

AYA Specific Programs

Session 4: Lifestyle Management and Behavioral Health across the Care Continuum

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AYA Programs

23 Self identified and findable

20 Programs reachable

20 Programs invited to participate in a 2-part information gathering.

Part 1: Interview on NCCN AYA Care Guidelines (n=20)

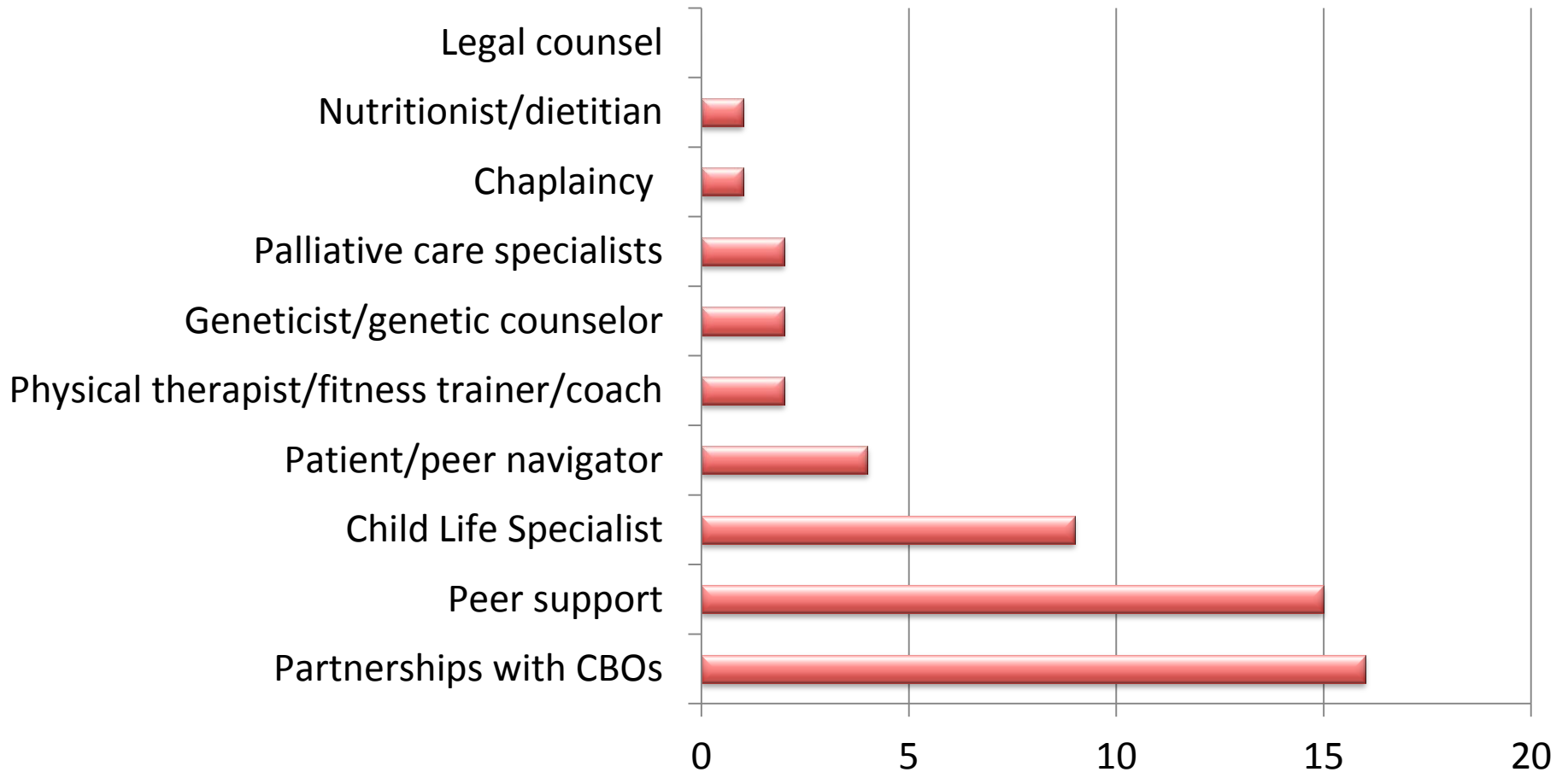
Part 2: Survey on LiveStrong YAA Critical Elements (n=17)

8 Program Components emerged in analysis

Presented here:

- Psychosocial relevant personnel in AYA Programs
- Psychosocial component
- Policy implications of these data

Personnel: Supportive Care and Support Services



Psychosocial Component Defined

- Comprehensive Assessment (NCCN)
- Intervention (NCCN)
 - Referral to mental health provider
 - Support for communication
 - Support groups for parents of AYAs
 - Support groups for AYAs
 - Social and recreational programming
 - Psycho-educational programs
 - Referral to chaplaincy/faith-based resources
 - Drug & alcohol addiction support
 - Peer support -- Face-to-face, Camps and retreats, Online
- Assessment of and attention to cognitive, psychiatric, and psychosocial needs of AYA patients (LS YAA)
- Referral to available age-appropriate resources during treatment (LS YAA)
- Assistance with disease and treatment effects (sexual dysfunction, and body image) (LS YAA)

Comprehensive Psychosocial Assessment

15 programs report patients with an indicated need, receive a comprehensive psychosocial assessment.

Features of the assessment	# of programs
AYA-specific assessment	6
Includes >12 of the 24 NCCN suggested components	6
General service for any patient	9
Includes 7-12 of 24 NCCN suggested components	2
Includes >12 of the 24 NCCN suggested components	7

Service	Available	Institution and/or partner	AYA program
Peer support -- Face-to-face	20	2	18
Social and recreational programing	18	0	18
Peer support – Camps and retreats	18	5	13
Peer support – Online	18	5	13
Support for Communication	18	6	12
Support groups for AYAs	17	6	11
Psycho-educational programs	13	3	10
Referral to mental health provider	20	12	8
Drug & alcohol addiction support	18	16	2
Support groups for parents of AYAs	12	10	2
Referral to chaplaincy/faith-based resources	19	18	1

Community partners

Service	Programs relying on community partners
Support groups for AYAs	5
Support groups for parents of AYAs	5
Peer support – Camps and retreats	4
Peer support – Online	4
Psycho-educational programs	2
Drug & alcohol addiction support	2
Referral to chaplaincy/faith-based resources	1
Peer support -- Face-to-face	1

Assessment of and attention to psychosocial needs of AYA patients

Assess:

- Ongoing needs assessment
- Formal assessment
 - all AYA pts
 - As identified necessary
- Neuropsychology testing based on diagnosis and need
- Intake questionnaire

Attend:

- Community referral
- Psychosocial support – child life, inpatient, SW, hospital school
- Therapy from psychologist as needed during treatment
- Activities for interaction, education and support
 - Post-treatment
 - On-treatment
- Support group
- SW involved in treatment planning
- AYA rooms and common space
- AYA room decoration and activity supplies

Assessment and attention to psychosocial needs

Fulfilled by different personnel

- Social work
- Psychology
- Psychiatry
- Hospital teachers
- Child Life Specialists
- Navigators

Compulsory or as needed

- Assessment and support as needed
- Every AYA assessed
- Access to MH professional
- Assigned MH professional
- Program has an MH liaison

Measurement of assessment and attention to psychosocial needs of AYA patients.

- # of referrals
- # of patient contacts
- Anecdotal information about helpfulness of resources and providers
- Patient satisfaction surveys sent by hospital, not AYA specific.
- Questionnaires assessing the patient's opinions and educational growth
- Psychologist evaluation of treatment effectiveness
- Evaluation of adherence with referrals and subsequent recommendations
- AYA patient advisory focus groups.
- Database tracking patient needs and interventions.

Referral to available age-appropriate resources during treatment

In-facility and community referrals

Who refers:

- Child life
- Navigator
- Counselor
- Psychology
- Ambassadors
- Program Coordinator
- AYA Program or team members
- Non-AYA providers
- AYA consult clinic

Referral resources:

- Brochures
- Website lists
- Resource library
- Resources on the website
- Resource database
- Patient survival guide
- Patient treatment guide and referral list

Assessment of referrals to age-appropriate resources during treatment

- # reached
- Quality improvement project surveys AYA patients on program and resource use and seeks suggestions for improvement

Assistance with sexual dysfunction, and body image

Evaluation and support by:

- Medical providers
- Social Work
- Psychology
- AYA consult clinic
- Palliative Care team or consult service
- Adolescent medicine service
- Child life
- Nurse navigator

Referrals and Programming:

- Referral to sexual health program
- Educational programs
- Peer support
- Support group
- AYA event night
- AYA conference topics

Assessment of assistance with sexual dysfunction, and body image

- Basic tracking over interventions
- # of consults
- # of referrals
- Satisfaction surveys sent to parents
- Patient evaluation and comments
- Evaluation of AYA navigator
- AYA patient advisory council focus groups

Some conclusions

- AYA Programs are structured differently and therefore meet patient needs using different methods.
- Assessment primarily only happens when need is expressed or informally identified.
- Assessment primarily only includes areas of need (expressed or informally identified).
- There is no standardization to interventions or assessments.
- Outcome evaluation is extremely limited.
- Results raise several questions: what should AYA programs offer, how is that decided and how should care be delivered? .

Policy Implications

- Consistent and appropriate psychosocial care should be provided based on comprehensive psychosocial assessment.
- Policies must target availability of developmentally-appropriate psychosocial care and not dictate the pathway to the care.
- Evaluation of quality must be required for all psychosocial care. Measuring satisfaction is not a substitute for measuring psychosocial outcomes.
- Psychosocial care must be evidence-informed.

**ADDITIONAL SLIDES FOR
REFERENCE ONLY**

Psychosocial Intervention:

Referral to mental health provider

All 20 programs reports making referrals for AYAs to mental health providers for cognitive dysfunction, other psychiatric symptoms, psychosocial support & counseling to help alleviate distress

Who delivers the intervention?	# of Programs
AYA Program involved	8
Institution and/or Partner	12

Psychosocial Intervention: Support for Communication

18 of 20 programs report providing some kind of support for communication between AYAs and parents, partners/spouses and siblings. The level of formality and comprehensiveness varied, as did how it was decided who received the support.

Who delivers the intervention?	# of Programs
AYA Program involved	12
Institution and/or Partner	6

Psychosocial Intervention:

Support groups for AYAs

17 of 20 programs report AYAs having access to support groups. The AYA Program is involved in deliver for most, but not all.

Who delivers the intervention?	# of Programs
AYA Program involved	11
Institution and/or Partner	6
Partner only	5

Psychosocial Intervention:

Social and recreational programing

18 of 20 programs report AYAs having access to social and recreational programing. The majority of AYA Programs are involved in delivering this programming, either independently or in collaboration with the institution or a community partner.

Who delivers the intervention?	# of Programs
AYA Program involved	18
Partner only	4

Psychosocial Intervention:

Referral to chaplaincy/faith-based resources

19 of 20 programs report referral of AYAs to chaplaincy/faith-based resources. These referrals are identified as a function of the institution and are primarily referrals to the institution's chaplain services. One AYA Program reports involvement in these referrals and 1 program is in an institution that does not have chaplain services.

Who delivers the intervention?	# of Programs
AYA Program involved	1
Institution and/or Partner	18
Partner only	1

Psychosocial Intervention:

Drug & alcohol addiction support

18 of 20 programs report access to drug & alcohol addiction support, primarily through the institution alone or the institution in collaboration with community partners.

Who delivers the intervention?	# of Programs
AYA Program involved	2
Institution and/or Partner	16
Partner only	2

Psychosocial Intervention:

Peer support -- Face-to-face

All 20 programs report access to face-to-face peer support. The formality or regularity of these interactions varied greatly. This also meant that the process of identifying participants and the quality of the interactions varied.

Who delivers the intervention?	# of Programs
AYA Program involved	18
Institution and/or Partner	2
Partner only	1

Psychosocial Intervention:

Peer support – Camps and retreats

18 of the 20 programs report access to peer support through camps and retreats. The level of AYA specificity in the programs delivered by institutions and partners without the involvement of the AYA program is varied. Some include the AYA age range, while others are created specifically for AYAs.

Who delivers the intervention?	# of Programs
AYA Program involved	13
Institution and/or Partner	5
Partner only	4

Psychosocial Intervention:

Peer support – Online

18 of the 20 programs report access to online peer support. Again, the level of AYA specificity in the programs delivered by institutions and partners without the involvement of the AYA program is varied.

Who delivers the intervention?	# of Programs
AYA Program involved	13
Institution and/or Partner	5
Partner only	4

Psychosocial Intervention:

Support groups for parents of AYAs

12 of 20 programs report AYA patient families having access to support groups for parents, mostly through community partners.

Who delivers the intervention?	# of Programs
AYA Program involved	2
Institution and/or Partner	10
Partner only	5

Psychosocial Intervention:

Psycho-educational programs

13 of 20 programs report AYAs having access to psycho-educational programs, which are mostly delivered by the AYA Program and in partnership at 3 sites.

Who delivers the intervention?	# of Programs
AYA Program involved	10
Institution and/or Partner	3
Partner only	2