



# **The Transformation of Filial Piety & New Ways of Remembrance in the 21<sup>st</sup> Century**

Lived Experience of Chinese Adult Child Caregivers

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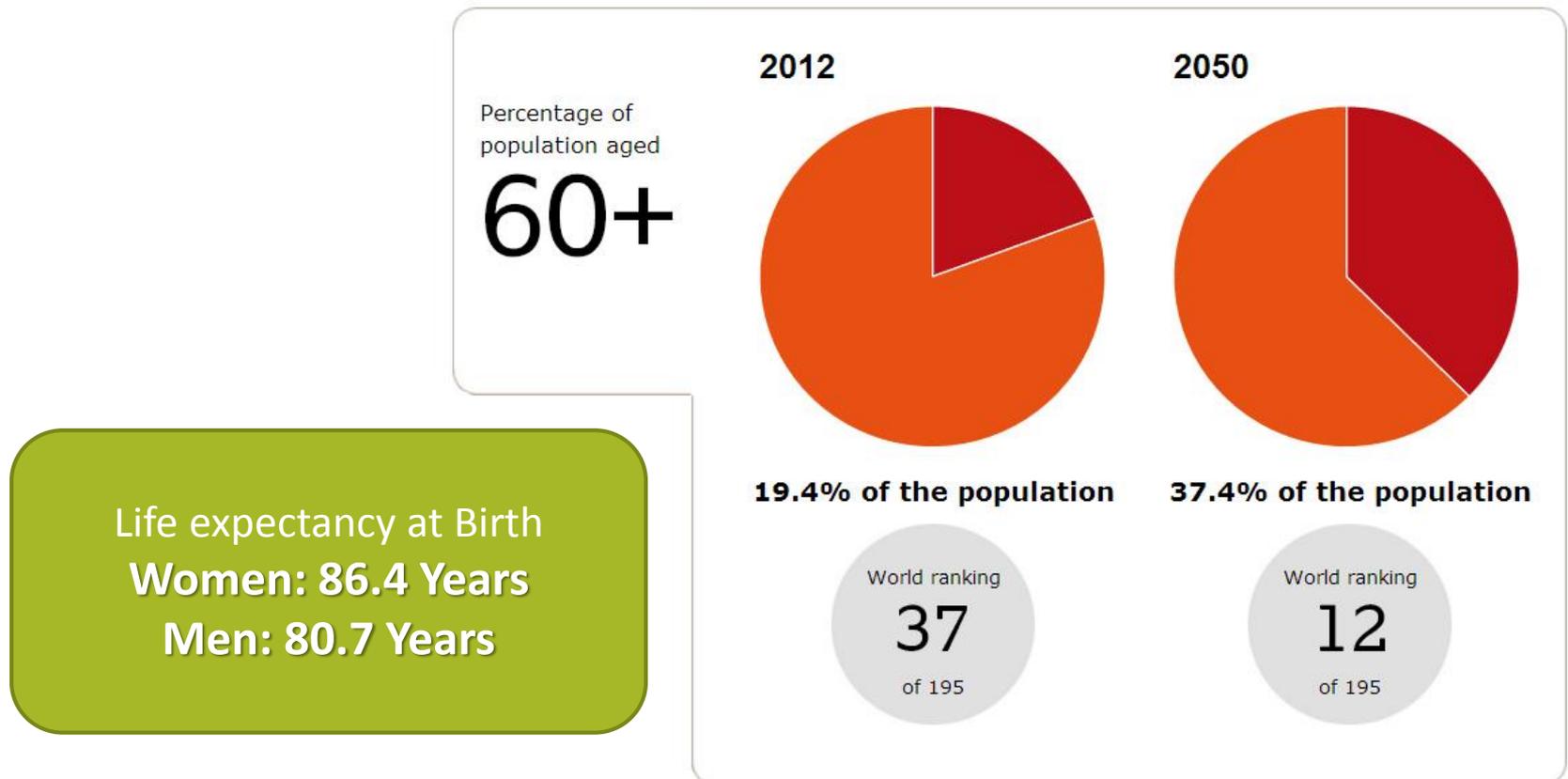
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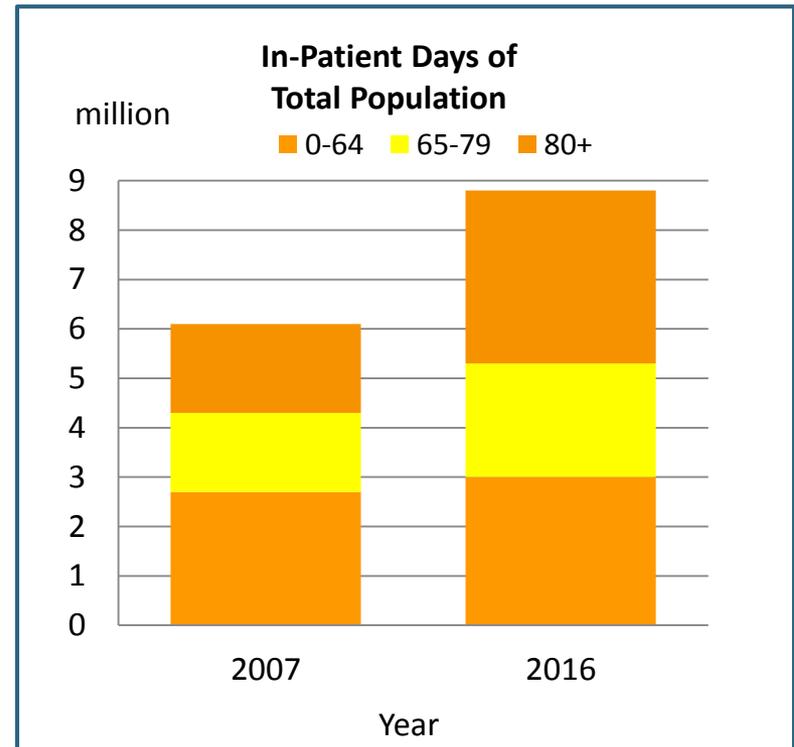
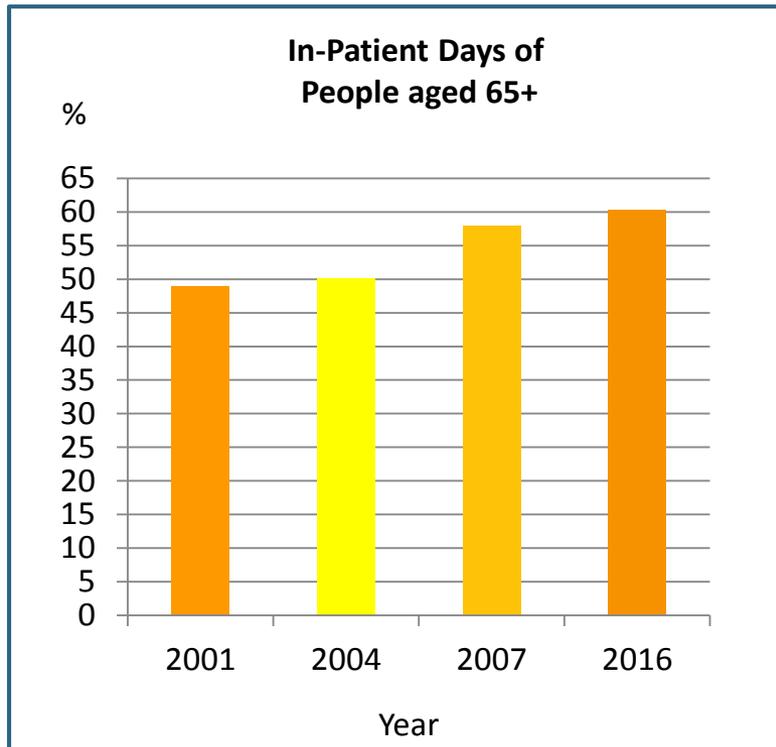
# Population Ageing in Hong Kong

- In Hong Kong, the number of persons aged 65+ has increased over 85% in the past 20 years, from 502,400 in 1991 to 940,600 in 2011



# Old Age Dependency & Health Care Needs

- Elderly dependency ratio in Hong Kong will also increase dramatically from 207 to 450 in the next 20 years



# Elderly Services & End-of-Life Care Policies

- One of the most confounding challenges is to optimize quality of life and promote death with dignity for the aged and terminally ill
  - ▣ Many Governments of Confucius Heritage Cultures have based its ageing and end-of-life care policies on the principles of **Filial Piety**
  - ▣ **'Filial Responsibility'** and the principles of **'Aging in Place'** become the impetus that drive elderly services in Hong Kong
  - ▣ Singapore – **Maintenance of Parents Act**
- Such policy agenda essential places family, and especially adult-children, at the forefront of caregiving for older terminal patients

# Traditional Ethics of Filial Piety

- **The virtue of filial piety defines duties and obligations:**
  - ▣ Maintenance of hierarchy within the family system
  - ▣ Authority Governance and power structure
  - ▣ Regulates intergenerational interactions
  - ▣ The collective before the individual
  - ▣ Serves as the foundation of social cohesion
  
- **Exemplars of filial attitudes and behaviors:**
  - ▣ Deep respect, submissive and non-resistance
  - ▣ Treating parents with rightful propriety
  - ▣ Minimizing parents' worries
  - ▣ Repaying parents' sacrifices
  - ▣ Preserving family honor and lineage



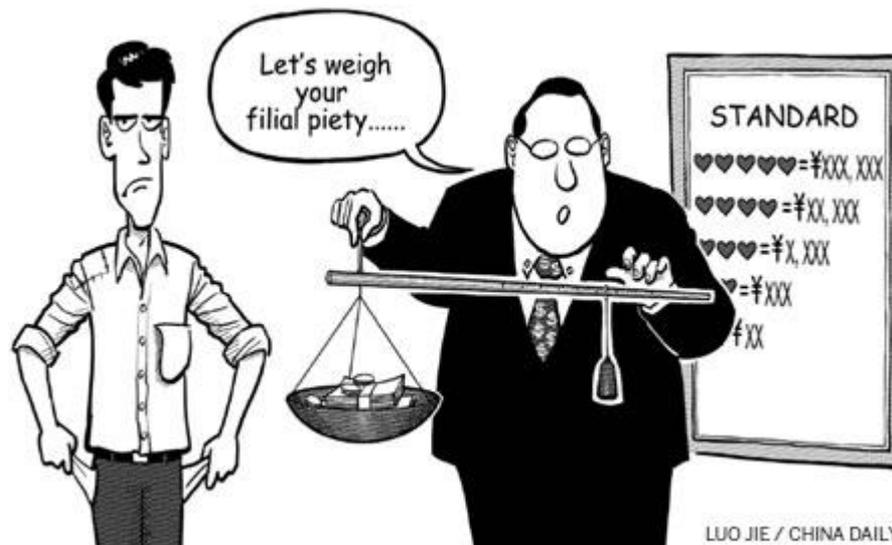
【百行孝為先】

# Social Change and Filial Practice

- **Modernization have led to the decay of filial piety**
  - Longer life expectancy, greater devotion to work, higher education levels, smaller family size, decrease intergenerational coresidence
  - Declining adherence to filial commitments among younger generations
  - Decreased ability and desire to shoulder parental care responsibility
  
- **Impact on Filial Caregiving**
  - Filial piety do not protect against caregiver burden
  - Filial piety is associated with higher level of depressive symptoms
  - Filial fulfillment is often situational and symbolic in nature
  - Filial obligation is expressed primarily through financial subsistence

# Public Policy vs Social Reality

- Vast dissonance between government policies that are based upon traditional filial values and the social realities of filial practices
- An imperative need to examine the evolving concept of filial piety in end-of-life 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 older terminal patients to elicit their narratives on EoL caregiving
  - ▣ Focuses on **contexts, narratives, lived experiences and relationships** to generate rich and in-depth data to illuminate the complexities of a particular social reality
  
- 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 processing & analysis
  - ▣ **Investigator Triangulation:** All 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

Filial Piety as

# 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.

Filial Piety as

# 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 also play a supporting role.

Filial Piety as

# 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.

Filial Piety as

# 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.

Filial Piety as

# 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... 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.”*

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



## Evolving Model of Filial Piety on Dignity in End-of-Life Caregiving

(Chan, Ho, Leung et al., 2012)

# Implications

To help dying patients, family caregivers and surviving family members minimize suffering as well as to maintain hope, achieve reconciliation, meaning and dignity, 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
- ▣ Enables the expression of love and gratitude
- ▣ Cultivates reconciliation, meaning making and filial compassion



# Life Review: Living Memoirs

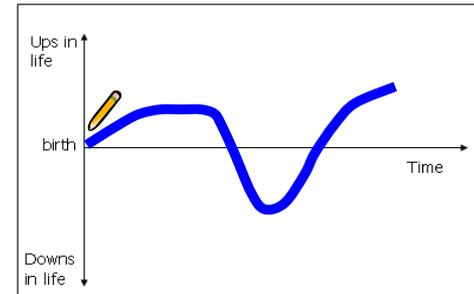
# What is Life Review?

- To find a meaning in one's life is the primary motivational force in man (Frankl, 1984)
- The final developmental task of dying patients is to achieve ego-integrity: integrity vs. despair (Erikson, 1950)
- Live Review (LR) involves sharing of past memory, re-experiencing emotions, re-development of self esteem & selfhood, and to reconstruct and reestablish meaning
- Through LR, we can construct and reconstruct our identities as survivors of loss in negotiation with others

# Life Review: A Reflective Process of Healing

- The inability to revisit pivotal moments in life as well as points of conflict restricts individuals from making amends for damaged relationships, and evidence suggests that regrets of this kind pose barriers to inner peace and solace (Neimeyer et al., 2011)
- Some life review and meaning-making tools includes:

- ▣ Autobiographic Time-line
- ▣ Life Story/Legacy Book
- ▣ Narrative Therapy



我的自傳: \_\_\_\_\_  
(My autobiography)

第一章(Chapter 1): \_\_\_\_\_

第二章(Chapter 2): \_\_\_\_\_

第三章(Chapter 3): \_\_\_\_\_

第四章(Chapter 4): \_\_\_\_\_

第五章(Chapter 5): \_\_\_\_\_

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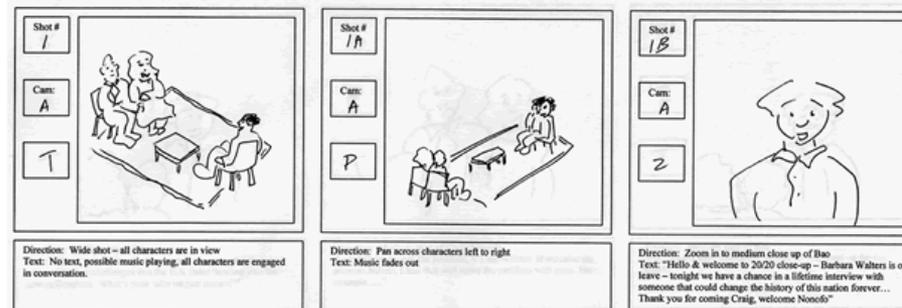


# Living Memoirs: Documentary Videography

- **Living memoirs** adopt a family life course perspective in the creation of artistic, highly sensory videos that celebrate the life of the ill or elderly person.
  - In the form of a short documentary and encompassing elements from life review and reminiscence therapy, it taps into the inner reflective world of the patient through a strength-based, semi-structured interview.
  - Led by an interviewer and facilitated by members of the patients' family, prominent personal history and family heritage are digitally recorded and crafted into a vivid and cohesive narrative that transcends time.

# The Living Memoir Process: **The Script**

- A week before the interview, the family is provided with a list of questions that inquire about a significant event or experience at each developmental stage of the patient's life.
  - They are invited to go through each question together, and to identify a family portrait, meaningful and symbolic object that helps to tell the patient's story at that particular moment in time.
  - These questions begin with memories of childhood and progressively extend into adolescence, adulthood, and the golden years; which serves to awaken a collective reminiscence of life's challenges and successes, sorrow and happiness, as well as suffering and wisdom.



# The Living Memoir Process: **Filming**

- Drawing on conversations stimulated by the documentary process, family members, including the patient, share stories with the therapist during a filmed interview session.
  - ▣ Adopt a meaning-oriented approach to dialogue that identifies and amplifies the strengths and capacities of the stories, which can turn into discussion of insights, values, hopes and goals, affirmation of love and appreciation, and ultimately, expression of forgiveness and reconciliation.
  - ▣ The filming can take place at the hospital, the family home, or during a family outing to create more cherished memories and meaningful discussions.



# The Living Memoir Process: **Editing**

- All pictures, family portraits and meaningful objects are photographed. Additional location shots that help to contextualize the patient's narratives can be made in postproduction.
- The filmed interview and all relevant materials are then edited with music and graphics by the therapist with considerations of the patient's preference. The end product is a 10-15 minute videography that coherently depicts the patient's story.



# The Living Memoir Process: Screening

- The patient previews the edited videography, and additional editing is made upon request.
  - Once the final edition is completed, a family screening is organized. Thereafter, a short debriefing session is held to create a space for sharing, understanding and healing.
  - The living memoir, which is artistic, vibrant and rich in both meaning and content, is then given to the family as a legacy document that can be bequeathed to future generations and serve as a healing resource in times of grief and remembrance.



# Living Memoir of **Mr. Leung**



## Other Innovative Ways of Remembrance

# Music and Medicine

- Music Therapy has shown to be effective in resolving the many needs of dying patients and bereaved families
  - ▣ Social needs (e.g. isolation, loneliness, boredom)
  - ▣ Emotional needs (e.g. depression, anxiety, anger, fear frustration)
  - ▣ Cognitive needs (e.g. neurological impairments, disorientation)
  - ▣ Physical needs (e.g. pain, shortness of breath)
  - ▣ Spiritual needs (e.g. spiritual connection, spiritual based rituals)
  
- A dynamic process for self & emotional expression
  - ▣ Music prompted reminiscence
  - ▣ Guided imagery and music
  - ▣ Music therapy relaxation techniques
  - ▣ Singing and Instrument playing with isoprinciple
  - ▣ Musical Gifts



# Dedicated Websites on Death and Loss

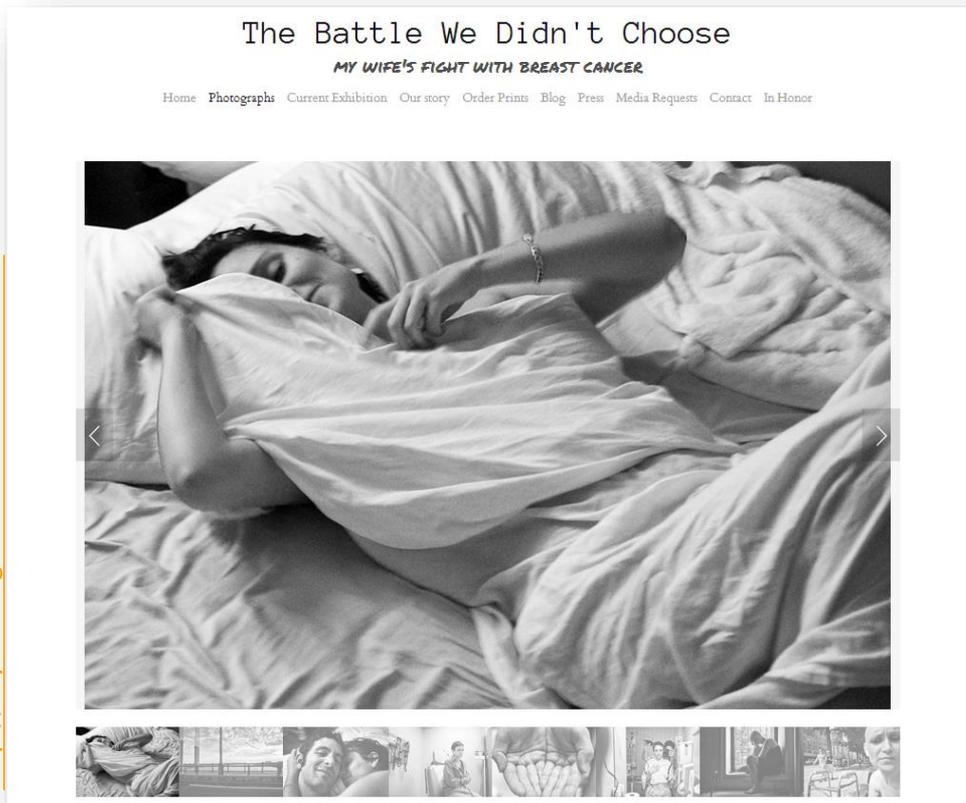
- Many dedicated and interactive websites are available for learning, coping and understanding death and loss.



# Social Media Resources and Support

- Terminally-ill patients and bereaved families are using social media as a means of documenting the last days and months of their lives.

<http://mywifesfightwithbreastcancer.com>



 **Scott Simon**   
@nprscottsimon 

Mother groans w/ pleasure--over flossing. "When they mention great little things in life, they usually forget flossing."

5:37 AM - 29 Jul 2013

56 RETWEETS 137 FAVORITES   

 **Lisa Bonchek Adams**  
@AdamsLisa 

Yes, you really can teach, share, listen, laugh, grow, love, mourn, cry, communicate, and change the world 140 characters at a time.

12:05 PM - 14 Jan 2014

256 RETWEETS 281 FAVORITES   

 **Shelby Terstriep**  
@DrTerstriep 

[#IStandWithLisa](#) for teaching the world "palliative care" means more than just pain medications [#bcm](#)

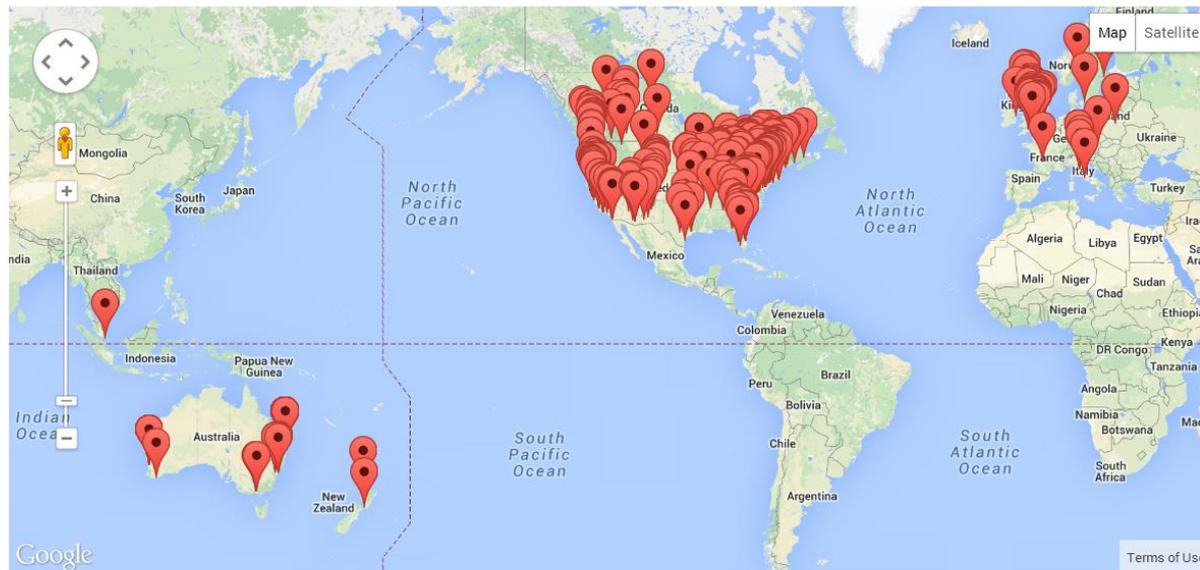
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3 RETWEETS 2 FAVORITES   

# Death Café

- At a Death Cafe people, often strangers, gather to eat cake, drink tea and discuss death, *'to increase awareness of death with a view to helping people make the most of their (finite) lives'*.

Death Cafe worldwide map



# The Way Forward

- **Public Health Palliative Care** facilitate active engagement from all members of society to creates a sense of ownership within the community that embraces existing social support networks and health care system in supporting the dying and the bereaved
- Effective utilization of **Innovative Therapies, Information Technology and Social Media** can ultimately ensures the **sustainable development** of dignified care for liberating dying individuals and bereaved families in the 21<sup>st</sup> century.

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.



*Love & Compassion, Tibetan Uchen Script*

Thank you  
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