

The ROSA experience: lessons from a health professional network to reduce the inequality of access to oncosexological care.

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## Why ROSA ? Findings in 2005 (1)

- Unquestionable progress
- 1. Scientific
  - cancer : 50% of cure increasing chronic disease = problem of quality of life
  - sexual health
    - pertinent parameter of both global health and quality of life
    - new treatments (Viagra R, oncoplasty....)
- 2. Socio-cultural
  - new patients rights (WHO 2000)
  - increasing demand of better "well-being" (quality of life)





#### Why ROSA ? Findings in 2005 (2)

- Oncosexological request = reality but... major problem of care offer
  - non visible and non organized
  - exclusively physician or centre dependant and mono-organ (breast, prostate...)
  - real inequality of care access ++
- Major brakes
  - health professional attitudes = little active and too partitioned off
  - oncosexology = not at all a priority









- As sexual health troubles should be taken into account without any problem of health care access, we have set up the pilot plan ROSA (Réponse Onco-Sexologique des Alpes).
- Our objective was to analyze the different problems observed during the period of setting up for drawing the lessons distinguishing the <u>inventory</u> phase (2006-2007) then <u>operative</u> phase (2008-2010)







# Material and method

ROSA process included successively



- 1) a proximity care response whatever the stage, treatment or topography of cancer, thanks to a dedicated (patient / couple) consultations SAICSSO
- 2) a regional response by structuring first, our health care territory (400 000 inhabitants) then our Alpine Arc cancer network (3 millions inhabitants) including several health care territories.
- General hospital of Chambery: role of pilot center (territorial referent in oncology and regional in sexoandrology)









#### Lessons 2006-2007 (1)

Awareness and aptitudes to oncosexological supportive care preliminary survey among health professional of our hospital 2006

- 1. excellent awareness to oncosexological dimension
- 2. large approval to the setting-up of dedicated consultation
- 3. strong gaps (knowledge's / skills)
- 4. strong demand for a better visibility of health care offer

5. same results +++ for additional surveys (junior urologist and radiotherapist + senior urologist + national LCC patient association) 2008-2009-2010

#### Lessons 2006-2007 (2) awareness of health professionals

- Mandatory but not sufficient parameter requiring a daily work at all levels
  - cancer = motivating because « serious » for all the actors but... sexology appears as not serious
  - institutional support = necessary condition but... not sufficient
  - shared project but in daily practice, it mainly relays on individual engagement of few persons owing to a real problem of lack of time (specialists = mainly "rapid medicine" and sexual health appears as time consuming )







#### Lessons 2006-2007 (3) major problem of knowledge's

- « oncosexological GPS<sup>2</sup>» = double need of information
  / formation
  - geographical GPS: to know where to orientate = to recognize the human / institutional resources = regional directory



- competences GPS: to know how to do = strong needs of standards of clinical practice / guidelines (under way in 2010)
- how to detect / talk about sexual health and its troubles = proved positive factor of resilience but...health professional dependent +++



#### Lessons 2008-2010 (1) problematic of better efficacy

#### Identify

- Adequate structures
  - center of supportive care = more legitimate and efficient (multidisciplinary by definition)
  - to relay on another existing structures
    - territorial / regional oncological network
    - associations of patients
- Optimal targets
  - all health professional (directly or not) involved in oncology
  - GP and nurse (key role)
  - associations of patients ++
- Optimal moment ++











#### Lessons 2008-2009 (2) when and how ? Personalized patient circuit in oncosexological health care (PPC) "After" cancer End Treatment Announce health care health care information check-up prevention information information

Usual evolution of hierarchy of values underlines the needs

- to stay listening and available = humanistic medicine
- to detect vulnerabilities
- to anticipate and prevent difficulties

### Lessons 2008-2009 (3) Authorize and legitimate

- Break the silence
  - talk sexual health (and no sex) = usually very easy and natural
  - correct the false ideas (contagious, price to pay, not important...)
  - be careful with "Dr Internet" (referent sites, controlled web.2)
- To not go beyond the demand (respect of individual liberty / dignity)
  - information = 100 % patients / partner / health professionals
  - no request of treatment = 1/3 patients
  - request of sexual health care = 2/3 patients
    - simple = 1/3
    - complex = only 1/3 +++





- Our 5 years ROSA experience show 3 main points :
- 1. the oncosexology must integrate into the health care course (PPC) as a new health care offer within the territorial supportive health care
- 2. the structuring of the offer must be preferentially progressive by creating first, locally dedicated consultations, then by informing / educating all the concerned both health professional and structures
- 3. For being a success, the approach must be pragmatic and transversal using the numerous human / institutional resources of their own health territory and region.