



2019

21 - 23 JUNE

SAN FRANCISCO

SUPPORTIVE CARE
MAKES EXCELLENT
CANCER CARE POSSIBLE

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AYAs' needs for information about sexuality: room for improvement?

MASCC/ISOO

Annual Meeting on Supportive Care in Cancer

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MASCC
Multinational Association
of Supportive Care in Cancer

ISOO
INTERNATIONAL SOCIETY
OF ORAL ONCOLOGY



#MASCC19

Conflict of Interest Disclosure

Leonore Albers, MD

Has no real or apparent
conflicts of interest to report.



Introduction

- Negative impact of cancer on sexuality in AYAs
 - interfere with sexual development
 - interfere with development relationships
 - impair sexual function
- 50% experience sexual problems after 2 years



Introduction

- Unmet psychosexual needs
 - Inadequate support
 - Lack of information



Table 3 Information and service needs (*n*=210), frequency (percent)

	Total need	Unmet need
Information about cancer	205 (98.1)	21 (10.2)
Internet sites	200 (95.2)	53 (26.5)
Diet and nutrition information	186 (89.4)	85 (45.7)
Exercise information	180 (86.1)	89 (49.4)
Complementary/alternative health care services	169 (80.5)	84 (49.7)
Assistance with health insurance, disability or social security	168 (80.8)	68 (40.5)
Camps, retreats	164 (78.5)	121 (73.8)
Mental health counseling	158 (76.3)	61 (38.6)
Infertility information	138 (65.7)	59 (42.8)
Counseling related to sexuality or intimacy	118 (57.3)	97 (82.2)
Family counseling	111 (53.4)	72 (64.8)
Religious/spiritual counseling	104 (49.8)	34 (32.7)
Adoption services	90 (43.5)	78 (86.7)
Infertility treatment/services	85 (40.9)	53 (62.4)
Transportation assistance	58 (27.8)	40 (68.9)
Child care	36 (17.5)	23 (63.9)
Alcohol or drug abuse counseling	8 (3.8)	6 (75.0)



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ONCOLOGY PROVIDER PERCEPTIONS OF AYA UNMET NEEDS

TABLE 2. UTAH ONCOLOGY PROVIDERS' PERCEPTIONS OF UNMET NEEDS FOR ADOLESCENT AND YOUNG ADULT ONCOLOGY PATIENTS (N= 91)

	<i>AYAs need assistance with support^a</i>		<i>Support goes unmet for AYAs^a</i>	
	N	%	N	%
Social and family support				
Sexuality or intimacy counseling	35	39.3	23	28.4
Appearance/body image support	36	40.9	16	19.3
Mental health counseling for anxiety, depression, or stress	41	46.1	13	15.5
Family or relationship counseling	28	31.5	12	14.6
Religious or spiritual support	16	18.2	8	10.1
Peer connections	30	34.5	15	19.0

We aimed to...

- explore AYAs view on information received regarding sexuality
- determine how AYAs prefer to receive their information
- determine optimal timing to discuss sexuality

= *recommendations to improve care*



Methods

- Study design: national cross-section survey
- Co-creation with AYAs
- AYA 15-39 years at time of diagnosis
- Distribution
 - (1) Dutch national AYA congress (n=145)
 - (2) Online private AYA community (n=80)

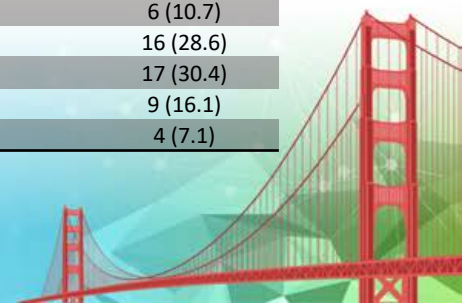


Results



	n (%)
Age (years)	
Mean 29.4 (SD 5.0, range 20-41)	56 (100.0)
Gender	
Male	12 (21.4)
Female	44 (78.6)
Relationship status	
Single	19 (33.9)
Relationship	31 (55.4)
Married	6 (10.7)
Cancer type^a	
Hematological cancer	16 (28.6)
Breast cancer	12 (21.4)
Gynaecological cancer	6 (10.7)
Testicular cancer	5 (8.9)
Brain cancer	4 (7.1)
Sarcoma	4 (7.1)
Thyroid cancer	4 (7.1)
Skin cancer	3 (5.4)
Colorectal cancer	1 (1.8)
Other ^b	2 (3.6)

Type of treatment^c	
Operation	43 (76.8)
Chemotherapy	43 (76.8)
Radiotherapy	32 (57.1)
Hormonal therapy	8 (14.3)
Immunotherapy	8 (14.3)
Other ^d	8 (14.3)
Time since diagnosis	
3-6 months	4 (7.1)
6 months – 1 year	6 (10.7)
1-2 years	16 (28.6)
2-4 years	17 (30.4)
5-10 years	9 (16.1)
10 years or more	4 (7.1)



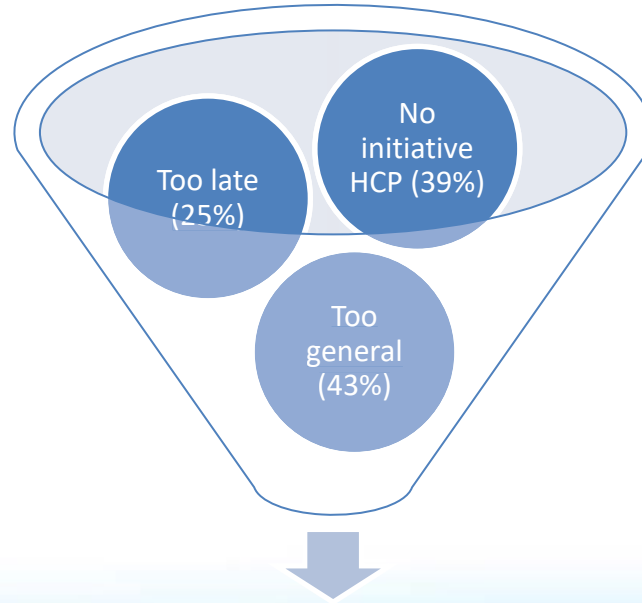
75% experienced negative impact on sexuality...

91% thinks information about sexuality is important...

74% felt sexuality was not enough discussed by the professionals...



41% = received information



79% = not satisfied



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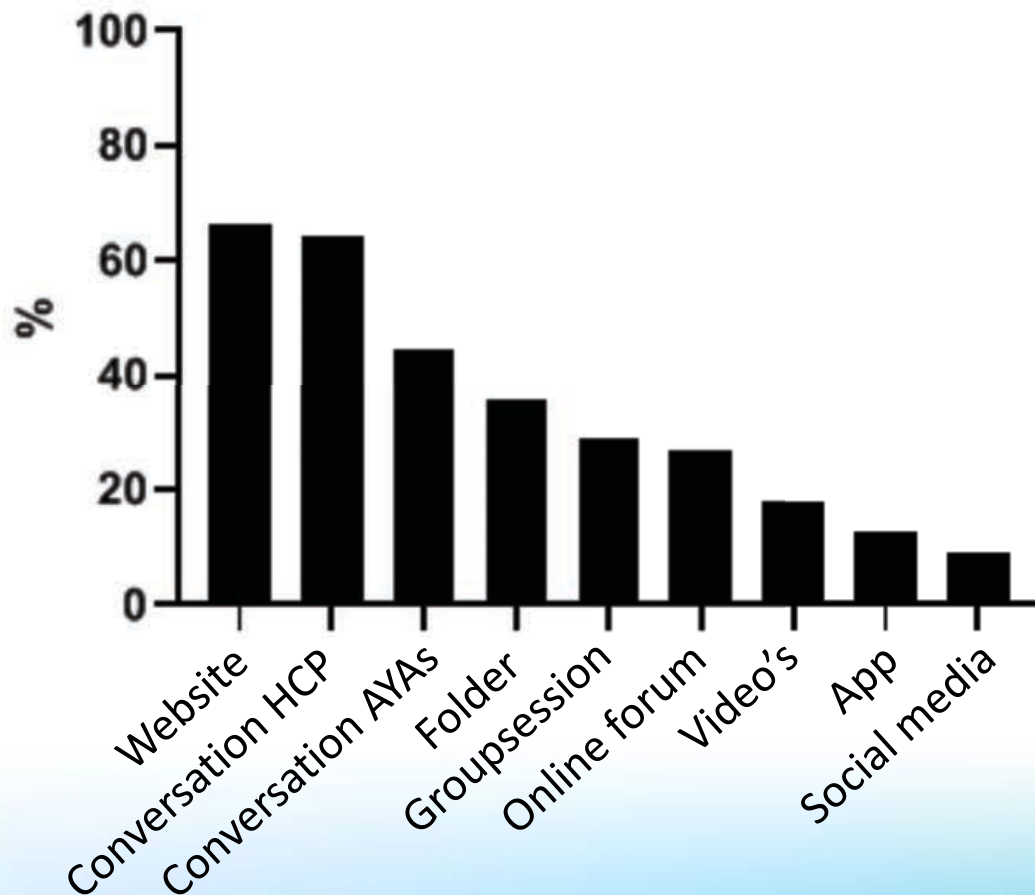


Barriers for not bring up the subject



	%
Feeling of shame	34
I do not have a partner	26
Intimacy and sexuality are not my priority	21
Intimacy and sexuality are private	18
Lack of privacy, my parents were present during the conversation	16





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Who would be most suited on discussing sexuality?

	%
Nurse practitioner	62
Sexologist	49
Physician	42
Psychologist	38
Social worker	16



Before treatment 64%

During treatment 52%

After treatment 50%



Conclusions

- Majority experienced sexual problems
- AYAs not satisfied with current information
- How? specific websites and conversations
- Who? nurse practitioner / sexologist
- When? throughout the cancer trajectory



Further..

- Further research focused on men
- More indepth with AYA and professionals
- Website & podcast for AYA and professionals



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Discussion

- Limitations

- 56 AYAs
- Selection bias
- Recall bias
- No validated questionnaire

- Strengths

- Co-creation
- Comparison with HCPs



Table 3

Satisfaction with received information of different items. (n=56)

- Percentages within total
- Percentages within received

	Satisfied ^b n (%)	Received n (%)	Dissatisfied ^b n (%)	Not received ^a n (%)
		Impartial ^b n (%)		
Information for partners	5 (26.3)	8 (42.1)	6 (31.6)	37 (66.1)
Sexual tools	4 (17.4)	13 (56.5)	6 (26.1)	33 (58.9)
Professional help with sexual issues	6 (24.0)	14 (56.0)	5 (20.0)	31 (55.4)
How to deal with sexual issues	4 (13.8)	17 (58.6)	8 (27.6)	27 (48.2)
Where to find relevant information	7 (22.6)	21 (67.7)	3 (9.7)	25 (44.6)
Which healthcare professional to approach in case questions occur	9 (29.0)	15 (48.4)	7 (22.6)	25 (44.6)
Consequences of treatment on sexuality	10 (28.6)	16 (45.7)	9 (25.7)	21 (37.5)

