Quality of Life in Adolescents with Cancer

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Quality of Life (QOL)

- Measurement of goodness of different aspects of life
- Emotional reactions to life events, disposition, sense of fulfillment, satisfaction with work and personal relationships
- In cancer
  - Physical, psychological, social, & spiritual well-being
Adolescents with Cancer

- Survival rates increasing
  - 10,380
    - <15 years old
  - 5,000
    - 15-19 years old
- >80% survival rate of 5 years in pediatrics with cancer
Effects of Cancer Treatment

- Nausea
- Pain
- Anxiety
- Perceived physical appearance
- Worry
- Fatigue
Literature Review
Measuring QOL

- Instruments with questions related to
  - Psychological, physical, & social well-being
  - Self-determination
  - Independence
  - Satisfaction with control of the disease process

- Instruments
  - Questionnaires
  - Interviews
  - Patient Report
  - Rating Scales
Measuring QOL Cont.

- Related to adolescents and young adults (AYA) with cancer
  - Emotional resilience
  - Adaption
  - Physical, emotional, & social functioning
  - Influence of others

- Report from the AYA
Factors that Affect QOL

- Pain & anxiety
- Fatigue
  - Decreases functional status
  - Increases depressive symptoms
- Nausea, lack of appetite
- Psychological distress
- Cancer survivors are more likely to have
  - Depression
  - Post traumatic stress disorder (PTSD)
  - Risk for negative social, behavioral, & physical outcomes
AYA as Own Population

- Commonly not addressed as own population
- Different journey than pediatrics or adults
- Lack of specialized care leads to unmet needs which leads to
  - Anxiety
  - Depression
  - Distress
- Unmet Needs include
  - Lack of information on care
- Pain management
- Physical & occupational therapy
- In-home nursing care
- Concerns not addressed
  - Fertility
  - Risk of relapse
  - Impaired body image
    - Weight
    - Loss of hair
    - Scars
  - Fitting in with peers
Development of the AYA

- Time of growth and development of
  - Independence
  - Confidence
  - Gaining a sense of self

- Cancer can interrupt
  - Maturing autonomy
  - Values
  - Relationships (including intimate)

- Adolescence time of
  - Personal experimentation
  - Forming new relationships
  - Discovering sexual awareness
  - Witnessing or participating in risk-taking behavior
Substance Abuse

- Average AYA reports 8.5-25% cigarette smoking, binge drinking, marijuana or illicit drug use
- Cancer diagnosis may increase the risk for these behaviors
  - Coping
  - Desire to fit in with peers
  - Fun
- Effects beyond the normal health risks for AYA with cancer
  - Hepatotoxicity
  - Pulmonary toxicity
  - Cardiac toxicity
  - Drug to drug interactions
  - Development of secondary cancers
Recommendations
Assessment of Needs

- Do not fit into pediatric or adult mold
- Proper needs assessment is essential for developing appropriate interventions
- Cancer Needs Questionnaire- Young people (CNQ-YP)
  - 70 items, 6 categories
  - First multi-dimensional measure for AYA cancer patients
  - Used before initial treatment
  - Reliable for assessing environment and care, feelings and relationships, daily life, information and activities, education and work
  - Educate more health professionals on tool
  - Able to screen QOL before it becomes a problem
Maintaining Normalcy

- Support and engage in normal tasks and milestones
- Working around treatment schedule to attend special events
- Family and friend visitation
- Peer support groups
- Family therapy
Health Promoting Behaviors

- Individual counseling
- Community events
- Religion
  - Decrease depression
  - Increase overall wellbeing
  - Chaplain involvement with patient and family
Holistic Care

- Holistic modalities
  - Hypnosis
  - Mind-body techniques
    - Breathing exercise
    - Distraction
    - Relaxation techniques
  - Virtual reality
  - Creative arts therapy
    - Dance
    - Music
    - Art therapy
  - Massage
  - Adventure therapy
Substance Abuse

- Prevention
- Intervention
  - Services and treatment
- Education
  - Counseled on how substance use can impact health more seriously due to medications and treatments
- Increase in QOL may help to avoid health harming behaviors
- Trusting relationships with AYA patients
- Health care providers remain on the look out for these behaviors
Self Efficacy

- AYA cancer patients should always be involved in plan of care
  - Answer all questions they have
  - Address every aspect of care
- Have a say in treatment decisions
- Help AYA patients to better cope
- Education
  - Inform patient on what they are going through
  - Disease process
  - Decrease overall stress
  - Feelings of control
Conclusion

- With cancer diagnosis and survival rates growing, amount of attention paid to QOL in AYA patients should be high.
- Although we cannot stop the disease, can help to increase QOL.
- Make recommendations available to AYA patients.
- Individualized care:
  - Normalcy.
- Creative solutions with this sub-group:
  - Reduce stress.
  - Manage symptoms.
  - Counseling.
  - Accommodation of other specific needs.
- Continue to discover and research best ways to increase AYA with cancer’s QOL.
Questions??
References


