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Lunch and Learn: Addressing Needs and Resources of Adolescent and Young Adult Cancer Patients

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Abstract

Historically adolescent and young adult (AYA) oncology patients have been an underserved population. Research indicates they are more likely to experience poorer treatment outcomes, which may result in part from unaddressed biopsychosocial stressors, poor treatment compliance, and poor provider rapport. Research also indicates that oncology providers do not have a formal standardized training they are required to attend on biopsychosocial needs and resources for the AYA population. Oncology care providers need knowledge of the biopsychosocial needs and resources of their AYA patients in order to provide care and resources that remove the effects of biopsychosocial stressors. This project was designed to address this need by creating a PowerPoint training for oncology care providers presented in a “Lunch and Learn” setting where providers are offered lunch as an incentive to attend training. This training utilizes a lifespan developmental theory lens to discuss the specific needs of the AYA oncology patient population and provides some available resources to address those needs. The creator of this project hopes that it leads to oncology care providers building rapport with their AYA patients in addition to proactively addressing their unique biopsychosocial needs and offering them resources that help negate effects from biopsychosocial stressors.

Need Statement

Oncology care providers need knowledge of the biopsychosocial needs and resources of their adolescent and young adult (AYA) patients in order to provide care and resources that remove the effects of biopsychosocial stressors.

Goal Statement

AYA oncology patients will not experience biopsychosocial stressors.

Mission Statement

To improve the wellbeing of adolescent and young (AYA) cancer patients by raising oncology care provider awareness of the holistic range of challenges affecting this population and available resources to address these challenges, as well as facilitate communication and rapport between providers and their AYA patients.

Outcomes and Outcome Indicators

Outcome 1: Oncology providers will be educated on AYA biopsychosocial stressors and available resources.

- **Indicator 1a: Achieve a rate of 90% of all current oncology clinic staff attending 1 training session within 1 year, as evidenced by sign-in sheets from the trainings (See Appendix A).**
- **Indicator 1b: Demonstration of 80% competence on a training post-test, as evidenced by at least 80% of questions answered “Agree” or “Strongly Agree” when asked about perceived knowledge increased by this training (See Appendix B).**

Outcome 2: Oncology providers will engage in discussion regarding biopsychosocial stressors and resources with patients.

- **Indicator 2a: AYA oncology patients will report engaging in discussion with providers regarding biopsychosocial stressors, as evidenced by patient survey (See Appendix C).**
- **Indicator 2b: AYA oncology providers will distribute resource sheets (See Appendix D) to patients, as evidenced by patient survey (See Appendix C).**

Introduction

Cancer is not a new disease to humanity, let alone individuals in adolescence and young adulthood. However, the challenges faced by the adolescent young adult (AYA) population have received increased attention as cancer rates for this population are increasing but survival gains are not relative to other age groups (Albritton et al., 2009). In the United States, the AYA age range is defined as ages 15 to 39. The cancers that are most commonly diagnosed in AYAs are lymphoma, leukemia, cancers of the reproductive tracts, brain tumors, sarcoma, thyroid, melanoma, colorectal, and breast cancer (Bleyer, 2007). Currently 89,500 AYAs are diagnosed with cancer annually in the United States (Cheung et al., 2021). This presents a large population experiencing the problem at hand: AYA oncology patients experience increased biopsychosocial stressors. A problem analysis (See Appendix E) shows that causes contributing to this problem are a lack of provider awareness of the developmental needs of the AYA population and if their needs continue to be unmet, this could lead to increased rates of death and disability in the AYA population and the loss of their gifts and talents they would otherwise contribute to society.

AYAs diagnosed with cancer and their needs were not widely studied until the early 2000's. Per Albritton et al. (2009) "The notion of AYA oncology grew out of the clinical perception that adolescents and young adults

experienced distinct delays in diagnosis, psychosocial hardship, and poor adherence to treatment” (p. 478). Further study on AYAs diagnosed with cancer uncovered a variety of concerns, such as poor treatment outcomes. One reason for decreased survival outcomes may be poor treatment compliance. AYAs may not be treatment compliant due to difficulty affording treatments, struggles with attending appointments, not tolerating side effects well, or not understanding the importance of completing prescribed treatment (Bleyer, 2007). AYAs may not be comfortable seeking help, as more than half reported not seeking help for a biopsychosocial concern due to feeling uncomfortable asking, or in response to being told their feelings were normal (Jones et al., 2020). Treatment providers surveyed often may be unaware of biopsychosocial stressors not associated with paying for treatment or treatment effects (Kirschhoff et al., 2017). Jones et al. (2020) reports 37% of individuals who sought help addressing a biopsychosocial concern with their provider did not receive help. D’Agostino et al. (2011) reports AYA oncology patients who feel their providers communicate in an overly negative and controlling manner and do not provide desired information, may not follow treatments as prescribed. Additionally, Zebrack et al. (2014) found individuals experiencing poor rapport and lack of trust in oncology providers may also be less treatment compliant.

The need for further provider training on specific issues affecting the AYA oncology population is a known and ongoing issue. The National Cancer Institute and the Lance Armstrong Foundation co-sponsored the Adolescent and Young Adult Oncology Progress Review Group (AYAO PRG), which met from 2005 to 2006 (Hayes-Lattin et al., 2010). Johnson (2013) reported the AYAO PRG made several recommendations to promote research, training, and improved care. Per Ferrari et al. (2021), the European Society for Medical Oncology and the American Society of Clinical Oncology and the European Oncology Nursing Society Cancer Nursing Education Framework cover some training on AYA oncology in their curriculums. In the United States, the LIVESTRONG Foundation collaborated with American Society of Clinical Oncology and the Nurse Oncology Education Program to create optional online Continuing Education modules for oncologists and oncology nurses (Johnson, 2013). At this time there is no required training for oncology providers that comprehensively addresses the needs of the AYA patient population. This led to the initiative to develop a training that informs oncology providers of the biopsychosocial needs of their AYA patients, encourages them to discuss these needs with their patients, and provides resources the provider can pass on to these patients.

Theoretical Framework

This project utilizes a theoretical framework underpinned by life span developmental theory. A central theme of life span developmental theory is that maturation and change, including psychological changes, are ongoing throughout one's life (Albritton et al., 2009). Per Albritton et al. (2009), "A life event as significant as cancer is clearly going to be processed differently depending on the life stage at which it is experienced" (pp. 485-486).

Cancer affects progression through a developmental stage: conversely, the developmental stage an individual is in shapes how one may experience the stressors of cancer. Due to the area of the brain responsible for logic, reasoning, planning and impulse control still undergoing development into young adulthood, AYA oncology patients may not fully understand long term consequences of their choices. Furthermore, activities that often occur during the adolescent young adult developmental period are involved in the transition to adulthood such as going to school, establishing a career, dating, getting married, and having children. Cancer and resulting effects often cause a multitude of unique psychosocial stressors to AYA oncology patients such as difficulties with starting or continuing education and/or careers, poor self-image/self-esteem, sexual side effects, infertility, changing relationships, feelings of isolation, and increased feelings of distress, depression, and anxiety (Albritton et al, 2009). Currently, despite

increased understanding of the extent of the problem and its consequences, consistent interventions have not been standardized to address it and AYA oncology patients continue to frequently report having unmet biopsychosocial needs (Jones et al., 2020).

Project Description

This project is a 90-minute “lunch and learn” PowerPoint training for oncology care providers that is designed to be held within a conference room in any hospital that has an oncology clinic. Within a one-year period, this training should be held three times, with up to 20 providers trained per session. The amount of people at each training is restricted to allow for more meaningful interactions with the trainer and small group work with participants. All providers at the hospital that have direct medical care contact with AYA oncology patients are encouraged to attend this training are encouraged to attend this training (oncologists, oncology nurses, other specialists that see AYA patients regularly, etc.). This training is designed to increase provider knowledge about what makes AYA patients different from the pediatric and older population, the biopsychosocial needs of AYA patients, and available resources to address these needs. In addition to increased knowledge, providers will be given physical copies of resource sheets they will be asked to give to their AYA patients. Ideally, the facilitator of this training would be the oncology clinic social worker that is familiar with the AYA oncology population. If the oncology clinic social worker is unable to facilitate this training, another social worker from the hospital that is familiar with the needs and resources of the AYA oncology population may do so and coordinate with the oncology clinic social worker for

outcome evaluation. This manual provides trainers with curriculum materials including a customizable advertising flyer (see Appendix F), the PowerPoint curriculum and notes for the training (see Appendix G). Also included are the outcome evaluation materials for this training including an attendance sign-in sheet (See Appendix A), a post-test for providers to complete at the end of the training (See Appendix B), survey for oncology patients aged 18-39 years old (see Appendix C), and resource sheets for AYA patients (See Appendix D). The following section of this manual will provide instructions to the trainer on preparing and executing the training and evaluating outcomes.

Trainer Instructions

Preparing for Training

1. The trainer should review the budget for this training with administrative staff at their hospital to ensure funding is approved for all aspects of the training. A brief accounting of the budget is included here.

Budget Description and Table

The largest cost of this training would be the salary of the social worker developing and running the training and associated activities. This is based on the starting base wage of a social worker at MultiCare Tacoma General in Tacoma, Washington is about \$33.25 an hour (Indeed, 2022). It is estimated that over one year, 80 hours of staff time will be spent developing and customizing this training and 16 hours spent advertising and coordinating scheduling of the training. On each training session day about 6 hours will be spent preparing for, conducting, and cleaning up after each session, with three sessions held within one year. It is estimated that each training session will require about 12 hours of follow-up time spent collecting, entering, and analyzing data, totaling about 36 hours in one year. Box lunches from Subway are

the suggested meal to be provided at each training at an estimated cost of \$16.67 per person, with total costs for each training coming to about \$333.33 dollars with each training session being able to train up to 20 staff (EzCater, 2022). The trainer and administrative staff may substitute another meal of their choosing depending on their preferences and budget. It is hoped that the hospital will host the training for their staff in a conference room at no cost. In the event this is not a possibility, a rental space for this training would be about \$50.00 per hour, based on rental rates in Tacoma, Washington (EVENUES, 2022). Technology costs (computer, Microsoft Office, and projector) and printing costs should be absorbed by the hospital as a part of their standard business operating costs; an estimate of what costs could be resulting from the training are included in the table below.

Budget Line Items	Direct Costs	Indirect Costs
Social Worker Salary \$33.25/hour x 150 hours	\$4,987.50	
Food \$333.33 x 3 trainings	\$1,000	
Technology		\$550
Printing		\$200
Total Costs	\$6,737.50	

- 2. While the PowerPoint training curriculum has been provided (See Appendix G), the trainer should still spend time reviewing current AYA oncology research and news to prepare for the training. This curriculum includes slides with training content with notes to help guide the flow of the training. Additionally, while the basic PowerPoint training curriculum is provided here in this manual for use, it is expected the trainer will customize and add their own notes as desired to customize the training to their preferences and needs, so long as the core curriculum structure is followed per the slides and provided guidance in the notes. The “Questions???” slide on the final slide prior to the References will need to be customized with the trainer’s name and email address so participants can connect if they have future questions.**

- 3. Before conducting the training in full for the first time, the trainer should review the training curriculum with 3-4 AYA cancer patient advocates with lived experience in order to verify validity of the provider post-test and patient survey tools for outcome evaluation. After reviewing the training content with the advocates, the trainer should review the questions on the provider post-test and patient survey and verify with the advocates that the questions are clear,**

easy to understand, and are measuring the subjects intended to be measured, per the stated outcomes and outcome indicators. Make any modifications deemed necessary prior to officially launching the trainings, as it is important all participants of the training and surveyed patients.

4. The trainer should book the conference rooms and equipment needed for the trainings. The room should have tables and comfortably be able to fit 20 participants and the trainer. The minimum equipment needed will be a laptop with Microsoft Office and a projector.
5. The trainer will need to set up an online scheduling sign up for the training dates by two months prior to the first training.
6. The trainer will advertise the training by customizing the provided advertising flyer (See Appendix F) with the training dates, times, locations, sign up hyperlink, and trainer contact information. One month prior to each training about 65 flyers will be printed off. Flyers will be placed in staff mailboxes with remaining flyers posted

in staff break areas. Additionally, the flyers will be sent via email attachment to staff as well with the hyperlink to sign up. Market the training as a “Lunch and Learn” with meals and beverages offered as an added incentive to attend training. This may incentivize busy professional staff to take time to attend training. Also make it known that this training will only be offered three times within the year and staff will need to sign up to attend. The perceived scarcity of the training may further entice individuals to sign up quickly. Furthermore, inform individuals that attendance will be recorded in their administrative training files. The trainer should also try to meet and get to know the supervisory staff of nurses, doctors, and other oncology clinic providers to communicate and the training and encourage supportive staffing and scheduling measures to maximize the ability for staff to attend the training.

- 7. One week prior to training send out an event reminder and request to contact you with any dietary needs.**

- 8. Two days before the upcoming scheduled training, place the lunch order and ensure all printed materials are ready for the training. You will need one printed copy of the PowerPoint with your notes,**

one copy of the attendance sign-in sheet (See Appendix A), 20 copies of the provider post-test (See Appendix B), and 100 copies of the patient resource sheets (See Appendix D). If there are any extra copies of forms that is ok because the same training forms will be used at each training to assure reliability.

- 9. On the day of training, pick up the lunches the morning of the training and store them in a refrigerator until right before you let people in the room for the training. If you are not getting cold box lunches, please arrange for food delivery and storage as appropriate for food safety.**

- 10. Allow yourself a couple of hours before training to review your presentation materials and ensure you are comfortable with the material and able to complete the presentation within the allotted time.**

- 11. Give yourself an hour to set up the room and training materials according to your needs.**

Conducting the Training

- 1. Have providers sign up on the provided sign-in sheet (See Appendix A) with you so you can ensure they are signing only themselves in. This ensures validity when measuring attendance. Do not use any other forms aside from this one for signing in, as this assures reliability of the attendance measuring process.**
- 2. The training itself should be fairly straightforward to complete as there are notes with the PowerPoint slides that guide the flow of training and activities with estimated amounts of time for discussions and group work.**
- 3. When indicated to hand out the resource pages (See Appendix D), offer five copies to each provider. Encourage them to make copies and give them to all of their AYA patients when they next see them. Ask them to keep one resource sheet for themselves for ongoing copies and their own reference but let them know more copies are available in the oncology social work office.**
- 4. At the end of the training, participants should be given the post-test (See Appendix B) to fill out (there is a prompt in the PowerPoint Slides), and they should complete it and turn it in to you prior to leaving the room.**

Evaluating Outcomes

- 1. If you are not the oncology clinic social worker, give the attendance sheet to them. The oncology clinic social worker should collaborate with the administrative staff of the oncology department so it is documented in the administrative files which providers have attended the training and it can be determined by the end of the year what the total percentage of providers that attended the training was.**
- 2. Use Microsoft Excel to analyze the participant post-test data to assess for reported increased provider knowledge of AYA patient needs and resources. One of the outcome indicators for providers being educated on AYA biopsychosocial stressors and available resources is demonstration of 80% competence on a training post-test, as evidenced by at least 80% of questions answered “Agree” or “Strongly Agree” when asked about perceived knowledge increased by this training.**
- 3. Within one to two business days following the training, the oncology clinic social worker will check for AYA patients aged 18-39 years old coming in for appointments whose providers were trained, as documented by the sign-in sheet (See Appendix A). The**

oncology clinic social worker will take this opportunity to check in with these patients and offer them a printed patient survey (See Appendix C) that can be filled out and left for the oncology clinic social worker to review and analyze. Patients are free to decline to fill out the survey or skip questions if they choose. All questions are yes or no (coded Y or N) questions asking about if providers engaged in discussions regarding topics from the training and if they were offered a patient resource sheet from their provider. Surveys marked all or mostly with “Y” answers indicate that providers may be using the knowledge learned from training in practice.

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Appendix B

Participant Post-Test

Lunch and Learn: Addressing Needs and Resources of Adolescent and Young Adult Cancer Patients

Date of Training Attended:

Please circle your response to each question

1. This training enhanced my knowledge of how to get to know adolescent and young adult oncology patients to provide individualized care.

Strongly Disagree Disagree Neutral Agree Strongly Agree

2. This training enhanced my knowledge of sexual and reproductive health needs and resources for adolescent and young adult oncology patients.

Strongly Disagree Disagree Neutral Agree Strongly Agree

3. This training enhanced my knowledge of diet and exercise health needs and resources for adolescent and young adult oncology patients.

Strongly Disagree Disagree Neutral Agree Strongly Agree

4. This training enhanced my knowledge of psychological health needs and resources for adolescent and young adult oncology patients.

Strongly Disagree Disagree Neutral Agree Strongly Agree

5. This training enhanced my knowledge of educational and career needs and resources for adolescent and young adult oncology patients.

Strongly Disagree Disagree Neutral Agree Strongly Agree

6. This training enhanced my knowledge of peer relationship needs and resources for adolescent and young adult oncology patients.

Strongly Disagree Disagree Neutral Agree Strongly Agree

7. Overall, I feel this training improved my knowledge of the biopsychosocial care needs and resources for my adolescent and young adult oncology patients.

Strongly Disagree Disagree Neutral Agree Strongly Agree

Appendix C

Adolescent Young Adult Patient Survey

Provider Seen:

Age (must be between 18-39):

Gender:

Please circle "Y" to indicate Yes or "N" to indicate No. You may skip any questions or decline to complete this survey at any time.

1. I felt my provider tried to get to know me as a person outside of my disease.
Y N

2. My provider gave me the opportunity to discuss any sexual and fertility/reproductive health concerns I had.

Y N

3. My provider gave me the opportunity to discuss any sexual and fertility/reproductive health concerns I had.
Y N

4. My provider gave me the opportunity to discuss any health concerns I had related to diet and exercise.
Y N

5. My provider gave me the opportunity to discuss any mental health concerns I had.
Y N

6. My provider gave me the opportunity to discuss any concerns I had regarding school and/or work.
Y N

7. My provider gave me the opportunity to discuss concerns I had regarding peer relationship support needs.
Y N

8. Overall, I felt my provider was fairly aware of age-appropriate resources and care for a wide variety of physical, mental, and social needs.
Y N

9. My provider offered me a handout with adolescent young adult cancer resources.
Y N

Appendix D

Adolescent Young Adult Cancer Patient Resources

Resource	Description	Online Information
American Society of Clinical Oncology (ASCO)	<ul style="list-style-type: none"> Information on fertility, dating, sex, and sexual health for cancer survivors 	Website: https://www.cancer.net/navigating-cancer-care/dating-sex-and-reproduction
Livestrong Fertility	<ul style="list-style-type: none"> Reproductive resources, and financial support for cancer survivors 	Website: https://www.livestrong.org/what-we-do/program/fertility
Alliance for Fertility Preservation	<ul style="list-style-type: none"> Assistance with locating fertility services, navigating insurance, and financial support for cancer survivors 	Website: https://www.allianceforfertilitypreservation.org
Stupid Cancer	<ul style="list-style-type: none"> Network hub of resources and programs for a variety of topics. Provides online groups on Facebook to connect individuals with peer cancer survivors regionally and facilitates peer led in person meet ups. Hosts one of the largest annual conferences for adolescent young adult survivors, caregivers, and care providers called Cancercon. 	Website: https://stupidcancer.org
Teen Cancer America	<ul style="list-style-type: none"> Resource hub for adolescents and young adults Play It Back Music program that helps adolescent and young adult cancer survivors express themselves through music 	Website: https://teencanceramerica.org
The Ulman Foundation	<ul style="list-style-type: none"> Network hub of resources for adolescents and young adults and caregivers. Includes programs for exercise and wellness, peer meetups, financial support, and more 	Website: https://ulmanfoundation.org
First Descents	<ul style="list-style-type: none"> Offers free weekend and weeklong physical activity adventure outings including surfing, rock climbing, and kayaking with fellow adolescent young adult cancer survivors 	Website: http://firstdescents.org
Cancer and Careers	<ul style="list-style-type: none"> Resources related to working and job seeking during and after a cancer diagnosis Provides a list of financial grant opportunities 	Website: https://www.cancerandcareers.org/en
Cactus Cancer Society	<ul style="list-style-type: none"> Peer led support and creative arts and activity groups 	Website: https://cactuscancer.org
Imerman's Angels	<ul style="list-style-type: none"> Provides 1:1 peer mentorship for cancer survivors and caregivers 	Website: https://imermanangels.org
Escape	<ul style="list-style-type: none"> Resources for LGBTQIA+ AYA cancer patients, survivors, and caregivers 	Website: https://escapeayac.org

Appendix E

Problem Analysis

Identifying the social problem:

- **Who is the population or unit of analysis of this social problem? Is it an individual, group, community? Adolescent and young adult (AYA) oncology patients.**

- **What is this population's experience, challenge, or problem? AYA oncology patients have increased biopsychosocial stressors.**

Write a broad problem statement for the population and their experience

- **Write in the current tense**
- **Do NOT provide the reason WHY this problem exists**
- **Do NOT identify a SOLUTION in your problem statement**

Societal value that explains why this problem exists:	Medical health is more important than psychosocial health.
The cause below is caused by this:	AYA oncology providers hyperfocus on medical aspects immediately related to treating cancer.
The cause below is caused by this:	AYA oncology providers are not aware of the importance of the developmental needs of the AYA population.
Problem statement below is cause by this:	Cancer makes it difficult for AYA oncology patients to meet normal biopsychosocial developmental needs.

PROBLEM STATEMENT	<ul style="list-style-type: none"> • AYA oncology patients have increased biopsychosocial stressors.
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The problem leads to this consequence:	AYA oncology patients may experience negative emotions due to increased biopsychosocial stressors.
The consequence above leads to this consequence	AYA oncology patients experiencing negative emotions may be less treatment compliant.
The consequence above leads to this consequence	AYA oncology patients that are not treatment compliant experience increased chances of disability and death.
Which costs society:	Increased rates of death and disability in the AYA oncology patient population lead to a loss of AYA contribution to society.