Communication in Genetics & Genomics

• Nursing
  - communication skills
  - competences

• Individual & family
  - family history
  - impact of intra-familiar communication
Why is communication important in nursing?

« Communication and Nursing are indivisible »

« Communication between the nurse and the patient is therapeutic in itself »

L. Webb - Introduction to communication skills - Oxford University Press - 2011
Why is communication important in nursing?

Acute illness ▶ Chronic disease

Patient ▶ Expert
Communication and interpersonal skills:
UK Nursing and Midwifery Council standards

- Communicate safely and effectively
- Use a range of communication skills and technologies
- Use verbal, non-verbal, and written communication
- Recognize the need for an interpreter
- Address communication in diversity
- Respect and protect confidential information
• Identify ways to communicate and promote healthy behaviour
• Maintain accurate, clear and complete written or electronics records
• Promote well-being and personal safety
• Build therapeutic relationships and take individual differences, capabilities and needs into account
• Be able to engage in, maintain, and disengage from therapeutic relationships
Linear model of communication

Sender encodes message

Message channel

Receiver decodes message

Adapted from L. Webb - Introduction to communication skills - Oxford University Press - 2011
Circular model of communication

Adapted from L. Webb - Introduction to communication skills - Oxford University Press - 2011
Genetics & Genomics
(réf. National Human Genome Research Institute)

Genetics = The study of the genes and their role in inheritance

Genomics = The study of all of a person’s genes (genome)
Genetics & Genomics

- Evolving field
- Complexity
- Ethical implications
- Genetic vulnerability
- Consumerism
Welcome to LABGENETICS
Genetics made easy

**Personalized diagnosis**

Are you pregnant? Ensure that your child is born genetically healthy within just 24 hours. **QF-PCR**

Find out about his/her predisposition to suffer heart attacks, Alzheimer, Parkinson or other hereditary diseases.

Are you a carrier of a genetic disease whilst wanting to have genetically healthy children? Call us.

Get informed about the possible reasons why you cannot conceive.

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Request your Free Home DNA Collection Kit for Paternity Tests.

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« All nurses will need to become knowledgeable about the basis of genetics and genomics and their applications to clinical care so that they can provide quality healthcare that is appropriate to their setting, population, geographical location, access, and coverage »
Nursing Competencies

• Skills and knowledge to evaluate family history
• Recognize clinical findings that indicate increased genetic risk

► Core competences for
1) Generalists and other field than genetics
2) Specialist in genetics

H. Skirton & al - Genetic education and the challenge of genomic medicine: development of core competences to support preparation of health professionals in Europe - EJHG (2010)
1. Identify individuals who might benefit from genetic information and services.
2. Tailor genetic information and services to the individual’s culture, knowledge and language.
3. Uphold the rights of all individuals to informed decision making and voluntary action.
4. Demonstrate knowledge of the role of genetic and other factors in health and disease.
5. Demonstrate a knowledge and understanding of the utility and limitations of genetic testing and information.
6. Recognize the limitation of one’s own genetic expertise.
Specialist nurse, specialist midwife and specialist allied health professional

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5. Demonstrate a knowledge and understanding of the utility and limitations of genetic testing and information.
6. Recognize the limitation of one’s own genetic expertise.
7. Obtain and communicate credible current information about genetics for self, clients and colleagues.
Genetics & Genomics in cancer care:

• Diagnosis
• Prognosis
• Treatment choice
• Risk evaluation
• Predisposing genes
Communication in a family

► 1st step to evaluate if there is an hereditary syndrome

• Knowledge of the family
• Knowledge of the disease in family members

• Common disease
• Familial secrets
• False paternity
Communication in the family

- 2nd step to evaluate if there is a mutation in the family

- Another family member
- Informing other family members
- Fear of familial discrimination
Communication in the family

- 3rd step to communicate the result in the family

- Time
- Integration of information
- Duty to inform

- Emotional issues
Impact of intra-familial communication:
Study UOPC - M.E. Laurencet & P.O.Chappuis

- Transmission of information?
- How many testing follow the first case?
- Which is the most frequent screening performed in our Unit?
Impact of intra-familial communication:
Study UOPC - M.E. Laurencet & P.O. Chappuis

• Screening performed versus potential
• Characteristics of probands (sex, age, children..)
• Characteristics of family members (affected,..)
• Probands affected versus asymptomatic
Impact of intra-familial communication:
Study UOPC - M.E. Laurencet & P.O.Chappuis

• 102 Families = 102 first screening
• 1228 Individuals (1st to 3rd degree)
• 1126 potential = 190 performed (17 %)

► 292 testing (181 ♀, 111 ♂)
► 936 individuals not tested (53 % ♂; 47 % ♀)
Testing in UOPC 1995 - 2010

- BRCA1/2: 48%
- MMR: 37%
- APC: 5%
- OTHERS: 10%
Results

• Screening performed *versus* potential
  - BRCA1/2 = 13 %
  - Lynch = 25 %
  - APC = 18.5 %

• Characteristics of individuals tested
  - women for BRCA1/2 (56 vs 1)
  - women & men for Lynch
  - first degree (parents, children, sisters, brothers)
  - having children
  - asymptomatic
  - same cancer
Results

• Characteristics of families tested
  - 23 % at least 3 testing
  - 62 % tested for BRCA1/2 and Lynch
  - 7 testing maximum for BRCA1/2
  - 9 testing maximum for Lynch
  - access to consultation
Intra-familial communication:

• Responsability

« I felt a sort of obligation to tell my family because knowing is a responsibility but suppose if some of my cousins have breast cancer and I didn’t tell them. So I thought I have to tell them and what they do with it, sorrrry, but that is... What each person is deciding.. »

• Not an easy task

« There is absolutely no guidance in how to inform your family members. Perhaps that’s why it is often received negatively in your family because people don’t understand it fully »

C. Maddock & al.- To know or not to know? -ecancermedicalscience (2011)
Intra-familial communication:

- Ethical, emotional and practical issues
  « People always have difficulty in when and how to tell their children »

« Please don’t forget the insurance risks. If a family member wants to ensure her or his life, they do not want a genetic test to tell them that they are predisposed towards getting a certain killer disease. This alone would prohibit an awful lot of people from getting themselves tested. And I don’t blame them either »

C. Maddock & al.– To know or not to know? –ecancermedicalscioence (2011)
Communication tools:

- Personalized letter with result and recommendations for surveillance/prevention
- «Simplified» letter for family members
- Support group
- Leaflets
- DVDs
- Internet – forum, blog
- Conferences
- Support by a Professional
Internet links

- www.orphanet.org
- www.cancerbackup.org.uk
- www.chu-rouen.fr
- www.europadonna.com
- www.genetics.com
- www.hon.ch
- www.genome.gov
- www.planetegene.com
Thank You for your Attention!