

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
 - Counselor 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??

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