

Well-being



The psychosocial & spiritual aspects of well-being in people with far-advanced disease.

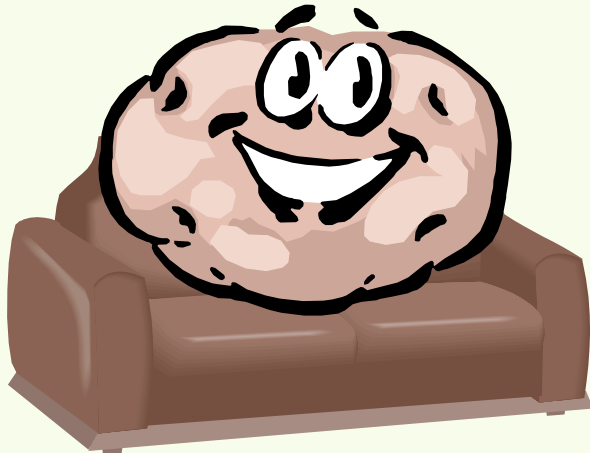
Quality of Life

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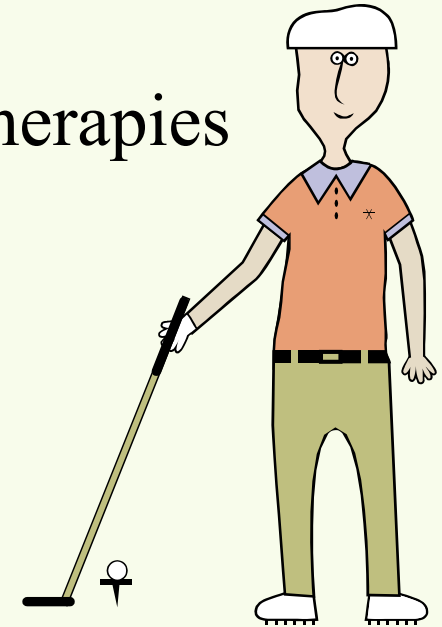
Identify approaches to enhancing on patient's quality of life.

Introduction

- Quality of life (QOL) varies from person to person.
 - Stage of life and activities
 - Stage of disease and concomitant therapies

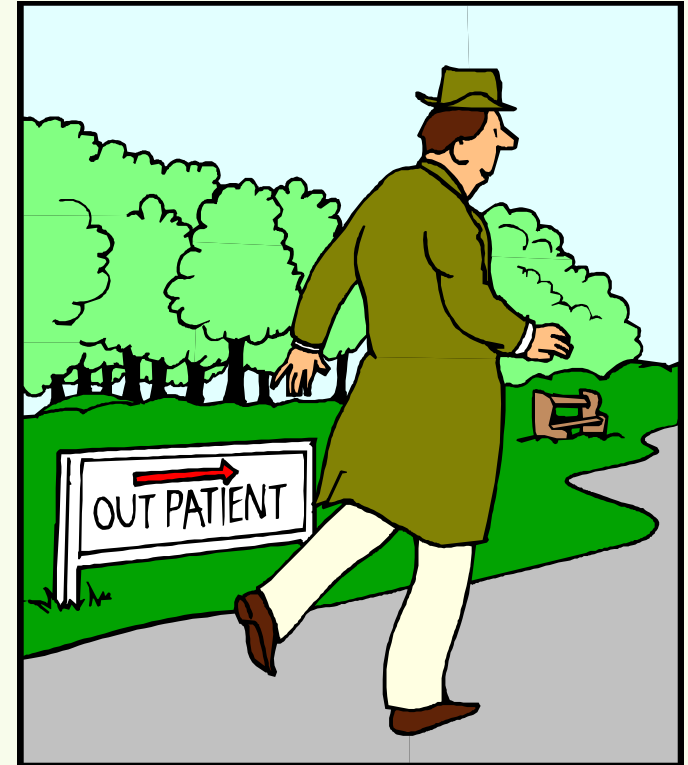


QOL



What's Recovery?

- Two approaches
 - Patient A:
 - “My golf handicap has returned to where it was before I was sick”
 - Patient B:
 - “I’m feeling so much better than I did two weeks ago.” “Why?”
 - “My sexual prowess has returned to normal.”



Assumptions

- Quality of life is an important outcome variable in illness care.
- Quality of life has a major impact on a person's living and dying.



Defining Quality of Life

- Lamers (1990) definition of quality of life:
 - “a subjective internal impression, an attitude, a way of conceptualizing reality.”
- **Audio** Lamers states: “caregivers cannot presume to know what constitutes good quality of life for another person...”
- Calman (1984) definition of quality of life:
 - **Audio** Calman observes: quality of life “measures the difference, at a particular point in time, between the hopes and expectations of the individual and that individual’s present experience.”
- Quality of life for a child
 - Living at home, going to school.

Related Terms

- Well-being
 - A general term that is presumed to reflect an individual's quality of life.
 - Often modified by reference to specific aspects of quality of life such as spiritual or psychological.



Quality of Life Determinants

- Meaning and transcendence are important determinants of quality of life
 - Transcendence implies rising above a set of circumstances, in this case, terminal illness.
 - While physical status has an impact, individuals may achieve high quality of life due to other factors that are of significance.



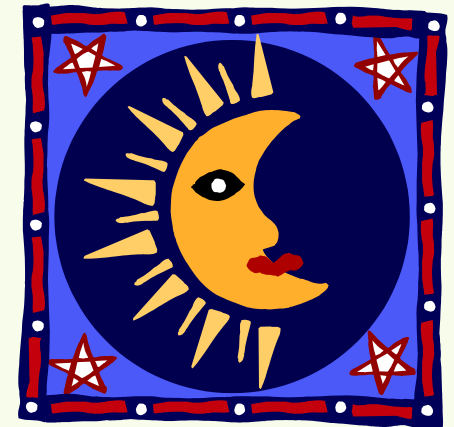
Measuring Quality of Life I

- American Society of Clinical Oncology on the importance of quality of life in the care of the patient
 - Members of the Task Force on End-of-Life Care stressed that “Cancer care optimizes the quality of life throughout the course of an illness through meticulous attention to the myriad physical, spiritual, and psychosocial needs of the patient and family.”



Measuring Quality of Life II

- Components of physical, social and spiritual well-being (Picket and Yancey, 1996)
 - Physical well-being (symptoms):
 - Multiple symptoms due to disease progression, debility, organic and metabolic changes
 - Ability of self-care
 - Pain
 - Nausea/vomiting and/or lack of appetite
 - Dyspnea
 - Delirium/restlessness/agitation
 - Fatigue/weakness/immobility/sleep changes
 - GI disturbances (constipation/diarrhea)
 - Urinary incontinence



Measuring Quality of Life III

Psychological well-being (mood states)

Anxiety/fear

Depression

Loneliness

Suffering

Dependency/lack of independence

Decreased self-esteem/self-respect

Guilt/anger

Adjustment to the disease/prognosis

Satisfaction with care

Despair

Acceptance of loss

Denial/acceptance

Social well-being (roles):

Sense of burden on family

Loss of control over life

Relationships with others

Changing family roles/status/family structure

Family interactions

Fear of abandonment/isolation

Financial concern

Declined leisure activities

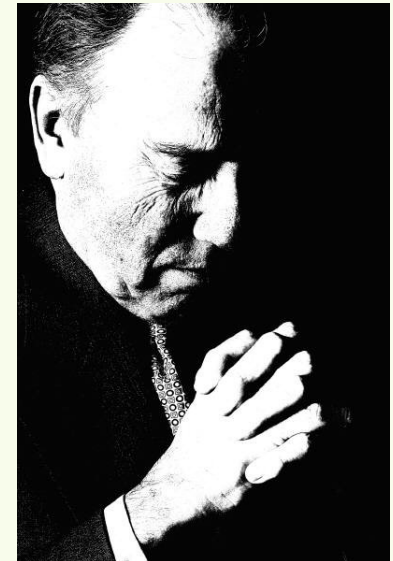
Employment status/workplace relations

Sexuality



Measuring Quality of Life IV

- Spiritual well-being (own sense of self):
 - Religion (rituals, practices, prayers, meditation)
 - Relatedness to God (Superior Being)
 - Meaning of life/existential:
 - Reason for events, purpose of life, belief in a primary force in life
 - Hope (reality-based)
 - Forgiveness/acceptance
 - Transcendence:
 - Redefines views of life, redefines relationships
 - Spiritual needs vary and fluctuate with changes in physical symptoms
 - Feelings of uselessness



Measuring Quality of Life V

- Two additional issues in measurement of QOL:
 - The importance of having items that are relevant to the patient.
 - Using an instrument that does not pose a burden to the patient.
- Measurement of quality of life is undertaken as an outcome measure of care for quality assurance

(Byock & Merriman, 1998)

Enhancing Quality of Life

- Healthcare providers have a major role in enabling terminally ill persons to die well.
- Ferrell indicates a number of ways to enhance quality of life at the end-of-life:
 - Effective communication/listening
 - Stress management/effective coping mechanisms
 - Available resources/support available
 - Support in decision making
 - Resolve conflicts
 - Complete unfinished business
 - Maintain “non-illness related aspects of life”
 - Cope with anticipatory grief



(Ferrell, 1999)