The Chinese University of Hong Kong The Nethersole School of Nursing CADENZA Training Programme

CTP003 Chronic Disease Management and End-of-life Care

Web-based Course for Professional Social and Health Care Workers

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Chapter 6

Assessing and optimising quality of life of older people with chronic diseases



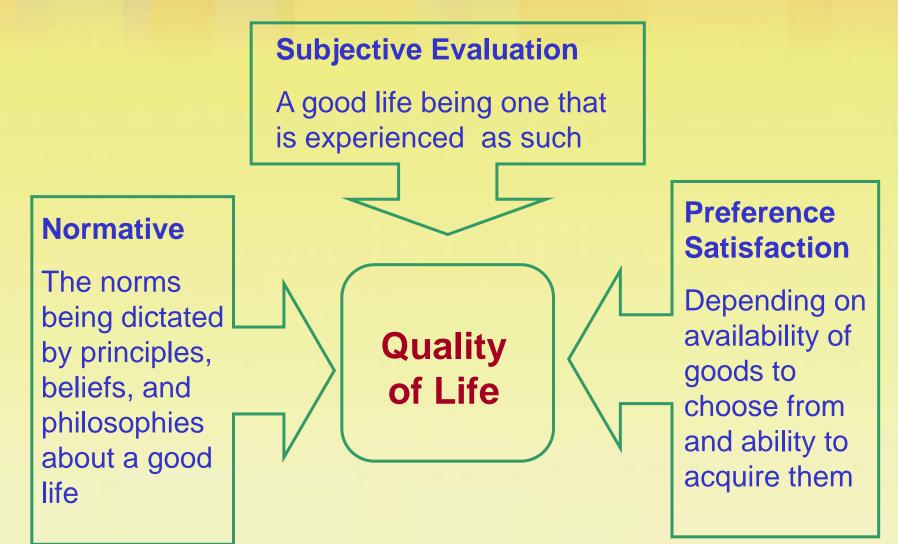
Lecture Outline

- 1. Definition of quality of life (QOL) and health-related quality of life (HRQOL)
- 2. Assessment of health-related quality of life
- 3. Older people's attitudes towards QOL
- 4. Relationship between QOL and chronic diseases
- 5. Optimising QOL of older people with chronic diseases

Definition of " Quality of Life "

- " The degree of well-being felt by an individual "
 Wikipedia, 2008
- "The patient's ability to enjoy normal life activities" Medical Dictionary, 2008
- "An individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns " WHOQOL, 1995

Approaches to Define Quality of Life



What is Health Related Quality of Life? (HRQOL)

Definition of HRQOL

- The effect of health on an individual's satisfaction or happiness.
- Health perceptions, symptoms and overall quality of life are included in the concept domains of HRQOL.
- The assessment of HRQOL is crucial in informed patient management.

American Thoracic Society (2007)

How is Health-related Quality of Life Assessed?

Two Basic Approaches

Self-assessed health instruments Generic instruments



1. Self-assessed Health Instruments

Specific instruments that focus on

4 problems associated with single disease states

4 patient groups

4 areas of function

Ware, 2000

2. Generic instruments

The generic instruments used in

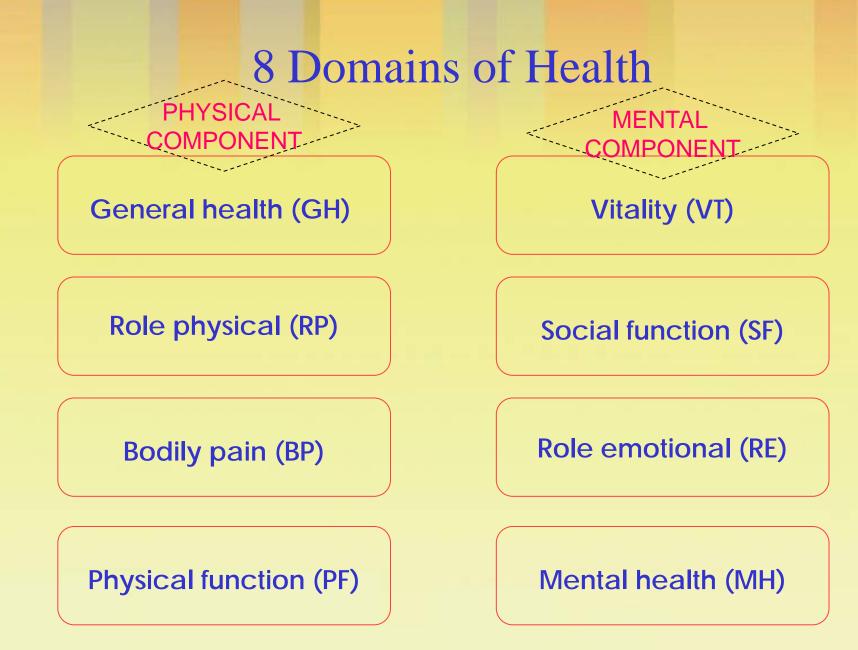


4 comparing populations generally and specifically
4 comparing the relative burden of diseases
4 identifying the health benefits produced by different treatments
4 screening individual patients

Ware 2000

Introduction of SF-36 Version 2.0

- SF-36 is an instrument used in more than 50 countries as part of the International Quality of Life Assessment (IQOLA) Project.
- A multi-purpose, short-form health survey.
- It includes 36 questions with 8 domains of health and includes functional health and well-being scores as well as psychometrically-based physical and mental health summary measures and a preference-based health utility index.



Scoring

- Scoring in <u>2 summary measures</u> aggregating 8 scales
- Summation of all items in the specific scale
- No further standardisation or weighting
- Physical component score (PCS): combines PF, RP, BP, and GH
- Mental Component Score (MCS): combines VT, SF, RE and MH



http://www.sf-36.org/tools/sf36.shtml

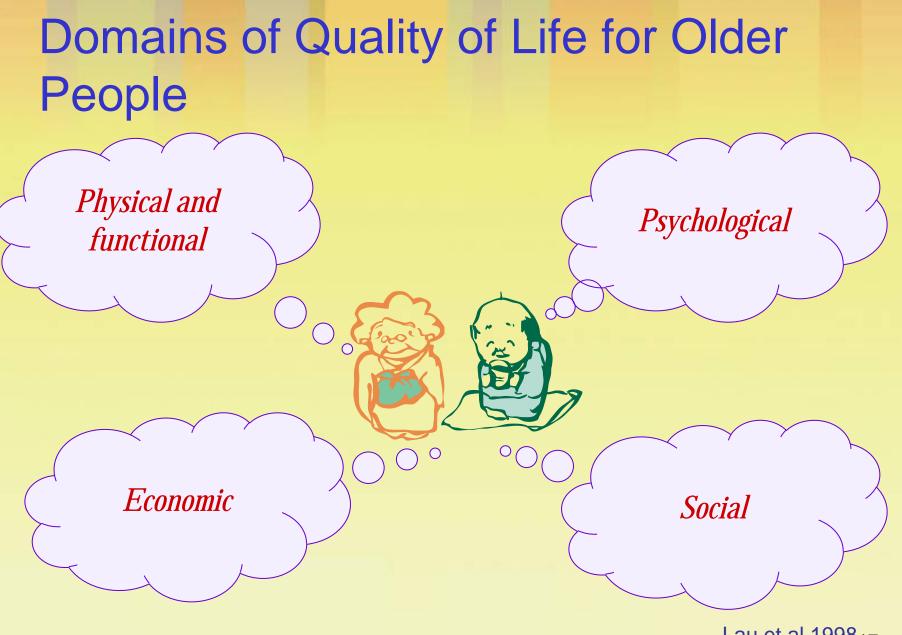
Score interpretation

Average: 50

- Below average: 0-49
- Above average: 51-100
- 10 points = 1 standard deviation
- Score below 50 indicates below average health status and should trigger further investigation
- Increasing deviations à higher need for further assessment



What is Quality of Life from an Older Person's Viewpoint?



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Lau et al 1998₁₇

Elements of Physical and Functional Well-being

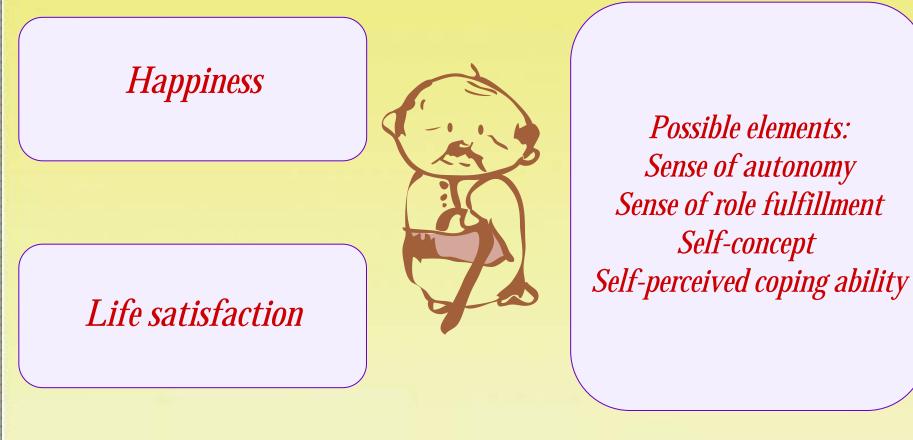
Good health Fewer illnesses, less pain, Able to eat, sleep, walk and run

> *Leisure Keep active*

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Lau et al 1998₁₈

Elements of Psychological Well-being



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Lau et al 1998₁₉

Elements of Social Well-being

<u>Social interaction:</u> Social activities and relationships, opportunities to socialise



Social support: Religion and culture, emotional support, new social contacts

Social networks: Formal: e.g., community elderly centres, governmental departments

Informal: e.g., family and friends

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Lau et al 1998₂₀

Elements of Economic Well-being



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Lau et al 1998₂₁

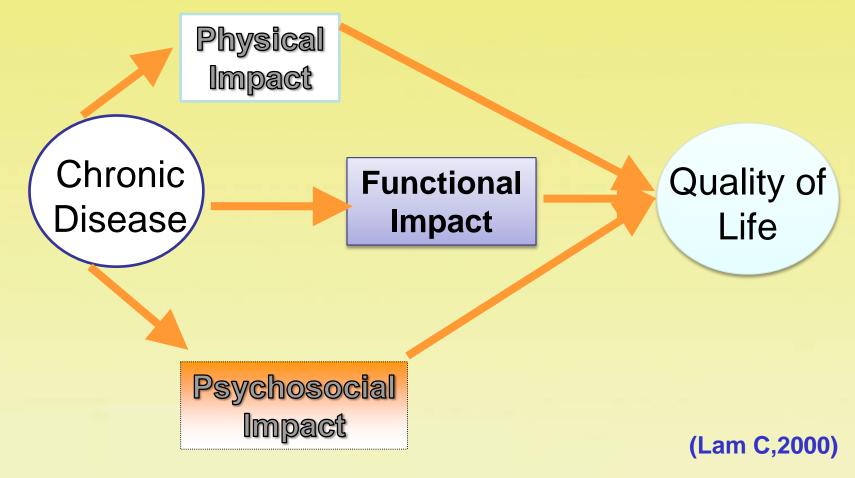
Quality of Life (QOL) for Older People

- The impact of chronic diseases on the physical and psychosocial wellbeing of older people.
- Chronic disease reduces the functional capacity of the individual.
- "The QOL for older people has typically been reduced to QOL as related to health." (Morewitz, 2007)
- The measurement of health-related quality of life (HRQOL) would strengthen and make better <u>clinical</u> <u>decision making</u> and <u>intervention</u>, and allow <u>evaluation of the effectiveness</u> of the intervention.

Relationship between Chronic Diseases and QOL



Chronic Diseases and Quality of Life



Chronic Diseases and Quality of Life

- Chronic disease has unfavourable effects on quality of life.
- In low-income countries, middle-aged adults are especially vulnerable to chronic illness.
- Chronic disease impedes the economic development of many countries.

Problems and issues of QOL in chronic diseases -- physical and functioning issues

Reduction of functional ability

Fatigue

Altered sleep and rest

Change in physical health

Change in leisure activities

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26 Grant & Rivera, 1998

Problems and issues of QOL in chronic diseases -- psychological issues

Feeling of loss of self-control

Anxiety

Depression

Distress arising from diagnosis and treatment

Difficulty in coping with chronic disease

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Grant & Rivera, 19987

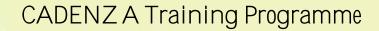
Problems and issues of QOL in chronic diseases -- social issues

Family distress

Change in roles and relationships within the family

Decreased enjoyment

Increased need for social support



Grant & Rivera, 1998 28



Problems and issues of QOL in chronic diseases -- economic issues

Increased financial burden arising from treatments and hospitalisations



Household adjustment

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Grant & Rivera, 1998 29

Health-related Quality of Health -HRQOL



Lam & Lauder's Study

Title:

The impact of chronic diseases on the HRQOL of Chinese patients in a primary care clinic in Hong Kong Objective:

To determine the impact of eight chronic diseases on the HRQOL of Chinese patients

Design:

A cross-sectional case-control study

Sample:

760 adult Chinese patients of a family medicine clinic in Hong Kong, with mean age 57.6.

Lam & Lauder, 2000

Results

- Patients with chronic diseases were more likely to be older, less educated, unskilled workers and persons whose spouses were deceased.
- Many chronic diseases had an adverse effect on the HRQOL of Chinese patients and that different conditions affected different aspects of life.
- Depression was the most disabling disease, and osteoarthritis of the knee had more impact on the HRQOL than many other chronic diseases.

Lam & Lauder, 2000

- OA of the knee was more disabling than hypertension and diabetes mellitus from the patients' point of view.
- Daily role functioning was the most commonly affected HRQOL domain



Lam & Lauder, 2000

The author suggested that it is necessary to include HRQOL as a routine outcome measure of care for patients with chronic diseases if health services are really for the betterment of the quality of life of people.

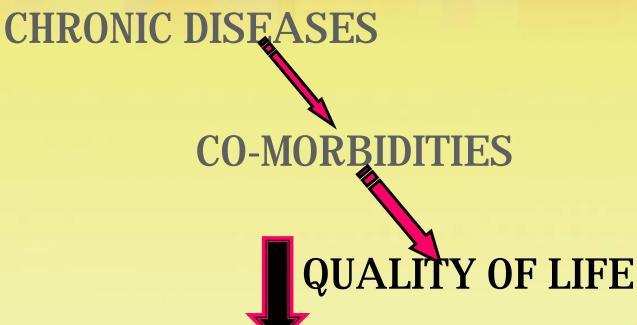


Lam & Lauder, 2000

A very important message in the study is that it would be useful if **positive and negative coping behaviours in each culture** could be identified so that appropriate counseling could be given to patients



Lam & Lauder, 2000





Walker's Study

Title:

Multiple chronic diseases and quality of life: patterns emerging from a large national sample, Australia

Objective:

To study the associations between co-morbidities and quality of life

Design:

Analysis of unit record cross-sectional data from Australian national surveys

Walker, 2007

Results

Older people, obese people, women, people with low socio-economic status and living alone have significantly greater probability of having co-morbidities



Walker, 2007

Among people with co-morbidities and/or with poor self-rated general health, those living alone, low educational qualifications and low socioeconomic status were more likely to have negative impact on QOL and greater psychological distress

Walker, 2007

Multiple chronic diseases were found to have a considerable negative impact on QOL.

The QOL in this study did not only refer to how people felt about their lives generally, but also in terms of the extent of their psychological distress.



Walker, 2007

Optimising QOL of Older People with Chronic Diseases



What People with Chronic Disease Need?

Coordination of care across settings and professionals



Systematic follow-up and assessment tailored to clinical severity

> A care team and practice system organized to meet their needs for information and support for their self-management

http://www.sgim.org/file_library/sgim/resource_library/meeting_handouts/aclgim/2007/warm_acgim_summit2007.pdf 42

A community-focused, patient-centred and knowledge-based integrated health care service is of the utmost importance in providing a comprehensive and integrated service to people with chronic disease in the community.



Community-based healthcare service programmes can provide

- a better quality of life for people with chronic disease
- a better drug compliance for chronic disease patients in family practice

The community based healthcare programme involved

- 1. A strong **primary health care team** with well trained family physicians and health professionals as primary care practitioners to provide services on health promotion; Curative; Rehabilitation and supporting services;
- 2. Support <u>self help activities</u> of individuals families and groups

A strong primary healthcare team coupled with self help activities:

- Minimize compartmentalised health care delivery
- offers an economical way to provide high quality holistic and comprehensive care

Lee 2003

Public private interface and collaboration is therefore important to provide a continuous, comprehensive and integrated health care services for chronically ill people.

Sharing of medical information is essential for continuous care.



To have a better understanding on the trend of **Primary Healthcare Delivery System** and Public – Private partnership in Hong Kong, please click into the below website and read Ch. 2 to 3. http://www.fhb.gov.hk/beStrong/eng/consultation/consultation_cdhcr_cd

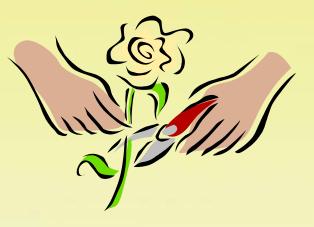
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Apart from improving the primary healthcare system, **patient support and self help groups** are also important in helping older people with chronic diseases enjoy a better quality of life.



There are lots and lots of patient support groups organized by the Hospital Authority and nongovernmental organizations (NGOs).

http://www21.ha.org.hk/smartpatient/en/finda_group.html



Summary

- The pursuit of health is a lifelong process.
- Life expectancy is becoming longer and <u>chronic</u> <u>illnesses</u> pose a great burden to the healthcare system in Hong Kong.
- A high quality health care system is vital in optimizing the health of older people with chronic illnesses.

- In addition, community resources, such as NGOs and volunteer groups should participate in order to achieve a healthy multi-generational society. Health is also the responsibility of each individual.
- Personal concepts of <u>health</u> with regard to older people with chronic disease and family members, are equally important.

- Adopting health-promoting behaviours with healthy lifestyles.
- Good compliance with treatment regimes definitely improves the quality of life for older people with chronic diseases.

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