

What does a Genetic Counsellor do in the University Hospital of Liège?



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Introduction

Lately, the University Hospital of Liège has been facing a growing demand for genetic consultations. In addition to increasing the number of clinical geneticists, the University Hospital (UH) also opened a first position of Genetic Counsellor (GC) in 2013, followed by a second one in 2017 and a third one in 2020. The GC profession is not official in Belgium yet even though it is recognized in many countries around the world and the "Centre fédéral d'Expertise des Soins de Santé (KCE)" is in favor of the development of the function of GC. This is why a national working group was set up in 2015 and a procedure is underway to create an MSc in genetic counselling in order to get a national recognition of this function.

The aim of this study was to characterize and evaluate the activities of GCs since the creation of this function at the University Hospital of Liege.

Methods

We performed a retrospective observational study of the patients of the UH of Liège who had consulted with a GC between 2013 (date of creation of the genetic counselling consultations) and December 2021. We also analyzed the other interventions/tasks of the GCs. We performed a descriptive statistical analysis with all this information.

Results

The data of the GCs' tasks between 2013 and 2016 were not coded in detail, so the most statistical work was done on the part of the data between 2016 and 2021.

At the University Hospital of Liège, the number of paired consultations has increased from 647 in 2016 to 787 in 2021 (+21,6%) and the number of specific GC consultations has increased from 93 in 2016 to 751 in 2021 (+707,5%). The number of administrative interventions has also increased from 25 in 2013 to 2160 in 2021 (+8540%) (Table 1).

The main task of the GCs since 2016 is to receive patients in consultation (59% of the time) either in pair with a geneticist (39% of the time) or in "genetic counselling" consultation under the supervision of a geneticist (20% of the time). The distribution between the different tasks has evolved and the "consultation" part has increased from 50% in 2016 to 70% of the time in 2021. Time dedicated to the "genetic counselling" consultations has increased too, from 6% in 2016 to 34% in 2021 (Table 2).

Other tasks are mainly administrative (41% of the time): preparing patient files, answering patients' questions before/after consultations (by phone or email), acting as a relay between patients and other doctors/paramedics, digitizing family trees, scheduling appointments, including patients in clinical studies and managing their data. Most of the administrative work is done in contact with the patient (39% of the time) and the rest of the time (2%) is taken up by collaboration with other health care professionals (Table 2).

Table 1: Evolution of CGs' tasks over time

Paired consultations with a Geneticist

900

700

600

600

400

1000

1000

2016

2016

2016

2017

2018

2018

2018

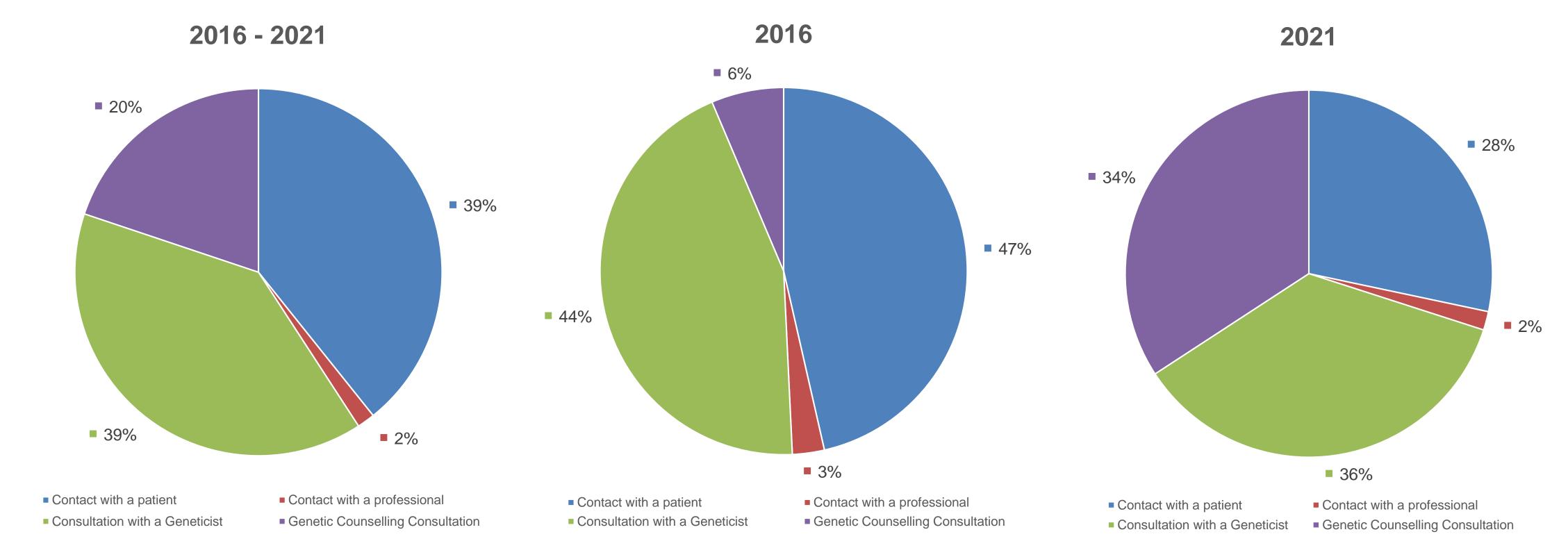
2018

2011

2013

2014

Table 2: Division of GCs' tasks between 2016 and 2021



Conclusion

The activity of genetic counsellors has been increasing since 2013. The number of specific "genetic counselling" consultations has increased from 93 patients received in 2016 to 751 patients in 2021 (+707.5%) and the administrative interventions have increased by 8540% these last years. The evolution of the quantity and distribution of tasks over time clearly shows the recognition of the CGs' work by our multidisciplinary team. The increase of specific genetic counselling consultations also indicates the importance of the genetic counsellors in the overall management of the patient and their contribution to meeting the increasing demand for genetic counselling.