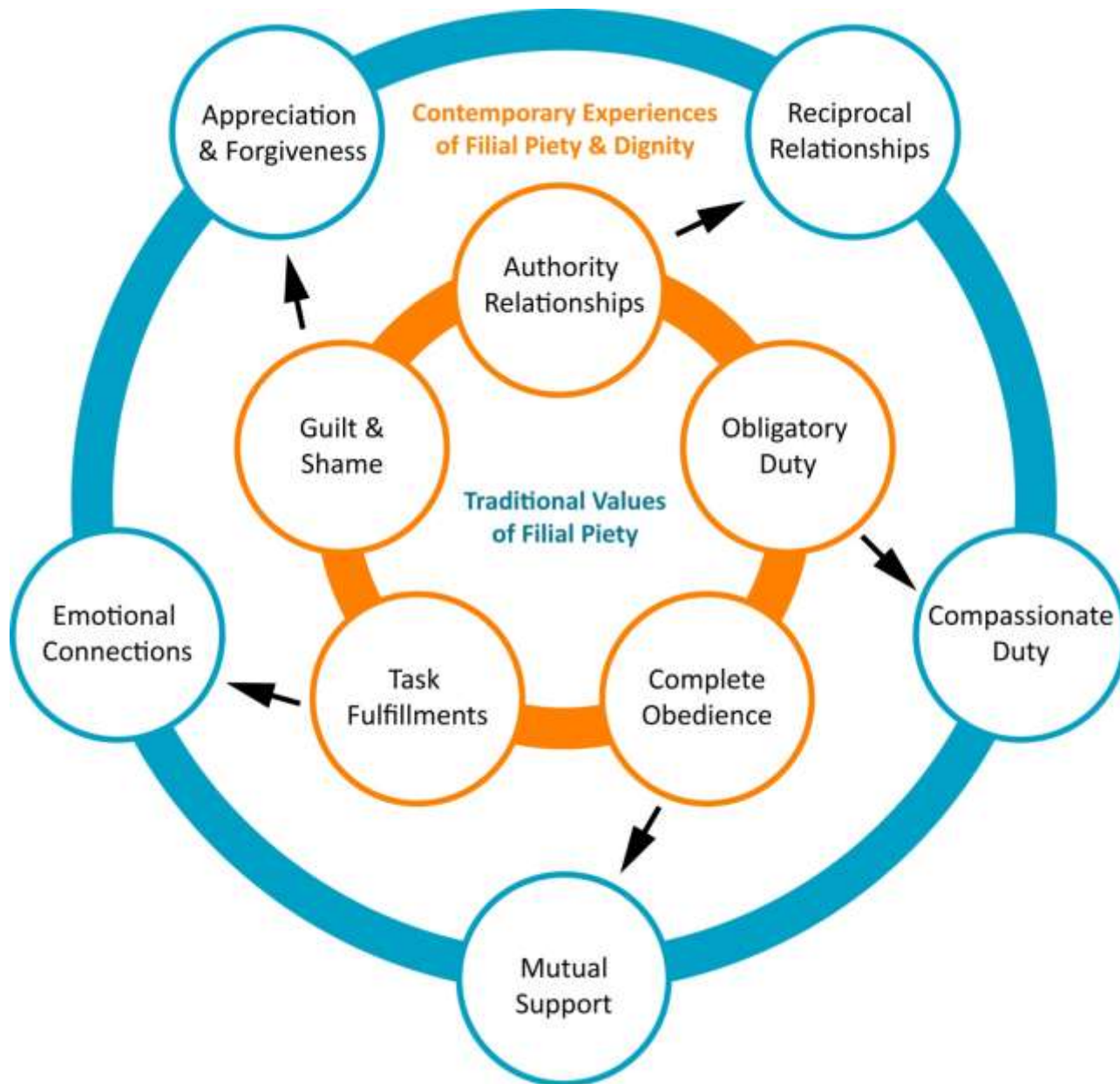
*“I really hope my father understands my difficulty and can forgive me for sending her to the nursing home. I am doing the best that I could in terms of financial support, but I know it is not good enough”*

*(Mary, 58, Nursing Home Support)*

Apart from forgiveness, there was also an intrinsic yearning to express appreciation among all caregivers .

*“I really want to thank my mother for all the things that she has done for me... But I am not used to saying these things with her. All I can do is to try my best to care for her and make her feel comfortable.”*

*(Yuki, 44, Daughter, Home Care)*



Evolving Model of Filial Piety and Dignity in End-of-Life Caregiving

Chan, Ho, Leung et al. (2012)

# Clinical Implications

To help family caregivers and patients minimize suffering as well as to achieve reconciliation, maintain hope, achieve meaning and dignity as death draws near, there is an imperative need for:

- ▣ Patient-Family practice in palliative end-of-life care
- ▣ Respect the legitimacy of family caregivers' strengths
- ▣ Promote participation and partnership in care
- ▣ Facilitates dialogue between family caregivers and patients
- ▣ Cultivates filial compassion and reconciliation
- ▣ Enables the expression of love and gratitude

# Policy Implications

To balance family integrity and social sustainability in the promotion of dignified end-of-life family caregiving, patients and caregivers must be empowered through greater homecare support and social assistance

- ▣ Strengthen collaboration between hospitals and social service agencies
- ▣ Greater access to the entire spectrum of care in the community
- ▣ Expand provisions of homecare services beyond office hours
- ▣ Involve social workers in homecare programmes
- ▣ Networking with Non-Government Organizations
- ▣ Training of carers in elderly homes and community centres



# Conclusion

Aging population is a global phenomenon, and caring for elderly parents is a critical issue that concerns not only Chinese societies but every country around the world.

As the manifestations of filial piety become increasingly universal through its equalitarian features of reciprocity, compassion and emotional connection, the implications derived from this research can guide palliative services for upholding dignity among all families facing morality regardless of race and ethnicity.

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Suffering breaks open our hearts,  
and through that breakage comes compassion,  
the true understanding of another suffering,  
the quiet joy of being with another in their pain,  
and the liberation of our dignity and shared humanity.



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