CURRENT SITUATION OF GENETIC COUNSELLORS AND NURSES

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INTRODUCTION

Genetic Counselling

- suggested the term of “genetic counselling”
- process of communication with patient and family
- genetic counselling would be of help to individual families
- genetic information:
  - “must be compassionate, clear, relaxed, and without a sales pitch.”
  - “given by social workers”

- Genetic Counselling vs Genetic Diagnosis
Genetic Counselling

- International Bioethics Committee, Paris (France), 1995
- Definition of «Genetic Counselling»
  - Process of communication:
    - Explaining a diagnosis,
    - Giving details and informations on the inheritance,
    - Helping patient with Decision of a test.

- Given by:
  - Medical doctors
  - Nurses (breast nurses)
  - Psychologists
  - Genetic Counsellors (and nurses)
Genetic Counsellors

- Oncogenetics
- Cardiogenetics
- Neurogenetics
- Prenatal Diagnosis
- Preimplantation Diagnosis
- Medical Genetics
- Ophthalmogenetics
Training Programs in Genetic Counselling

Global Estimate of Trained Genetic Counselors (2017)

The Americas: ~5250 GCs
Europe and Middle East: ~1000 GCs
Asia: >350 GCs
Africa: <50 GCs
Australia: ~300 GCs
## Training Programs in Genetic Counselling

<table>
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<tr>
<th>Well Established Profession</th>
<th>Developed Profession</th>
<th>Profession In Development (graduate training programs started)</th>
<th>Profession In Development (no MS training programs yet)</th>
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<td>Spain (2008)</td>
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<td>Sweden, Switzerland</td>
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<td><strong>ITALIA ... AUSTRIA ...</strong></td>
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Assessment of the Full Portfolio: 2019

11 Approved
3 deferral request
2 failed
1 major revision (next year)
Training Programs in Genetic Counselling

Genetic Nurses & Genetics Counsellors

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Training Programs in Genetic Counselling

- Assessment of competence of Genetic Nurses and Counsellors in Europe
- Proposed European Curriculum for MSc Genetic Counselling
- Proposed Code of Practice for Genetic Counsellors in Europe
- Proposed Core Competences for Genetic Counsellors in Europe
- Proposed Professional and Educational Standards for Genetic Counsellors in Europe
Relation between medical doctors and non-medical health professionals

The first emerging theme includes several aspects. Genetic counsellors, as well as medical geneticists, agreed genetic counsellors frequently acts as ‘patient advocate’, with a patient-centred approach, focussing on patients’ needs and expectations in the session.
Relation between medical doctors and non-medical health professionals

Genetic counsellors are described as:
- providing additional perspectives and dimensions to the team,
- Having the ability to get close to patients and families as a whole,
- Highlighting the psychosocial dimension of the process.

Genetic counsellor contributions also involved the ethical dimensions of the practice, including research in this area, as well as their knowledge regarding the legal framework.

Genetic counsellors add efficiency to the genetic team. Their influence in genetic services seems to enhance the attention to patients and families at a lower cost, and to provide more accessibility, reduced waiting times, providing autonomous consultations and handling many administrative tasks before and after the appointments.
Relation between medical doctors and non-medical health professionals

The contribution that genetic counsellors provide to genetics health-care services can be summarized as:

- the provision of better care by highly skilled professionals at lower cost,
- securing greater accessibility and proximity with the patients and families
- complementing the work with medical geneticists,
- relevant for the quality of health-care service.

All the above can be used to argue the need of increased integration of genetic counsellors in countries where they are underutilized and the promotion of professional recognition of genetic counsellors across Europe and worldwide.
The recognition of the profession of Genetic Counsellors in Europe

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THANKS FOR YOUR ATTENTION