

Quality of Life in Adolescents with Cancer

Alexis Guastella
Molly Ryan

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

- American Society of Clinical Oncology (2014). Childhood cancer: Statistics. Retrieved from <http://www.cancer.net/cancer-types/childhood-cancer/statistics>
- Clinton-McHarg, T., Carey, M., Sanson-Fisher, R., D'Este, C., & Shakeshaft, A. (2012). Preliminary development and psychometric evaluation of an unmet needs measure for adolescents and young adults with cancer: The Cancer Needs Questionnaire - Young People (CNQ-YP). *Health and Quality of Life Outcomes*, 10(13), 1-11.
- Hinds, P. (2010). Progress in quality of life in children and adolescents with cancer. *Seminars in oncology nursing*, 26(1) p 18- 25.
- Hsu, M., Tu, C., (2013). Improving quality-of-life outcomes for patients with cancer through mediating effects of depressive symptoms and functional status: A three-path mediation model. *Journal of Clinical Nursing*, 23, 2461–2472-2461–2472. (2013).
- Lavdaniti, M., & Tsitsis, N. (2015). Definitions and conceptual models of quality of life in cancer patients. *Health Science Journal*, 9(26), 1-5.

References Cont.

- Monteiro, S., Torres, A., Morgadinho, R., & Pereira, A. (2013). Psychosocial outcomes in young adults with cancer: Emotional distress, quality of life and personal growth. *Archives of Psychiatric Nursing*, 27, 299-305.
- National Cancer Institute (2014). Cancer in children and adolescents fact sheet. National Cancer Institute. Retrieved from: <http://www.cancer.gov/cancertopics/factsheet/Sites-Types/childhood>
- Nelson, A., Haase, J., Kupst, M.J., Clarke- Steffen, L., and Brace- O'Neill, J. (2004). Consensus statements: Interventions to enhance resilience and quality of life in adolescents with cancer. *Journal of pediatric oncology nursing*, 21(5) p 305-307. doi: 10.1177/1043454204267925
- Phillips, F. and Jones, B.L.. "Understanding the Lived Experience of Latino Adolescent and Young Adult Survivors of Childhood Cancer." *J Cancer Surviv* 8 (2013): 39-48. Print.
- Russell, K.M.W., Hudson, M., Long, A., and Phipps, S. (2006). Assessment of health related quality of life in children with cancer. *Cancer* (106, 10) doi: 10.1002/cncr.21871
- Scarpelli, A.C., Paiva, S.M., Pordeus, I.A., Ramos-Jorge, M.L., Varni, J.W., and Allison, P.J. (2008). Measurement properties of the Brazilian version of the pediatric quality of life inventory cancer module scale. *Health and quality of life outcomes* (6,7) doi: 10.1186/1477-7525-6-7

References Cont.

- Scarpelli, A.C., Paiva, S.M., Pordeus, I.A., Varni, J.W., Viegas, C.M., and Allison, P.J. (2008). The pediatric quality of life inventory family impact module: reliability and validity of Brazilian version
- Strömngren, A., Niemann, C., Tange, U., Farholt, H., Sonne, N., Ankersen, L., ... Kurita, G. (2014). Quality of life and symptoms in patients with malignant diseases admitted to a comprehensive cancer centre. *Support Care Cancer*, 22, 1843–1849-1843–1849.
- Theofilou, P. (2013). Quality of life: Definition and measurement. *Europe's journal of psychiatry*, 9(1) p 150-162. doi: 10.5964/ejop.v9i1.337
- Thrane, S. "Effectiveness of Integrative Modalities for Pain and Anxiety in Children and Adolescents with Cancer: A Systematic Review." *Journal of Pediatric Oncology Nursing* (2013): 1-13.
- Williams, K.A. (2013). Adolescent and young adult oncology: An emerging subspecialty. *Clinical Journal of Oncology Nursing*, 17(3), 292-296.
- Wynn, B., Frost, A., & Pawson, P. (2012). Adventure therapy proves successful for adolescent survivors. *Kai Tiaki Nursing New Zealand*, 18(1), 28-30.