



# 2019

21-23 JUNE

SAN FRANCISCO

SUPPORTIVE CARE  
MAKES EXCELLENT  
CANCER CARE POSSIBLE

Information about sexuality-related issues: what do they need?

# MASCC/ISOO

Annual Meeting on Supportive Care in Cancer

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**MASCC**  
Multinational Association  
of Supportive Care in Cancer

**ISOO**  
International Society  
on Oncology



#MASCC19

# Conflict of Interest Disclosure

Leonore Albers, MD

Has no real or apparent  
conflicts of interest to report.



# Introduction

- Cancer → negative impact on sexuality
- Sexuality → important QoL concern
- QoL → more important due to better prognosis



# Introduction



# We aimed..

- Identify patients groups more in need
- Identify what substantive information is needed



# Methods

- Initiative: Dutch Federation of Cancer Patient Organizations (NFK)
- Nationwide online survey regarding information needs
- Questionnaire in co-design



# Results





Participants n=2657	
n (%)	
<b>Gender</b>	
Male	1193 (45.2)
Female	1444 (54.8)
<b>Age (years)</b>	
Median 61 (19-94 years)	
<b>Relationship status</b>	
Not in a relationship	267 (10.7)
In a relationship	2221 (89.3)
<b>Time since diagnosis*</b>	
< 2 year	530 (23.1)
≤5 year	736 (32)
≤10 year	556 (24.2)
> 10 year	471 (20.5)
<b>Type of cancer</b>	
Breast	905 (34.1)
Prostate	531 (20.0)
Gastro-intestinal	455 (17.1)
Gynaecology	135 (5.1)
Urological (minus prostate)	172 (6.5)
Other	260 (9.7)





Participants n=2657	
<b>Stage of cancer</b>	
Local disease	1708 (74.3)
Metastatic disease	477 (20.7)
<b>Treatment</b>	
No treatment	29 (1.1)
Surgery	1954 (73.5)
External beam therapy	1205 (45.4)
Internal beam therapy	172 (6.5)
Hormonal therapy	791 (48.7)
Chemotherapy	1073 (40.4)
Immunotherapy	186 (7.0)
<b>Self-reported negative impact of cancer on sexuality</b>	
Yes	1767 (66.7)
No	884 (33.3)

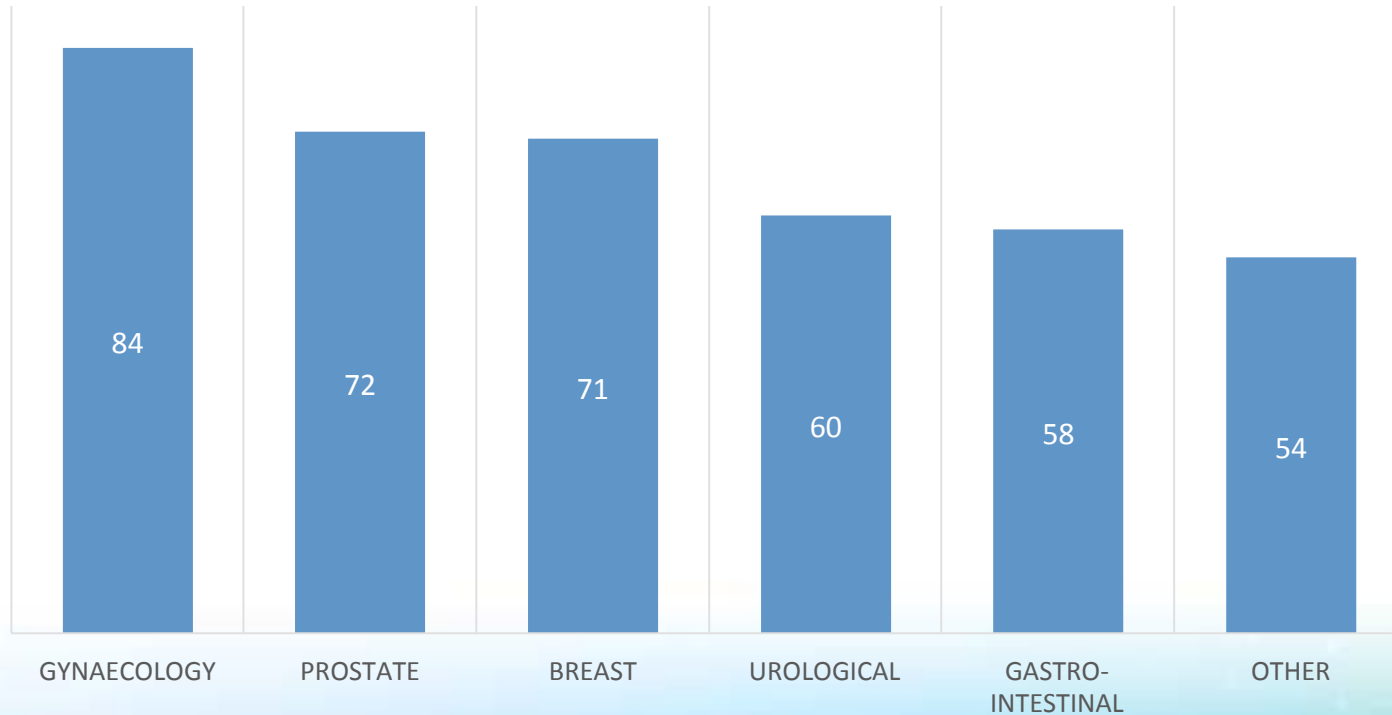


Who are they?

65% were in need of information about sexuality



## NEED FOR INFORMATION PER TYPE OF CANCER



Variable	P Value
Age ( $\leq 62$ years)	$<0.001$
Gender	0.6
Stage of disease	0.3
Relationship	0.3
Negative impact on sexuality	$<0.001$
<u>Time from diagnosis</u>	
< 2 years	0.04
2-5 years	0.9
6-10 years	0.7
> 10 years (decline)	0.02
<u>Treatment</u>	
No treatment	0.6
Surgery	0.9
External beam therapy	0.2
Internal beam therapy	0.4
Hormonal therapy	0.6
Chemotherapy	0.4
Immunotherapy	0.4



# Results

Who are they?

65% were in need of information about sexuality

46% did not find useful information

What do they want?



# Results

	Overall	Breast	Prostate	Urological (minus prostate)	Gastrointestinal	Gynaecological
Practical tips	60	81	67	64	57	63
Practical information	59	71	52	47	54	63
Experiences from others	54	55	56	58	48	63
Information for partners	37	42	40	33	30	35
Contact with other cancer patients	17	17	16	17	15	20
Referral to a professional	16	15	18	21	19	17
Information video	8	5	15	12	9	6
Information for care providers	8	10	6	5	4	11



# Results

## How to improve communication?

Health care provider should.....

- ... provide information systematically = 64%
- ... actively involve my partner = 44%
- ... initiate the subject = 34%
- ... offer the opportunity to get a referral to a sexologist = 34%





# Conclusions



Age

Time from  
diagnosis

Sexual complaints



Practical tips..



..provided by a health care professional



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## DISCUSSING SEXUALITY IN CANCER CARE: WHAT DO PATIENTS NEED? A national wide survey among cancer patients and survivors

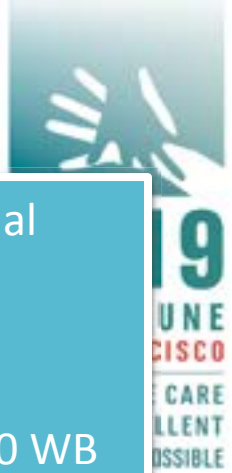
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# Discussion

- Limitations...
  - Recruitment
  - Prostate- and breast cancer overrepresented
  - Non-validated questionnaire



# Discussion



Age

Relationship

Time from diagnosis

Sexual complaints

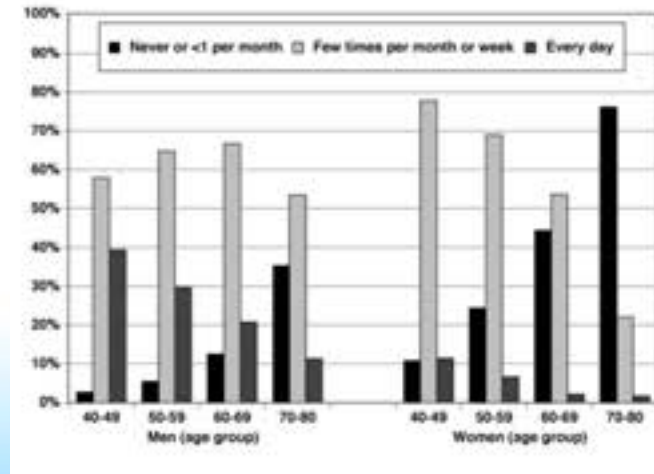
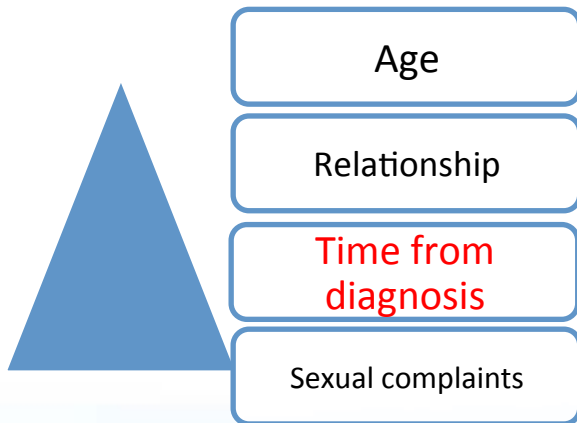


Fig. 1 Frequency of thinking about sexual activity in the European population of the GSSAB, 2001-2002

# Discussion

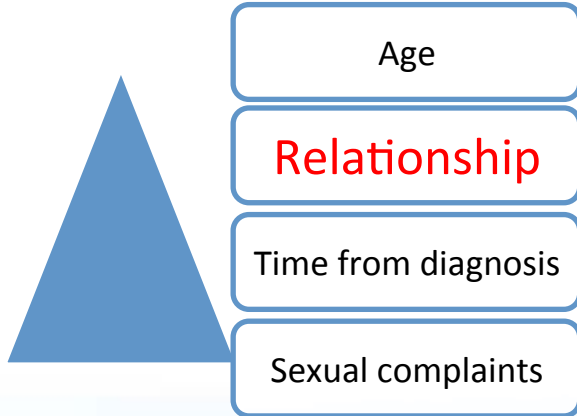


.. This study: 57% in need > 10 years after diagnosis  
...sexual side effects remain into long-term survivors  
...information widely available

# Discussion



Fig. 1 Frequency of thinking about sexual activity in the European population of the GSSAB, 2001–2002



...this study: 44%: actively involve my partner  
...partners reported frustrated feelings, sadness etc  
...further research: information for partners



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