“Personhood” the foundations of people-centered care and health systems
“人本醫療” - 醫療系統的基礎

Professor Eng-Kiong YEOH, GBS, OBE, JP

Director, The Jockey Club School of Public Health and Primary Care
Head, Division of Health System, Policy and Management,
Faculty of Medicine, The Chinese University of Hong Kong

香港中文大學醫學院
Faculty of Medicine
The Chinese University of Hong Kong

Outline

1) Personhood

2) Foundations of Person-centered Care

3) Moral Basis of Health Systems

- Although cancer kills you … it doesn't remove your very humanity… doesn't turn you into a vegetable … All diseases are depersonalizing to some extend. But you're still human. But a person with a serious dementia is no longer human. He's a vegetable. That's devastating. Fearsome. Terrifying, to anyone who's ever seen it – the thought that it could happen to you.

  (Smith 1992:51)

1) PERSONHOOD

What is a “Person”?

By Paul Klee (German 1879 – 1940)

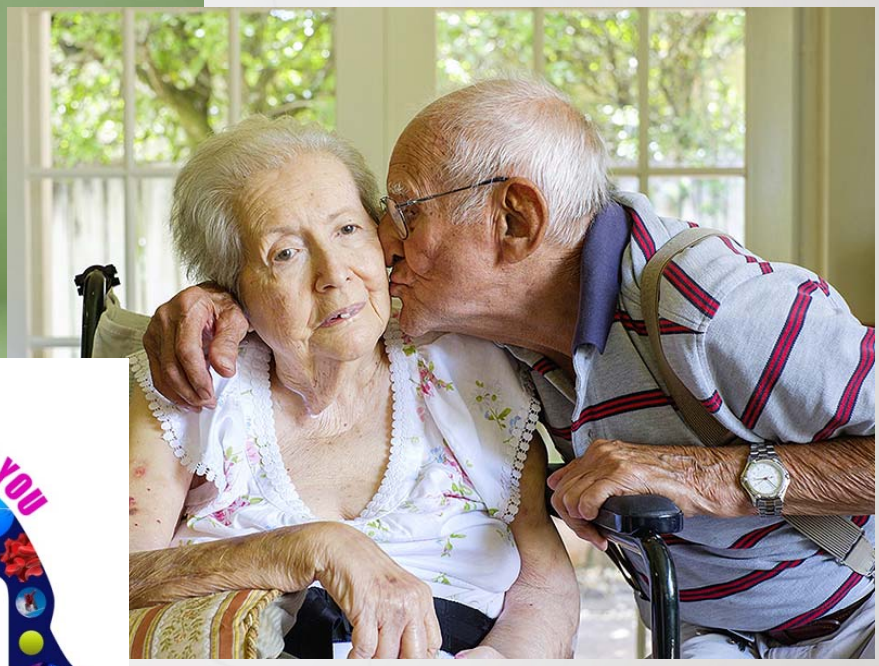
Person and Human

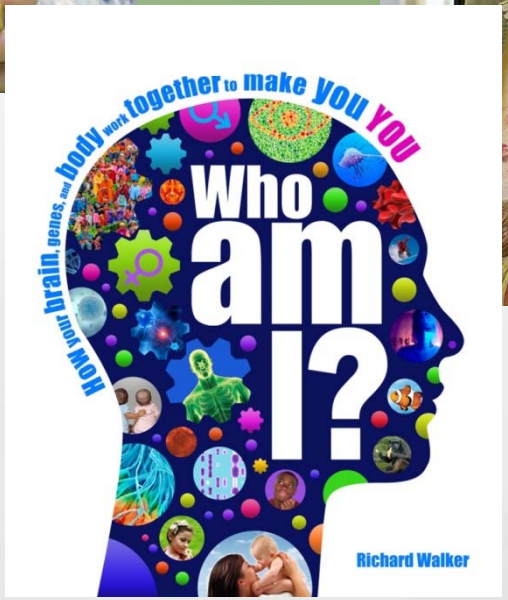
Non-human Person

Non-person Human

Who is a “Person”?

Who is this “Person”?





Personhood at the end of life

- Tony Bland suffered serious brain damage, persistent vegetative state. Bland's parents accepted their son had ceased to exist in any real, biographical sense although his body remained alive, asked the English courts to declare that it would be lawful for medical staff to withdraw feeding, other life sustaining measures so that their son would die.

- Lord Keith of Kinkel, "It is, however, perhaps permissible to say that to an individual with no cognitive capacity whatever, and no prospect of ever recovering any such capacity in this world, it must be a matter of complete indifference whether he lives or dies".

Personhood: Who is this person?

- May lived at home and cared for by an attendant. On visits, the community nurse found May reading. She was particularly fond of mysteries, “her place in the book jump randomly from day to day”. May did not remember her name but always seemed pleased to see her. She enjoyed painting the same circles everyday. She also enjoyed listening to music & appeared happy to listen to the same song again. May descried as “deniably one of the happiest people”.

- When a person can no longer accumulated new memories as the old rapidly fade, what remains? Who is May?

- May was a psychology professor who relished complex mental activities. May, while fully competent, executed an advance directive & was well informed, knowing that dementia affects different people differently, some happy and some distressed. She makes clear that even if she were to be experiencing no visible distress and were seemingly “pleasantly demented”, she would wish to be allowed to die if and when the opportunity were to present itself. May, now demented, contracts pneumonia likely to be fatal, unless she is prescribed antibiotics.

- Should May be treated or not?

Adapted from Helga Kuhse, Personhood & Health Care 2006

Philosophical critique of advance directives

Discontinuity of interest

The values and interests of the competent person no longer are relevant to someone who has lost the rational structure on which those values and interests rested. If the person is no longer competent enough to appreciate the degree of divergence from her previous activity that produced the choice against treatment, the prior directive does not represent her current interests merely because a competent directive was issued.

(1991:7; Dresser 1986)

Discontinuity of interest

"conflict between past competent interests and current incompetent interests. Need of the competent patient for control and certainty and the need of the incompetent patient for treatment."

Because advance directives either confuse the present interests of an incompetent patent with interests she had when competent, or forthrightly privilege the competent person's interests in control and certainty over the incompetent patient's current interests, they pose a threat to incompetent patients.

(1991:7)

Precedent autonomy

- Competent person's interest in controlling her life takes precedence over any interests the future incompetent individual might have.
- Distinction between experiential interests or preferences and more significant critical interests or commitments.
- Critical interests (the values and projects were consciously) are more morally significant than our merely experiential interests, such as eating an ice-cream, watching television.
- Values and projects give coherence to our lives (Dresser 1995).
- Psychological view of personal identity (Parfit 1986).
- Psychological continuity – necessary condition for personal identity.
- Exemplified by memories, intentions, beliefs, desires.
- Conceptual grounds for claiming that the severely demented patient is not the same person.

Psychological continuity

- A patient slipped into a persistent vegetative state irreversibly lost capacity to experience states of consciousness, is not the same person, no longer a person

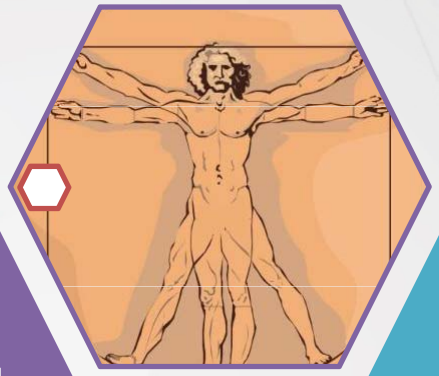
Personhood

- Buchanan (1988) severely demented lack the capacity for self-consciousness, rationality, and purposive agency, conception of themselves as existing over time. Although capable of experiencing states of pleasure and lack the capacity to sustain hopes and fears and a vision of their lives as extending into the future.
- Tooley (1983) ability to see oneself as existing over time, a necessary condition for being a person and “right to life”. Wrongness of an action related to the extent to which the action prevents some interests, desires, or preferences from being fulfilled.
- Refusal of life-sustaining treatment by a person should be honored if the individual succeeds her is not a person, does not have an interest in her own continued existence

Concept of Personhood

- Moral: Beings as moral agents
- Metaphysical: 1) Beings exhibiting certain criteria
  2) Mind and/or soul not reducible to the physical body
- Physical: No physical metaphysically distinct soul or mind
- Legal: Includes corporation
- Persons and Human Beings
- Degrees of Personhood: Partial person and pre-person

Perceptions of “Personhood”



(1) Inherent/ Transcendental Personhood

(2) Capacity-based approach to Personhood

(3) Interpersonal theories of Personhood

(4) The body

(1) Inherent/ Transcendental Personhood

Kitwood (1997)

- Sacred and Unique
- Every person had an ethical status
- Should be treated with deep respect

But…

- Belief does not necessarily guarantee that they are treated humanely and with respect
- Person's essence or soul may be no longer possible to reach

(2) Capacity-based approach to Personhood

Warren (1973) - Six Criteria for Personhood:

- Consciousness
- Reasoning
- Self-motivating activity
- Capacity to communicate
- Presence of self-report
- Self-awareness

Buchanan (1988)

- Capacity to perceive oneself as existing over time

(3) Interpersonal theories of Personhood

➔ *Relationship-based Understanding of Personhood*

Malloy and Hadjistavropoulos (2004)	"Who one is and who one can be are defined in the context of authentic relationships"
Kitwood (1997)	"It is a standing or status that is bestowed upon one human being, by others, in the context of relationship and social being. It implies recognition, respect and trust"

(3) Interpersonal theories of Personhood

Infant	Person with Dementia
• Caregivers consider infant's sounds and gestures are purposeful and meaningful • Caregivers attuned to and responds to the gestures and bodily rhythms of the infant • Key role in supporting and maintaining the interaction • Reflect a belief in the personhood of the infant	• Less degree of understanding and tolerance • Often consider as having had communication capacity/ lost it • Need additional support from others to maintain contact and share meaningful interaction • Advance dementia: difficulty communicating in ways that other people are willing to accept as meaningful • Depends on others to recognise

"Protoconversation"

Meaning of living with dementia and disturbing behaviour narrated by 3 persons in a residential home

- **Being surrounded by disorder**
  - "Sick" fellow residents spoil the order with unpredictable action and "some of them raise hell".
  - "Care providers have coffee in our dining room up to ten people babbling about nothing talk without saying anything."
- **Being trapped by restriction**
  - "I don't need a nanny, I am not allowed to go out on my own… it is a hell of a life."
  - "They have their stupid rules… they have their orders and I have my wishes."
- **Being set aside**
  - "It's boring… what am I going to do today and tomorrow?... Not much you can do here… who do you talk to?"
- **Being included**
  - "I go on well with the care providers… sometimes they ask for my knowledge and I enjoy giving information."

Graneheim, Jansson 2005

(3) Interpersonal theories of Personhood

Sabat (2001) – Three different selves:

1) Self of personal identity
2) Attributes a person possess
3) Social self or personae presented to others

People who have dementia…
➔ lose ability to maintain their social roles
➔ without having opportunity or capacity to take on alternative roles
➔ depends on mutual recognition and cooperation and **personhood**

Losing social roles
Does not necessarily imply
Loss of all notion of Self

Lawrene (2007)

"The challenge in dementia is to continue to seek for and not to dismiss that person."

(4) The Body

Hughes (2001) Moody (2003)	• Situated-embodies-agent view • Personhood is linked to a physical body in cultural and historical context
Merleau-Ponty (2002)	• Body-subject is capable of thought, reflection and communication "As dementia progresses the person can no longer rely on the unified form. Consciousness is expressed through bodily activity but the body, as a vehicle for expression, is breaking down. ***This does not mean that there is no consciousness***."

2) FOUNDATIONS OF PERSON-CENTERED CARE

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Person-centered care

- Antithesis of reductionism
- Asserts that patient are person
- A shift away from a model in which the patient is the passive target of a medical intervention

Benefit…

➔ Contribute to improved concordance between care provider and patient on treatment plans, better health outcomes and increase patient satisfaction

Ekman et al. (2011)

Patient-centered Care vs. Person-focused Care

Patient-centered Care	Person-focused Care
Generally refers to interactions in visits	Refers to interrelationships over time
May be episode oriented	Considers episodes as part of life-course experiences with health
Generally centers around the management of diseases	Views disease as interrelated phenomena
Generally views comorbidity as number of chronic diseases	Often considers morbidity as combinations of types of illness (multimorbidity)
Generally views body systems as distinct	Views body systems as interrelated
Uses coding systems that reflect professionally defined conditions	Uses coding systems that also allow for specification of people's health concerns
Is concerned primarily with the evolution of patients' diseases	Is concerned with the evolution of people's experienced health problems as well as with their diseases

Person-centered care vs. Personalized Medicine

Both approaches are intended

➔ to “Individualize Care”

➔ to compensate for our inability to predict

➔ to adapt care to exceptions from the medical norm

Personalized medicine explains and predicts individual exceptions based on genetic or other phenotype variations

Person-centered approach to care can explain and predict *individual exceptions based on who the person* is: their context, their history, their family and loved ones, their individual strengths and weakness

Routines to Person-centered Care

1. Initiating: patient narratives
2. Working: shared decision making
3. Safeguarding: documenting narrative

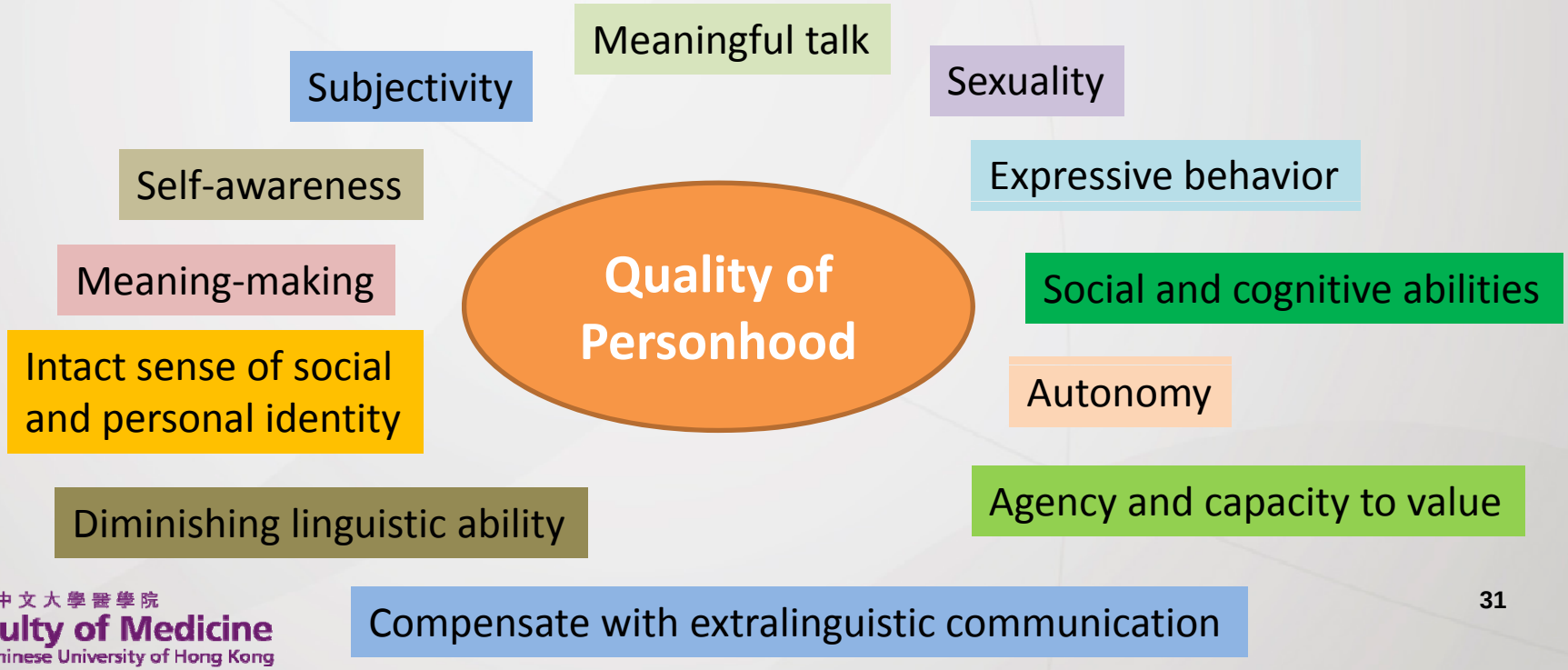
Person-centered Dementia Care

- Care that is centered on:
  - The whole person, not on the disease brain;
  - Remaining abilities, emotions and cognitive abilities – not on losses;
  - The person within the context of family, marriage, culture, ethnicity, gender
- Care that is centered within a wide society and its values

Cheston & Bender (1999)

Signs of Personhood

- ➔ Qualities of personhood in individuals suffering from dementia
- ➔ Seeks actively to make sense of and cope with is happening



Positive Interactions

Kitwood (1999)

(1) Social Interactions

Interactions	Details
Recognition	Individual known as a unique person
Negotiation	Consulted about preference, choices, needs
Collaboration	Caregiver aligns with recipient to engage a task
Play	Encouraging expressions of spontaneity and a self
Stimulation	Engaging in interactions using senses
Celebration	Celebrating anything the individual finds enjoyable
Relaxation	Close personal comfort

(2) Psychotherapeutic Interactions

Interactions	Details
Validation	Acceptable of reality, and feelings of being alive, connected and real
Holding	Provision of a safe psychological space, both psychological and physical
Facilitation	Enabling a person to do what otherwise he or she would not be about to do, by providing those parts of the action… that are missing

(3) Leading Role

➔ People with dementia can take a leading role in:

Interactions	Details
Creation	Spontaneously offers something to the interaction
Giving	Individual offers him/herself in a positive emotional or helpful

Benefit of Person-centered Care

- Quality of life
- Decreased agitation
- Improved sleep patterns
- Maintenance of self-esteem

3) MORAL BASIS OF HEALTH SYSTEMS

Moral Basis of Health Systems

1) Health Professionals

Professional obligation to care, developing technical expertise, understanding of central principles of morality and appreciation of personhood of patient.

2) Health Care Institute

Embody the commitments of the profession, appreciation of the complex and varying needs of the different people they serve in the organization and delivery of services to meet the standards.

3) Health Systems

- Policies and mechanisms that would allow the duty to be fulfilled healthcare delivery system designed for care of person.
- Moral basis of prioritisation

“Person-centered care is a journey in discovering and celebrating Personhood”

(Prof. EK Yeoh, 2015)

Thank You!

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