



***Sex,** love and rock 'n roll*

Quarello Paola

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Bologna, 4 ottobre 2023

XLVIII

CONGRESSO NAZIONALE

AIEOP

Bologna

2-4 Ottobre 2023

Il sottoscritto Quarello Paola

ai sensi dell'art. 3.3 sul Conflitto di Interessi, pag. 17 del Reg. Applicativo dell'Accordo Stato-Regione del 5 novembre 2009,

dichiara

che negli ultimi due anni NON ha avuto rapporti diretti di finanziamento con soggetti portatori di interessi commerciali in campo sanitario

Sessualità

“un aspetto centrale dell’essere umano lungo tutto l’arco della vita; la sessualità comprende il sesso, l’identità e i ruoli di genere, l’orientamento sessuale, l’intimità e la riproduzione”



Adolescenza:

- Relazioni romantiche
- Esperienze sessuali
- Identità di genere

JAMA Pediatrics May 2016 Volume 170, Number 5

Clinical Review & Education

Review | ADOLESCENT AND YOUNG ADULT HEALTH

Cancer in Adolescents and Young Adults A Narrative Review of the Current Status and a View of the Future

Ronald D. Barr, MB, ChB, MD, Andrea Ferrari, MD, Lynn Ries, MS, Jeremy Whelan, MB, BS, MD, W. Archie Bleyer, MD

Box. Special Challenges for Adolescents and Young Adults With Cancer

"Delay" in diagnosis

Financial issues before, during, and after treatment

Location of care and clinical trial enrollment

Adherence to therapy

Need for psychological support

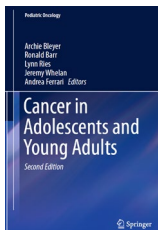
Rehabilitation and exercise

Sexuality and body image

Oncofertility

Transitions in medical management

Palliative and end-of-life care



Access and Models of Care

20

Andrea Ferrari, Karen Albritton, Michael Osborn,
Ronald Barr, Rebecca H. Johnson, Dan Stark,
and Jeremy Whelan

Table 20.2 Critical elements of quality cancer care for AYAs with cancer

Early detection and diagnosis

Timely referral, initiation of treatment, and adherence

Healthcare providers knowledgeable of biomedical and psychosocial issues specific to AYAs with cancer

Supportive care and palliative care

Clinical trials and AYA oncology research

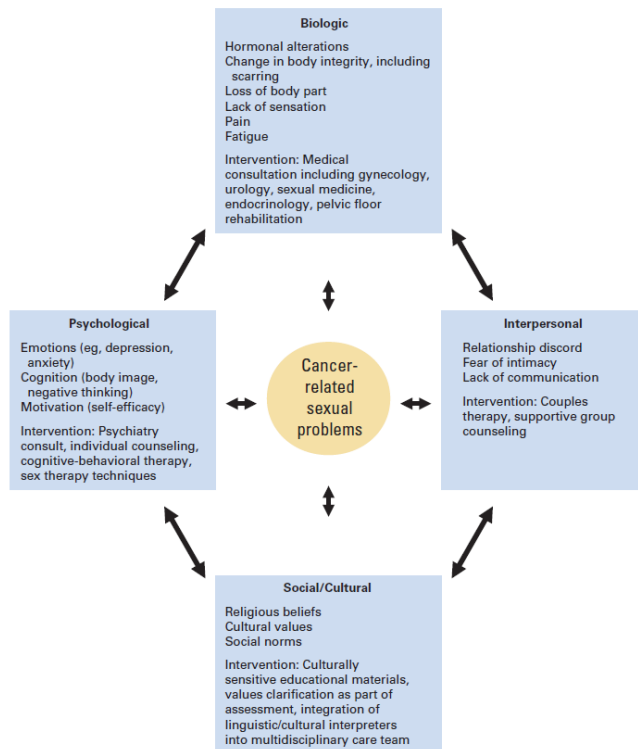
Fertility preservation and counseling

Cognizance among providers of the unique psychosocial context for AYA growth and development

Assessment and attention to cognitive, psychiatric, and psychosocial needs of AYA patients

Referral to available age-appropriate educational, peer support, financial, and legal resources

Facilitation of transition to survivorship





Survey online

- GdL infermieristico, approvazione CD, formulazione e diffusione questionario
- 52 domande (dicotomiche, multiple, likert 0-5, brevi aperte)
- Tutti i soci con diffusione ai colleghi dei centri



AIEOP
ASSOCIAZIONE ITALIANA EMATOLOGIA
ONCOLOGIA PEDIATRICA

Tempistiche

- 31 Maggio 2019 – 31 Luglio 2019
- 3 remind

Healthcare Professional Communication on Sexual Health: A Report from the Italian Working Group on Adolescents and Young Adults with Cancer

The Oncologist, 2023

Paola Quarello^{1,2,†}, Angela Toss^{3,4,†}, Paola Berchialla⁵, Maurizio Mascarin⁶,
Matteo Lambertini^{7,8}, Marta Canesi⁹, Giuseppe Maria Milano¹⁰, Lorena Incorvaia¹¹,
Giuseppe Luigi Banna¹², Fedro Peccatori^{13,†}, Andrea Ferrari^{14,†}

	AIOM		AIEOP		P	Total	%
	N	%	N	%		N	
Professional type	165	45.8	195	54.2		360	100.0
Medical/pediatric Oncologist	165	100.0	195	100.0	<.001	360	100.0
Nurse	158	95.8	130	66.7		288	80
Psychologist	6	3.6	46	23.6		52	14.5
Other	1	0.6	16	8.2		17	4.7
Gender	0	0.0	3	1.5		3	0.8
Male	165	100.0	195	100.0	.003	360	100.0
Female	72	43.6	55	28.2		127	35.3
Age	93	56.4	140	71.8		233	64.7
<40 years	165		195		<.001	360	100
>40 years	123	74.5	70	35.8		193	53.6
Center activity volume	42	25.5	125	64.2		167	46.4
<10 AYAs/year	165	100.0	195	100.0	<.001	360	100.0
>10 AYAs/year	89	53.9	50	25.6		139	38.6
	76	46.1	145	74.4		221	61.4

- Comunicazione
- Barriere comunicative
- Aspetto educativo

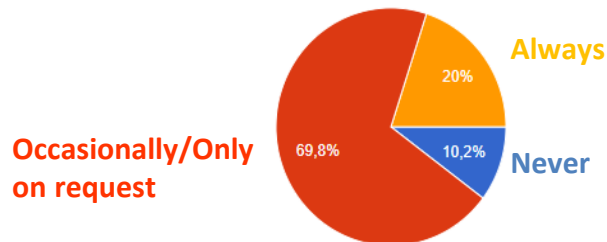
Table 2. Communication practices.

	AIOM	AIEOP	P
	N (%)	N (%)	
Is it a routine at your center to investigate about adolescent patients' sexual health at some point during the treatment?			
Yes	96 (58.2%)	90 (46.2%)	.03
If a sexuality issue arises during therapy or follow-up, is there a specific and shared protocol to which the patient should be referred to?			
Yes	43 (26.1%)	78 (40%)	.007
Who do you think should talk to the patient about sexual health issues?			<.001
Multidisciplinary team	133 (80.6%)	28 (14.35%)	
Oncologist	13 (7.8%)	53 (27.1%)	
Psychologist	11 (6.66%)	79 (40.5%)	
Sexologist	7 (4.24%)	32 (16.4%)	
Nurse	0 (0)	2 (1%)	
Parent	1 (0.6%)	1 (0.5%)	

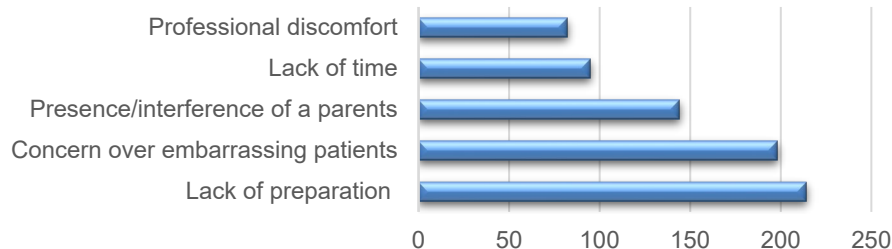
Table 3. Communication barriers.

	AIOM	AIEOP	P	Male	Female	P	<40 years	>40 years	P
	N (%)	N (%)		N (%)	N (%)		N (%)	N (%)	
How frequently do you talk to your patients about their sexual health?			.001			NS			<.001
Always	32 (19.4%)	20 (10.8%)		6 (4.7%)	33 (14.2%)		21 (10.9%)	31 (18.5%)	
Occasionally	60 (36.4%)	75 (38.5%)		53 (41.7%)	82 (35.2%)		59 (30.6%)	76 (45.5%)	
Only on request	70 (42.4%)	79 (40.5%)		49 (38.6%)	100 (42.9%)		98 (50.8%)	51 (30.5%)	
Never	3 (1.8%)	21 (10.8%)		6 (4.7%)	18 (7.7%)		15 (7.8%)	9 (5.3%)	
What factors do you believe make it challenging to discuss sexuality with the patient?									
Lack of preparation	103 (62.4%)	111 (56.9%)	.341	62 (48.8%)	152 (65.2%)	.004	128 (66.3%)	86 (51.5%)	.005
Professional discomfort	37 (22.4%)	45 (23.1%)	.983	32 (25.2%)	50 (21.5%)	.499	53 (27.5%)	29 (17.4%)	.02
Concern over embarrassing patients	94 (57%)	104 (53.3%)	.559	71 (55.9%)	127 (54.5%)	.885	125 (64.8%)	73 (43.7%)	<.001
Presence/interference of a parents	51 (30.9%)	93 (47.7%)	.002	54 (42.5%)	90 (38.6%)	.543	74 (38.3%)	70 (41.9%)	.52
Lack of time	59 (35.8%)	36 (18.5%)	<.001	37 (29.1%)	58 (24.9%)	.455	59 (30.6%)	36 (21.5%)	.056
None	7 (4.2%)	12 (6.2%)	.568	7 (5.5%)	12 (5.2%)	1.000	3 (1.6%)	16 (9.6%)	.0006

“How frequently do you talk to your patients about their sexual health?”



“What factors do you believe make it challenging to discuss sexuality with the patient?”



Barriers and facilitators to sexual and reproductive health communication between pediatric oncology clinicians and adolescent and young adult patients: The clinician perspective

Natasha N. Frederick¹  | Kevin Campbell²  | Lisa B. Kenney^{3,4} | Kerry Moss¹ | Ashley Speckhart⁵ | Sharon L. Bober³

Pediatr Blood Cancer. 2018;65:e27087.

TABLE 3 Barriers to SRH communication with AYA oncology patients

Barrier	Participant endorsement (n)	Examples from interviews
Lack of knowledge/experience having the conversation	14	<p>We don't get a lot of training about how to ask about those things, or how to address sexual risk behaviors or drug use, things outside of our strict cancer treatment domain. I feel kind of like I lack the skills in some regards to talk about some of the subjects. (003)</p> <p>It is not something I do, and so by that I'm assuming like asking whether they are having issues with sex, or whether the child is getting erections or discomfort during sex. That is not something I have actively done. The oncologist seems like the plausible person to do that, like you're serving as their doctor. You're covering all sorts of other side effects; I don't know that I feel particularly empowered to do that from a knowledge-based standpoint. (008)</p>
Lack of resources/referrals for patients	17	<p>We don't have a lot. We have information on fertility preservation but we don't have anything on like a good general overview on sexual health, which we should have. (002)</p> <p>I think my understanding, which may be wrong, is that there can be functional as well as psychological sexual health for lack of a better word. The functional is easier for me. I can send them to urology or GYN, but from the psychological part, I don't know where to send them. I don't know what to advise them. And then, if there's a combination of the two, I don't have a person to send them to for that. (014)</p>
Low priority	16	<p>What's hard is that some of these kids are so extremely sick that other things sort of trump that as far as priorities when you're sort of going through. And I think that's one of the reasons why it just never, we never sort of get to that. (005)</p> <p>We come in and you kind of talk about there are so many things going on while you're getting treated and when you're not feeling well, that it's just one of those things you don't really think about in terms of, "Are these patients sexually active?" (002)</p>

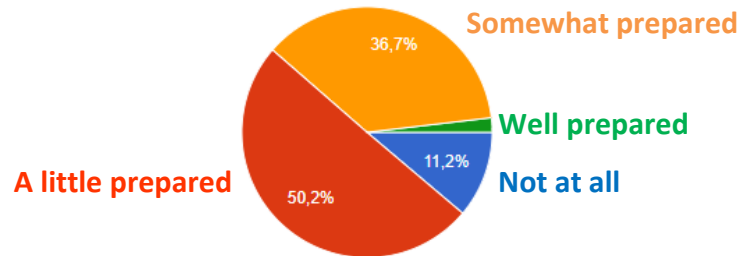
Parents/family	16	<p>But I definitely have a lot of hovering parents who if we spend too long in the room talking... I think some parents do get anxious. Maybe we need to make that more a part of our practice that we kick parents out, like you do an adolescent clinic... I really don't think that having a parent to the room is conducive at all. (003)</p> <p>There's certain patients where I feel comfortable in talking with them about their sexuality and everything else like that, and others where I kind of get the feeling where it might not be as welcomed, especially from the families. (016)</p>
Patient discomfort	11	<p>I can remember one young adult, who was treated for medulloblastoma, that I was following as a fellow, who was on therapy and he had a concern about his ability to have erections. And he brought that up in the clinic visit. And I remember it because it was a kid I was really close to and knew really well and it was very awkward discussion between us. And I remember trying to make it normal for him. But it was hard for him to say to me. (022)</p> <p>And they may or may not feel comfortable bringing up some of the issues to their doctor for fear of judgment or admonishment or whatever it is that they're worried about. (003)</p>
Clinician discomfort	16	<p>With some of them, it's easier to talk about physical function, ability. Some others may be a little bit more dicey. I guess the sexual health and function for young men, I found that hard to talk about, just because they see me as a youngish woman, and so that, I think, was sometimes a little bit awkward. I try to talk about it, but it was easier to talk about technical details, like contraception and fertility, but the actual sexual health was harder. With females, again it was easy to do. (006)</p> <p>And I have to say I actually feel very uncomfortable talking about some of these issues, because you see them as a kid, and now you're like, "Oh, you're a teen, and you're sexually active." I'm like, "Okay, this is really weird, because I watched you grow up." And whereas like when they came in as a teen, I sort of was like in adolescent mode, I was like, "I've got to make sure we cover all these things." (011)</p>
Time	12	<p>It's honestly something that I think I have not personally made a priority in the limited time that I have with patients. Not because I don't think it's important. And not even because I don't necessarily feel comfortable talking about it because I would. I think it's a time issue. (015)</p> <p>I think with our limited fifteen minutes visit that we have, I think it's almost impossible to do that. (021)</p>

The belief that sexuality is not part of the presenting problem (cancer)

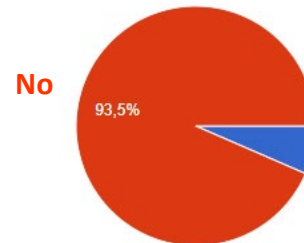
Table 4. Education.

	AIOM	AIEOP	P	Male	Female	P	<40 years	>40 years	P
	N (%)	N (%)		N (%)	N (%)		N (%)	N (%)	
How prepared do you feel to discuss sexual health with an AYA patient?			.101			.356			.0002
Well prepared	3 (1.8%)	4 (2.1%)		3 (2.4%)	4 (1.7%)		4 (2.1%)	3 (1.8%)	
Somewhat prepared	45 (27.3%)	70 (35.9%)		47 (37%)	68 (29.2%)		42 (21.8%)	73 (43.7%)	
A little prepared	105 (63.6%)	99 (50.8%)		64 (50.4%)	140 (60.1%)		125 (64.8%)	79 (47.3%)	
Not at all	12 (7.3%)	22 (11.3%)		13 (10.2%)	21 (9%)		22 (11.4%)	12 (7.2%)	
Have you received specific training on potential sexual health issues in AYA patients with cancer?			.519			.794			.5
Yes	6 (3.6%)	11 (5.6%)		7 (5.5%)	10 (4.3%)		7 (3.6%)	10 (5.9%)	

“How prepared do you feel to discuss sexual health with an AYA patient?”



“Have you received specialized training on potential AYA sexuality-related issues?”






FACILITATING STRATEGIES TO IMPROVE SEXUAL HEALTH COMMUNICATION

- Self-reported questionnaire for the patients
- Material to hand out
- Checklist for healthcare providers
- Use of a notification to prepare patients prior to the conversations

Central Components	Sample Probes/Talking Points
Initiating conversations	<p>"I'd like to ask you some questions about your sexual health. Is that okay? You don't have to answer any questions that you don't want to."</p> <p>"If it is okay with you, I'd like to share some information with you about how [cancer/treatment] may affect your sexual health. Even if this doesn't feel relevant for you right now, it might be helpful information for you to have for the future."</p>
Asking and eliciting important questions	<p>"It is important for me to know what is important to you. This includes your personal life like sex and intimacy. How would you describe your sexual orientation? Are you attracted to men, women, both, or neither? What about your gender identity? Do you identify as a man, woman, or non-binary?"</p> <p>"Sometimes young people with cancer feel like they don't get enough information from their doctors/nurses about their sexual health, and I want to make sure I'm giving you all the information you need. What else would you like to know?"</p> <p>"It's common for teens and young adults to feel that cancer has affected their sense of intimacy or romantic relationships. Has this been true for you?"</p>
Normalizing and validating	<p>"Talking about sex and gender can feel awkward, and I confess I may not use or say the right words. I invite you to correct me or help me so that I can take better care of you." Always ask how your patient would like to be referred to and their preferred language.</p> <p>"Many young people with cancer experience concerns with their sexual functioning. Often, they don't realize that these issues can be related to their treatment, and in some cases, there are things we can do to help. We are here to answer any of your questions about what might be related to your cancer treatment."</p> <p>"Sometimes teens and young adults with cancer are curious about how their cancer treatment can affect their sexual health but don't feel comfortable asking. Would it help if I share some information about it?"</p>
Creating a safe space	<p>"I want to make sure I am giving you the best care I can and all the information you need to stay healthy. Is there anything about your sexuality or sex life that I haven't asked about but you think it would be important for me to know?"</p> <p>To an adolescent: "I'd like to talk to you about your sexual health. I want you to know that this conversation will be confidential, which means that I won't tell anyone else what you tell me."</p> <p>To a parent: "As part of his/her cancer care, we routinely have conversations with your son/daughter about their sexual health. What should I know about how you have discussed this in your family so far?"</p> <p>"Sometimes teens and young adults feel more comfortable discussing their sexual health with a clinician of their same gender. Is that something you would prefer?"</p>

Investigating sexuality in adolescents with cancer: patients talk of their experiences

Laura Veneroni^a, Elena Pagani Bagliacca^a , Giovanna Sironi^a, Matteo Silva^a,
Michela Casanova^a, Luca Bergamaschi^a, Monica Terenziani^a, Jessica Trombatore^a,
Carlo Alfredo Clerici^{b,c}, Antonio Prunas^d , Marco Silvaggi^e, Maura Massimino^a ,
and Andrea Ferrari^a

Comunicazione



- Solo il 20% dei ragazzi ha ricevuto informazioni da parte di medici/infermieri/psicologi su come la malattia e le terapie avrebbero potuto influenzare affettività e sessualità
- 46% di ragazzi hanno affrontato questo argomento con gli amici
- 79% dei ragazzi pensano che gli aspetti legati alla sessualità non sono considerati adeguatamente dallo staff curante e meriterebbero più

- **Giada 16 anni, sarcoma Ewing** *«...nessuno me ne ha parlato, ero a disagio ma forse lui più di me»*
- **Simone 18 anni, leucemia mieloide acuta** *«ho pensato, se è un aspetto importante me ne avrebbero parlato, quindi ho fatto di testa mia, mica posso iniziare io a parlarne, davanti ai miei genitori per di più»*
- **Serena 15 anni, linfoma di Hodgkin** *«io ci ho pensato molto, volevo chiedere ma non ho mai trovato il momento, forse ora devo pensare alle terapie, in fondo sono fuori gioco...»*



Studio ASiA

Studio della Affettività e Sessualità nel paziente giovane adulto ed Adolescente con cancro

Versione dello studio	1.0
Tipo di studio	Studio osservazionale prospettico
Promotore	Associazione Italiana di Oncologia ed Ematologia Pediatrica
Autori	Andrea Ferrari Paola Quarello Angela Toss

Promotore	Associazione Italiana di Oncologia ed Ematologia Pediatrica (AIEOP)
Centro Coordinatore	AOU Città della Salute e della Scienza di Torino - Ospedale Infantile Regina Margherita, Torino
Razionale	<p>I cambiamenti fisici e psicologici associati a una diagnosi di cancro e al suo trattamento possono avere un impatto importante sulla sessualità, soprattutto nell'adolescenza ed in età giovane adulta. Questo problema è talvolta trascurato dal personale medico responsabile della gestione del trattamento e poche sono le segnalazioni di valutazioni adeguate all'età sull'argomento, o di interventi per discuterne e promuovere il benessere sessuale.</p> <p>La sessualità è un aspetto cruciale di una vita normale e per i giovani malati di cancro deve essere presa in considerazione in un modello di cura su misura per questa tipologia di pazienti.</p>
Disegno dello studio	<p>Studio no profit, multicentrico, osservazionale prospettico</p> <p>Dopo la firma del consenso informato per la partecipazione e per il trattamento dei dati personali, ai pazienti verrà chiesto di compilare un breve questionario in formato elettronico per valutare diversi aspetti della sfera sessuale.</p>
Obiettivo primario	Valutare le aree critiche della sfera sessuale (relazioni personali, l'orientamento sessuale, gli aspetti funzionali, l'immagine corporea e la comunicazione) dei pazienti adolescenti e giovani adulti con patologia oncologica.
Popolazione in studio	Stima dei pazienti che verranno arruolati: 200
Criteri di inclusione	<ul style="list-style-type: none"> -Età alla diagnosi tra 15 e 39 anni -Diagnosi di patologia oncoematologica o di tumore solido -Trattamento attivo (minimo 2 mesi) dalla diagnosi o recidiva o entro due anni dal termine delle cure -Consenso scritto per la partecipazione allo studio e il trattamento dei dati personali -Possesso di un indirizzo e-mail e di accesso ad un collegamento al web
Criteri di esclusione	<ul style="list-style-type: none"> -Incapacità di leggere e comprendere il questionario in maniera autonoma -Non rispetto dei criteri di inclusione

Pediatric Oncology
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Cancer in Adolescents and Young Adults

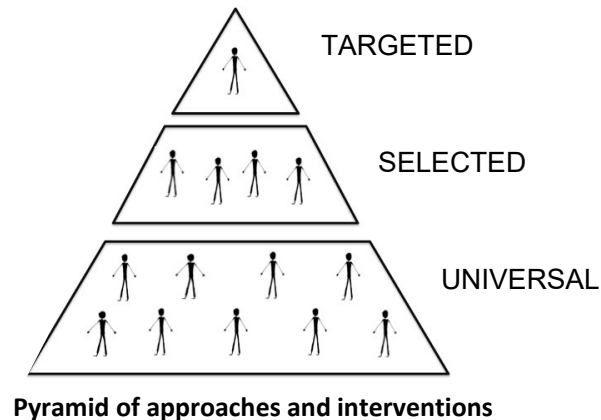
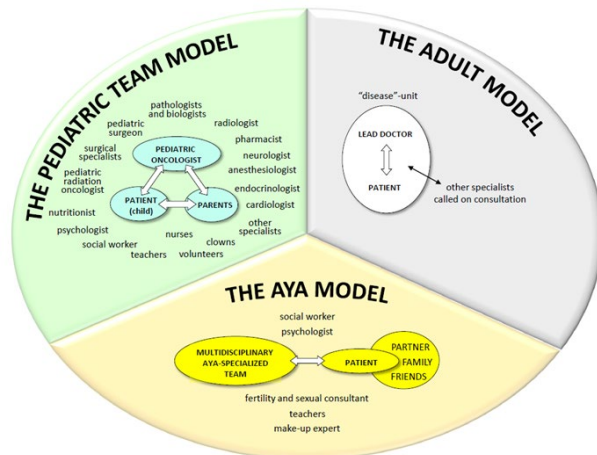
Second Edition

Springer

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Access and Models of Care

Andrea Ferrari, Karen Albritton, Michael Osborn,
Ronald Barr, Rebecca H. Johnson, Dan Stark,
and Jeremy Whelan



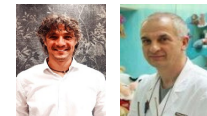
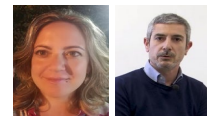
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Terry Perillo, Bari
Giuseppe Milano, Roma
Marco Spinelli, Monza
Maurizio Mascarin, Aviano



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