



QUALITY OF LIFE OF CANCER PATIENTS AND SURVIVORS

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BACKGROUND

- Trend toward improved survival rates and increased length of life
- Advances in prevention, diagnosis, and treatment
- Side-effects and discomforts can come from the cancer treatment or from the cancer itself
- Longer life does not always equate to an improved quality of life
- Therefore, personalized plans of care for people with cancer need to address:
 - physical needs
 - psycho-social and emotional needs
 - support such as help at home or financial advice.

DEFINITIONS OF “QUALITY OF LIFE”

- Quality of Life – multiple definitions and dimensions
- Degree of satisfaction an individual has regarding general well-being
- Mental status, physical abilities, stress level, symptom burden, sexual health, and overall self-perceived health status
- A measure of the optimum energy or force that endows a person with the power to cope successfully with the full range of challenges encountered in the real world
- Satisfaction with one’s own quality of life is highly individualized and should be considered when planning care for a cancer patient/survivor throughout the continuum of care
- An individual’s personal sense of well-being or satisfaction with the attributes of life is difficult for a health care provider to evaluate

CONTINUITY OF CARE

- Quality enrichment methods can include activities that reduce boredom and allow a maximum amount of freedom in choosing and performing various tasks
- At the time of diagnosis, during the treatment phase, and after treatment, regardless of treatment outcome
- If after-treatment care is inadequate, the patient and family may feel abandoned by the health care system
- Once treatment has been completed, it is vital that people continue to receive the appropriate care and support
- Important to monitor symptoms in the hospital and at home

FOUR-STEP PROCESS

- Symptom Assessment
- Evaluate Symptom Severity and Burden
- Determine Impact of Symptoms on Quality of Life
- Develop an Individualized, Continually-Evolving Plan of Care

CORE SYMPTOM ASSESSMENT

- Core symptoms related to the cancer diagnosis or the cancer therapy should be assessed with regularity
 - Pain
 - Sleep disturbance
 - Shortness of breath
 - Fatigue
 - Dietary and Elimination changes
 - Appetite, Taste, Nausea, ability to chew
 - Mood
 - Relationships, sexuality, and intimacy
 - Physical changes, hair loss, body image
 - General enjoyment of life

MEASURING SYMPTOM SEVERITY & BURDEN

- The MD Anderson Symptom Inventory (MDASI)
- Multi-symptom patient-reported outcome (PRO) measure for clinical and research use
- Linguistically Validated in 30+ Languages
- Available in paper-and-pencil, electronic, and telephone-based interactive voice response (IVR) format
- Standardized assessment of
 - Type & severity of symptoms experienced by patients with cancer - 13 items
 - The degree of interference with daily living – 6 items
- <https://www.mdanderson.org/research/departments-labs-institutes/departments-divisions/symptom-research/symptom-assessment-tools/md-anderson-symptom-inventory.html>

ADDITIONAL MDASI MODULES

- Additional measures that are specific for type of cancer
 - MDASI-AML/MDS - (Acute Myeloid Leukemia/Myelodysplastic Syndrome)
 - MDASI-BT – (Brain Tumor)
 - MDASI-CGVHD – (Chronic Graft-vs-Host Disease)
 - MDASI-LC – (Lung Cancer)
 - MDASI-OC – (Ovarian Cancer)
 - MDASI-HF – (Cancer with Heart Failure)
 - MADSI-TCM – (Traditional Chinese Medicine)
 - And several others – GI, Stromal, Head & Neck, Multiple Myeloma, Spine, Thyroid

MEASURING QUALITY OF LIFE

- Valid and reliable metrics are available to consistently measure quality of life related to symptom burden
- Utilized to increase the effectiveness of supportive care for cancer patients and their care providers
- Cancer Treatment Centers of America[®] (CTCA) use quality of life metrics as part of its routine assessment of patient well-being and quality of care
- Research demonstrates Patient Reported Outcome (PRO) data are a valuable part of a patient's treatment plan

NHS QUALITY OF LIFE MEASURE

- NHS in England
 - 2017 - questionnaires to measure effectiveness of health care
 - Specifically measures quality of life for recovering cancer patients
 - Personalized follow up to individual needs and preferences
 - Available on My NHS
- <https://www.england.nhs.uk/2017/09/new-quality-of-life-measure-for-recovering-cancer-patients/>

PLAN OF CARE

- For some survivors, intensive clinical support will be ongoing, while others may feel confident to take control and manage their own care, seeking support only when they feel assistance is needed
- Specific and personalized plans of care will vary based on
 - the type of cancer
 - the cultural context of care
 - access to healthcare services
 - individual needs and preferences
- Individualized and continuously evolving

MAXIMIZING OUTCOMES

- To maximize outcomes and improve satisfaction, health care assistance needs to move beyond physical symptom management
- Do not neglect supportive care in the home, financial assistance, and other psycho-social domains
- Important to measure and address outcomes that matter to the patient/survivor!