



Well-being

Quality of Life

Instruction Material/ Content

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Introduction

While the notion of quality of life at the end of life may seem an oxymoron, it is not. What constitutes quality of life varies not only from person to person but also with the stage of life and stage of disease and concomitant therapies. For example, participation in team sports may be relevant to an individual at one point in life but not at another.¹ Therapies that diminish a patient's strength will have a greater impact on the physically active person and less so on the "sedentary individual." Cohen and Mount² quote McDonald, who provided the following illustration:

Two patients receiving chemotherapy for metastatic carcinoma were seen by their oncologist during the same afternoon clinic. "I'm feeling so much better than I did two weeks ago," commented the first. "Why," asked the doctor. "My golf handicap has returned to where it was before I was sick," came the enthusiastic response. By chance the conversation with the very next patient was similar. "I'm feeling so much better than I did two weeks ago." "Why?" "My sexual prowess has returned to normal" (p.40).²

The approach taken to quality of life should vary accordingly. The focus of this segment is quality of life at the end of life. As a result, the plethora of studies about quality of life at earlier phases of the illness trajectory will not be considered here.

Assumptions

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

Defining Quality of Life

Lamers defines quality of life as "a subjective internal impression, an attitude, a way of conceptualizing reality" (p. 122).³ He makes the further point that caregivers "cannot presume to know what constitutes good quality of life for another person any more than we can say with certainty we know exactly how you feel." (p. 122).³

Calman observes that 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." (p. 124)⁴ Given that the hopes and aspirations of the 18-year-old and 81-year-old may differ, their sense of what constitutes quality of life (QOL) will differ accordingly.

Cohen and Mount² address the impact of life-threatening illness for quality of life. "To the degree that QOL reflects perceived meaning, QOL may be expected to fluctuate in the face of life-threatening illness as each new reality is progressively integrated and the implication for each component of the person appreciated anew" (p.41).² This definition is useful in that it addresses the continuous iterative process that is a part of terminal illness and therefore quality of life.

An example of this iterative process is the experience of Mrs. Thomas. She had surgery to relieve a bowel obstruction caused by spread of her cancer. The surgery resulted in a colostomy. Although she knew that the surgery would prolong her life, her fastidious self was offended by the colostomy and its contents. Further, her sexual relationship with her husband was an

important part of their relationship. With the colostomy, she no longer felt appealing to her husband. Nursing staff so felt it was important that Mrs. Thomas be taught how to irrigate her colostomy. They prevailed on the hospice nurse to help prepare Mrs. Thomas for discharge.

Mrs. Thomas had a relationship with the hospice nurse whom she had been seeing for psychological support. The hospice nurse visited Mrs. Thomas regularly, inquiring about her well-being and whether she was ready to learn more about her colostomy. On each occasion, Mrs. Thomas declined. The hospice nurse responded that they would place the issue on the shelf and take it down when Mrs. Thomas was ready.

On a visit to Mrs. Thomas, the hospice nurse was happy to learn that Mrs. Thomas was ready to learn more about her colostomy. As they began to discuss colostomy care, Mrs. Thomas raised the question of her sexuality with her colostomy. The hospice nurse commented that the colostomy bag covers should be available with gingham during the week and black lace on the weekend. Mrs. Thomas laughed. The gingham and black lace would allow her to redefine her concept of quality of life.

The environment affects the well being of the child. Another example of this is the following: When the mother was in the hospital with her dying son and she would move her legs, the boy would call out and say, "Mommy do not leave me." When the child was taken home, the mother was able to go downstairs to wash clothes and this absence was okay with the child. In the home setting, the child asked to eat pie crust and the mother was able to make a pie crust for him. In his own bedroom the child could point to the book he wanted his dad to read to him. The home usually offers the best setting for a dying child as long as there are adequate health care providers involved.

Dying children may still be able to go to school and participate in out of home activities such as going to the grocery store to pick out the food they want to eat. Children have the remarkable ability to use their energy so as to participate for short periods of time in activities in which they wish to participate.

It is interesting to observe how many authors write about quality of life without defining its meaning. Definition occurs de facto by operationalization of the facets of the concept.

Related Terms

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

Quality of Life Determinants

Meaning and transcendence have been recognized as important determinants of quality of life.² Transcendence implies rising above a set of circumstances, in this case, terminal illness. Transcendence also suggests a change in thinking, say, from seeing the glass as half empty to seeing it as half full. But it is more than a change in cognition. Meaning and transcendence address how the person views him or herself and being terminally ill. While physical status has

an impact, individuals may achieve high quality of life due to other factors that are of significance. Cohen and Mount² give the following striking example:

CD was 30-years-old when he presented with a widely disseminated germinal testicular tumor. Radical surgery and chemotherapy initially resulted in his serum tumor markers reverting to negative and the hope of cure, but within months his disease progressed with ensuing extreme cachexia. He died slowly over a 12-month period. CD had always stood out from his peers. He had always been a winner. Strong. Outgoing. Gracious. A world-class athlete, he was a member of the national ski team. He was successful in business and engaged to be married. A champion from a family of competitive champions, he was now melting before the raging forces of the embryonal cell. Then, just days before he died he married his fiancée and said goodbye to those people he loved, observing, "This last year has been the best year of my life." (p. 41)²

Measuring Quality of Life

The importance of quality of life in the care of the patient with cancer has been emphasized by the American Society of Clinical Oncology. 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."⁵

What is of note in this statement of principle by ASCO is the emphasis on spiritual and psychosocial as well as physical, together with an emphasis on patient and family. Most assessments of quality of life examine these parameters.

Payne examined the following parameters in a study of cancer patients receiving palliative chemotherapy: anxiety, depression, self-esteem, health locus of control, physical performance, symptoms, social roles, relationships, perception of treatment. The factors that were most significant in explaining differences in quality of life were depression and anxiety.⁶

Picket and Yancey subsume depression and anxiety in the category psychological well-being.⁷ They also identify components of physical, social and spiritual well-being. Their comprehensive assessment was included in Ferrell's End-of-Life Care Content Guideline.⁸

Physical well-being (symptoms)⁷

- Multiple symptoms due to disease progression, debility, organic, and metabolic changes
- Ability of self-care
- Pain
- Nausea/vomiting
- Lack of appetite
- Dyspnea
- Delirium/restlessness/agitation
- Fatigue/weakness/immobility/sleep changes
- GI disturbances (constipation/diarrhea)
- Urinary incontinence

Psychological well-being (mood states)⁷

- 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)⁷

- 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

Spiritual well-being (own sense of self)^{7,9}

- 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 (realistic-based)
- Forgiveness/acceptance
- Transcendence:
 - Redefines views of life
 - Redefines relationships
- Spiritual needs vary and fluctuate with changes in physical symptoms
- Feelings of uselessness.⁷

In order to measure quality of life once there is agreement as to how this concept is to be operationalized, two additional issues must be addressed. The first is the importance of having items that are relevant to the patient. And the second is using an instrument that does not pose a burden to the patient.

Byock and Merriman¹⁰ in the Missoula-Vitas quality of life index, version 25S have six categories including: global, symptom, function, interpersonal, well-being, and transcendent. The response categories range from best possible to worst possible or agree to disagree. In addition to the 25 questions that are divided among the categories, there is one question that is global, namely “How would you rate your overall quality of life?”¹⁰

Measurement of quality of life is undertaken as an outcome measure of care for quality assurance. It is also assessed to identify areas that need improvement in order to enhance quality of life.

Enhancing Quality of Life

Healthcare providers have a major role in enabling terminally ill persons to die well. Ferrell¹¹ 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”
- Changing perception of space, span, or focus of time (Take one day at a time)
- Coping with anticipatory grief
- Define attainable goals
- Engage in spiritual practices
- Conserve energy with demands (use resources)
- Help the individual explore losses and their meanings¹¹

These activities focus on resolution of past problems, adjustment to illness related factors, reorganization of current activities to more effectively meet demands, and exploration of non-medical life-enhancing practices. In addition to these suggestions, the importance of scrupulous attention to symptom management cannot be emphasized enough. As Dame Cicely Saunders would say, a patient who is in a wet bed can think of little else.

Finally helping a patient recognize the legacy that he or she is leaving contributes to quality of life. For example, development of a book of memories that contains mementos of an individual’s life, a tape of memories or favorite music or a videotape of significant events can be very meaningful for both the patient and family, significant others, and friends.

In sum, quality of life is what the patient determines is important. To be helpful, providers would do well to address any concerns or problems the patient identifies. In so doing the nurse will be helpful to the family as well as the patient. Enhancing quality of life enables the patient to die well.

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