Digital technologies in genetic counselling

An overview of ethical aspects

UMC Utrecht

Marlies van Lingen*1, Noor Giesbertz2, Annelien Bredenoord3, Lieke van den Heuvel1, Peter van Tintelen1, Karin Jongsma4
1University Medical Center Utrecht, Genetics, Utrecht, Netherlands, 2Netherlands Cancer Institute, Amsterdam,
3Erasmus University Rotterdam, School of Philosophy, Rotterdam, Netherlands, 4University Medical Center Utrecht, Julius Center, Utrecht, Netherlands
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Research Day

m.n.vanlingen@umcutrecht.nl

Introduction

As the demand for genetic counselling grows rapidly, technical solutions are proposed and developed to increase efficiency and to overcome logistic or societal barriers. Existing and emerging digital technologies designed for genetic counselling range from digital platforms to conversational agents. Other platforms, such as the eCG Family Clinic for cardiovascular genetic counselling, aim to support the full counselling process from pre-test counselling to at-home DNA testing and disclosure of results.

Ethical reflection is necessary to facilitate sound implementation of digital technologies into genetic medicine. Therefore, we identified ethical aspects of the implementation of digital technologies in the field of genetic counselling, when compared to in-person counselling.

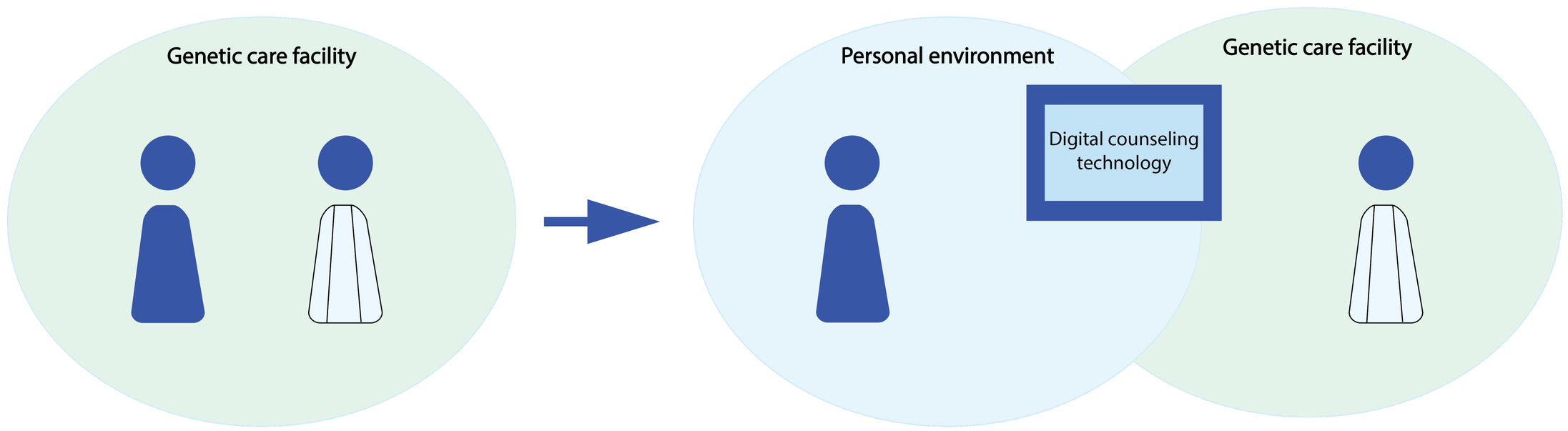

Figure 1 – Visual representation of the current in-person counselling (left side) and potential genetic counselling after the introduction of digital technologies (right side). Counselees and genetic healthcare professionals are represented in each figure.

Results

We identified three promises of digital technologies in genetic counselling in the literature related to: 1) respect for autonomy, 2) fairness, and 3) efficiency (Table 1). These considerations are related to the interaction between genetic healthcare professionals, counselees, and digital technologies (Figure 1).

Promises	Benefits	Challenges
Respect for autonomy	•Counselee empowerment: increased control over counseling and information	•Ensuring quality of informed consent •Shared decison making •Data privacy and genetic privacy
Fairness	•Accessibility increase •Information availability	•(Digital) illiteracy •Demand of skills •Introduction of bias
Efficiency	•Increased time per counselee •Workload and wait list improvement •Flexible and scalable technology	•Psychosocial support •For AI: safeguarding transparency and explainability •Respecting and managing family context

Table 1 – Overview of ethical aspects related implementation of digital technologies in genetic counselling

Discussion and conclusion

- Introduction and implementation of digital technologies in genetic counselling brings ethical benefits and challenges, related to respect for autonomy, fairness and efficiency.
- Ethical benefits and challenges are related to the extent in which tasks of a genetic healthcare professional are delegated to a digital technology and the complexity of the technology included. These factors impact the roles and responsibilities that should be allocated to the digital technology.