

Communication with AYA Patients



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Goals for Discussion:



- How can we as health care providers communicate better with the AYA population to maximize their lifestyle/behavioral health across the cancer care continuum?**
- Can being an active participant in their care during cancer treatment promote their active participation in health promoting activities as survivors?**

AYA Developmental Considerations:



- **1. Cancer diagnosis can disrupt independence from parents – communication dyad vs. triad?**
 - Tonorezos and Oeffinger, *Cancer* 2011;117(10suppl):2295-300
- **2. Formation of self-identity includes identification with peers, cancer diagnosis disrupts this – role for peer support to optimize health outcomes**
 - Sansom-Daly UM, Wakefield CE et. *BMC Cancer* 2012, 12:339
- **3. Survivorship – intrusion and avoidance of cancer identify, want to re-immense with healthy peers**
 - Hobbie WL, Stuber M, et al, *J Clin Oncol.* 2000 Dec 15;18(24):4060-6
- **4. Mobile population – may not regularly attend follow-up visits in the cancer center setting, insurance barriers, geographic changes for job/school may have difficulty in locating and accessing care**

Considerations for Provider Communication with the AYA:



- **Age (teen vs. young adult)**
- **Cultural considerations**
- **Mode of communication**
 - i Verbal
 - i Paper
 - i Other modes of technology (e.g. text messaging, videoconferencing)

Talking about Cancer – Diversity Considerations:



– AYA HOPE study:

- i Kent EE, Smith AW, et al. J Adolesc Young Adult Oncol 2013 June; 2(2): 44-52
- i Explored the social information needs of AYA survivors, diagnosed between 15-39 years of age
- i Findings:
 - i (1) Talking about cancer experience with family and friends – Latinos more likely to report this need ($p = 0.01$)
 - i (2) Meeting peer survivors - > 20 years of age more likely to report this need ($p < 0.03$)

Traditional Dyad – Doctor-Patient Communication:



- **How do we facilitate this dyad so that the AYA is an active participant in their care during cancer treatment and throughout the cancer care to promote their active participation in health promotion?**

Physician-Patient communication:



- **Zebrack B, Chesler MA, Kaplan S. Supportive Care Cancer 2010, 18:131-135**
- **In-depth qualitative study – What helps, what hurts?**
 - i **Information:**
 - ÷ **Helpful – answering questions**
 - ÷ **Hurtful – fact-telling, delivered in a patronizing manner**
 - i **Interpersonal/social support:**
 - ÷ **Helpful - positive attention – feel more like a “normal person;”**
 - ÷ **Hurtful – denial or dismissal of their feelings or experience**

Survey of Young Adult Survivors:

- Casillas J, Syrjala KL, Ganz PA, et al. *J Cancer Surviv.* 2011 Dec;5(4):371-81.
- Survivors aged 18-39 years (n=376) recruited from the LIVESTRONG™ Survivorship Centers of Excellence Network sites
- Completed a survey assessing self-reported receipt of survivorship care planning and confidence in managing their survivorship care.

**Descriptive Statistics –
Self-Report of**

**1) Survivorship Clinic
Utilization**

**2) Receipt of Late Effects
Counseling**

**3) Receipt of Survivorship
Care Planning
Documents**

	No.	%
Currently go to oncology/survivorship clinic	265	71
Frequency of visits to oncology/survivorship clinic (among the 265 participants currently attending)		
More than once a year	128	48
Every 1-2 years	125	47
Less frequently	12	5
Doctor has discussed late or chronic effects of cancer treatment		
Yes	288	77
No	88	23
Have copies of medical records		
Yes	248	66
No	128	34
Have written treatment summary		
Yes	191	51
No	185	49
Have written cancer survivorship follow-up care plan		
Yes	163	43
No	213	57
Number of these above 3 items in possession		
0	71	19
1	104	28
2	105	28
3	96	26

Odds ratio for membership in low confidence group by participant characteristics

Characteristics	Multivariate logistic regression OR (95% CI)	P
Race/ethnicity		
Minority	2.29 (1.30-4.02)	.004
Have follow-up survivorship care plan		
No	2.65 (1.52-4.61)	.001
Yes	1.00	

Conclusions:

- Lacking a survivorship care plan is associated with higher odds of being in a low confidence group
- Survivorship care plans seem to prepare survivors to be more self-assured in being their own health advocates

Conclusions:

- Ethnic minorities were a high-risk group for low confidence in managing their survivorship care
- Interventions to improve receipt of survivorship care plans within diverse populations of young adult survivors is an important area of investigation
 - i Explore how these may not only improve doctor-patient communication but also doctor-doctor communication as the AYA population is mobile and may be interfacing with several different health care settings

Modes of Delivery of Health Care Information:



- **How can we as health care providers communicate better with the AYA population to maximize their health promoting behaviors across the cancer care continuum?**
- **Example/WIP...**

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PADRES
Contra El Cáncer.
parents against cancer



A Community-Academic Partnership

PADRES Contra El Cáncer-UCLA Partnership

- Qualitative research study to assess barriers and facilitators to survivorship care in Latino AYA survivors
- Participants included both survivors and parents
- RESULTS/major themes:
 - i Facilitators to survivorship care:
 - ÷ Critical to include the nuclear family in survivorship care discussions
 - i Barriers to survivorship care:
 - ÷ Cancer stigma associated with survivorship discussions
 - ÷ Continued emotional distress related to discussions regarding their cancer diagnosis and treatment

Casillas J et al., *Psychooncology*. 2010

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Cancer Survivorship: Telling a Story through the Eyes of “Esperanza” (Hope)

- **P20 CA157070: Funding opportunity through the NCI and the Center to Reduce Cancer Health Disparities**
 - Feasibility studies for a collaborative Minority Institution/Cancer Center to establish collaborative partnerships
- Our focus for this grant:
 - Emphasis on research infrastructure building within the community
 - Equal partnership between academic and community partners
 - Development of culturally-relevant educational intervention for Latino AYA cancer survivors delivered in the community setting

Community Advisory Group (CAG)



- **Completion of 4 CAGS**
- **All in the community setting**
- **Recruitment from the community setting through PADRES and UCLA**
- **Inclusion Criteria:**
 - **AYA Survivors**
 - **Parents, siblings and extended family members**
- **English and Spanish groups**

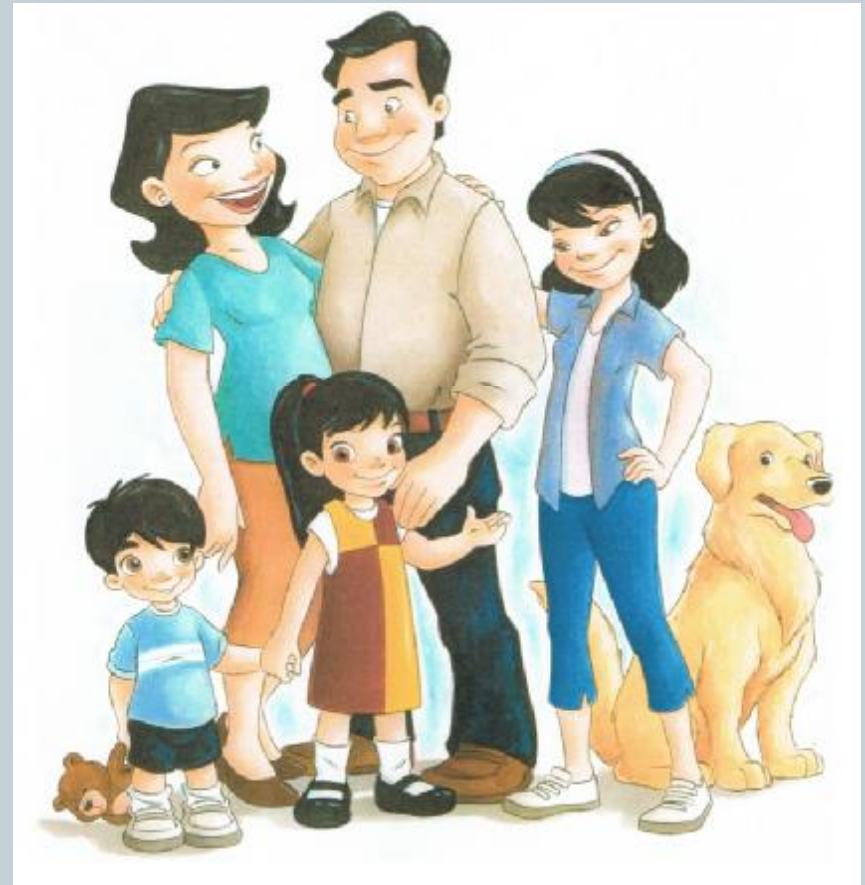
CAB Major Themes:



- i Avoidance of survivorship discussions because it negatively affects AYA survivors' self-esteem
- i Desire to move on from the cancer experience
- i Survivorship care plan would be helpful in navigating their care
- i Lack of health insurance is a source of significant stress because it prohibits access to survivorship care and interactions with the providers
- i Address language barriers and remember low literacy impedes access to health information

Culturally Relevant Health Education Materials:

- The photonovela development
 - Script written based on CAG's major themes
 - Actor read-through of content with CAG members
 - Now with animation with Pixar artist
- Photonovela educational intervention:
 - Improve *families'* survivorship care discussions including the practical aspects of seeking care (e.g. insurance)
 - Decreasing cancer stigma
 - Improving their knowledge about the importance of survivorship care planning and healthy lifestyles
 - Increase intent to seek survivorship care



Teachable moment:



- **When should health promotion interventions be delivered?**
 - i On therapy? Transition to off therapy?
 - i May be age differences for the teachable moment across the age continuum for the AYA cancer patient (15-39)
 - ÷ Diet choices (school vs. home)
 - ÷ Activities, medical restrictions (diagnoses for the AYA patient)
- **Ganz PA. J Clin Oncol. 2005 Aug 20;23(24):5458-60. Epub 2005 Jul 25. “A teachable moment for oncologists: cancer survivors, 10 million strong and growing!**
- **Denmark-Wahnefried et al. J Clin Oncol. 2005 Aug 20;23(24):5814-30. Epub 2005 Jul 25. “Riding the crest of the teachable moment: promoting long-term health after the diagnosis of cancer.**

Summary for discussion:



- **Some unique challenges for providers when discussing health promotion with the AYA cancer patients**
 - Avoidance, cancer stigma in the context of risk-based counseling
- **What may work to help communicate better with the AYA population when discussing health promotion across the cancer care continuum**
 - Survivor empowerment through doctor-patient communication using the SCP as a tool
 - Innovative health education materials (age and culturally relevant)
 - Diverse modes of communication
- **How to enable access to interventions across the cancer care continuum (eg - mobile population, insurance factors)**
 - Community options for low cost, accessible, attractive interventions