Setting up of oncosexuality in France
Lessons from the operative phase

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Disclosure of interest : none
- French epidemiological data = 2/3 of patients reported sexual sequels © Enquête Vican 1 and 3 M survivors © Les cancers en France en 2013.

- To care sexual and intimate difficulties is a daily navigation problem

- The majority does not receive the optimal information, care and cure they need.

- The response is only health care professional (HCP) dependant
“Oncosexuality process” in France

3 successive phases (2005-2016)

- **territorial** = pilot plan (ROSA)
- **regional** = cancer network of Rhône-Alpes
- **national**
  - French-speaking supportive cancer care association
  - Association of interregional cancer networks coordinators

For recognize the best action levels, we have distinguished the **inventory** (2005-2008), **operative** (2009-2012) and **reinforcement / expansion phases** (2013-2016).
Lessons from the inventory phase 1

• Not a problem of demand but of health care offer

• Major brakes +++
  – offer is unknown and not visible
  – gaps of knowledge's / skills concern a huge majority of HCPs
  – shared difficulties of communication / dialogue
Lessons from the inventory phase 2

- **Positive point** = real and high overall awareness to the oncosexual dimension

- **Negative points**
  - still “not serious / medical problem”
  - based on engagement of few motivated persons
  - resistances = multi factors (medical, sociocultural…)
  - HCPs = mainly reactive

To obtain both support and approval of HCPs & health institutions is a mandatory step but… not a sufficient parameter +++
To well define the fields of cancer and sexuality

**Oncofertility**
cancer impacts / treatments

**Sexual health and its dysfunctions**

**Intimate life and its troubles** « onco-intimacy »

**Oncosexuality**
cancer impacts / treatments

**Supportive oncological care**

Bondil et al Bull Cancer 2012
5 key-points for setting up

1. Semantic = very important +++

2. CANCER domain +++

3. Natural and legitimate place = supportive cancer care +++

4. Oncofertility and / or oncosexuality concern a majority of:
   - cancers
   - patients / couples / parents
   - treatments
   - HCPs

5. Problems clearly change according to patient age and time

Bondil et al Bull Cancer 2012
Lessons from the operative phase 1

Optimal oncosexuality setting up = multi-target process

3 complementary action axis for responding to patient / HCP needs

- Organization
- Information / training
- Therapeutical

Individual and collective challenge
1. to structure / coordinate the cancer care continuum (CCC)

2. to identify and promote an “oncosexual” trajectory by defining:
   - expected place and role of each HCP ++
   - expectations and needs of patient / couple (heterogeneous) ++

3. to inform / sensitize / train = all concerned HCPs / health institutions / patient associations

4. to know where to orientate = to have a specific directory ++

Lessons from the operative phase 2
Lessons from the operative phase 3

Approach = always transversal + multidisciplinary

- Information and training must be adapted to the specific needs of different HCPs acting all along the CCC
- Relevant response = standards of care / clinical practice guideline (CPG)

Problem
To have CPG for HCPs = necessary for improving care quality but …. not sufficient step

Diffusion + implementation CPG strategies
Awareness training = all HCP

Audiovisual 1
The health professionals

Audiovisual 2
The patients

Audiovisual 3
Physiology, troubles and solutions. To adapt semantic and keep in health care attitude

Audiovisual 4
Daily practice. How care / cure during each step of CCC?

CGP implementation = mandatory step

level 1

Awareness training = all HCP

2 hours

level 2

4 hours = motivation training

level 3

2 days = expert training
Lessons from the expansion phase

• 3 additional key-points

1. To reinforce the politics of information (patient, survivors, HCP, institutions…)

2. To correct the persistent inequality of care access and quality

3. Impact of attitude / exemplarity / involvement of physicians
   – for legitimating oncosexual demand
   – for organizing the supportive care response and appropriation
New specific national meetings

3rd Symposium Cancer & Sexuality
Friday, October 19th 2012
Lyon - International Agency for Research on Cancer (IARC)

- The health care offer in oncosexology: problems and solutions
- Cancer and sexuality: what differences between male and female?

3rdes Rencontres Cancer & Sexuality & Fertility
Lyon - 6 and 7 November 2014
Ecole Normale Supérieure de Lyon

3èmes RENCONTRES CANCER, SEXUALITÉ & FERTILITÉ

1ères RENCONTRES CANCER & SEXUALITÉ
Jeudi 18 October 2012
Lyon - Centre International Recherches sur le Cancer (CIRC)

“Mise en place de l’oncosexologie dans le parcours de soins en cancérologie”
organisé par AFSSOS et le réseau Espace Santé Cancer de Rhône-Alpes

INFORMATIONS et INSCRIPTIONS : COMM Santé
04 50 67 19 19 - cancer-sexualite2012@comm-sante.com

2èmes RENCONTRES CANCER & SEXUALITÉ
Lille - 7 and 8 November 2013
Maison d’Éducation Permanente

“L’INTIMITÉ ET LA SEXUALITÉ DANS LES CANCERS FÉMININS”
- Pourquoi et comment intégrer ces thèmes dans les soins en cancérologie ?

5èmes RENCONTRES CANCER, SEXUALITÉ & FERTILITÉ
Nice - 24 & 25 November 2016
Palais de Congrès

“Le Cancer avant 40 ans”
Place, prévention et prise en charge de la fertilité et de la sexualité liées aux spécificités :
- De l’oncogériatrie
- Des adolescents
- Des jeunes adultes avant 40 ans
- Des partenaires et des proches
Developing and implementing new CPGs

- 2010: Cancer, sexual health and life (2016 to be updated)
- 2012: Cancer, sexual health and intimacy: breast cancer treated with chemotherapy & hormonotherapy
- 2013: Cancer and fertility
- 2015: Male cancers (prostate and testis)
- 2016: Childs and teen-agers: cancers and sexuality

Free open access on afsos.org
• Oncosexuality is a key issue for a really patient-centered approach.

• To break the silence, to legitimize the demand and to organize better health care access are key points.

  ✓ to sensitize and train all HCPs in contact with cancer patients
  ✓ to organize the supportive care all along the CCC
  ✓ to develop and implement standards of care and CPG as cornerstone (international project ISSC + AFSOS)

Conclusions