

Reproductive decision support in hereditary cancer

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Valorization

Valorization

This paragraph describes the societal value of the results from this thesis. The importance of the results for the patient group and the broader setting of clinical oncogenetics will be discussed.

In this research project we aimed to develop (**Chapter 2 and 3**) and evaluate (**Chapter 4 and 5**) an evidence-based online patient decision aid to support couples with a predisposition to cancer during reproductive decision-making. A predisposition for hereditary cancer usually has an autosomal dominant inheritance pattern, implying that there is a 50% risk in each pregnancy of transmitting the mutation in one of the cancer genes to offspring. Transmission implies passing on an increased lifetime risk of developing cancer. In the last decade, mainly qualitative studies have been initiated to investigate the experiences of couples confronted with this increased risk for their offspring, regarding their reproductive decision-making process. These studies found that, overall, couples experience the reproductive decision-making process as difficult and emotionally demanding.¹⁻⁵ Couples have to cope with their own increased risk of developing cancer and they are concerned about the risk of passing on the predisposition to cancer to offspring.⁶ A recent study among couples with Hereditary Breast and Ovarian Cancer (HBOC) who had made a reproductive decision after reproductive counselling, showed that 69% expressed a need for additional support during reproductive decision-making in addition to existing reproductive counselling.⁵

In the Netherlands, all couples of reproductive age who plan to have children have access to preconception counselling by general practitioners, gynecologists and/or midwives. In addition, persons of reproductive age who might have a predisposition for hereditary cancer may be referred to one of the nine Clinical Genetic Departments in the country to receive information about genetic testing and their reproductive options to prevent transmission of the mutation to offspring. Follow-up consultations with a specialized clinical geneticist, psychologist or social worker can be scheduled on request for persons with a cancer predisposition who indicate that they have specific questions concerning the reproductive risks or are in need of additional support.

The present research demonstrates the added value of our online decision aid to support couples during reproductive decision-making in addition to existing reproductive counselling. Decision aids are useful for providing patients with information and additional support during decision-making⁷ and have been proven effective in improving decision quality while enhancing, not replacing, the traditional process of patient

counselling by healthcare providers.⁸ Although research efforts with regard to decision support in the area of hereditary cancer are lagging behind compared to applications in non-hereditary cancer (e.g. treatment options), in prenatal testing and in pregnancy care in general,⁸ the concept of decision support in itself is not new in the area of hereditary cancer. There have been initiatives to support persons with a predisposition to hereditary cancer in their decision-making regarding genetic testing,^{9,10} communicating genetic test results with family members and children¹¹ and regarding risk-reducing surgeries.¹² However, a patient decision aid specifically tailored to couples involved in reproductive decision-making in hereditary cancer, has not been developed and reported on before.

A collaboration was set up with a steering group including counsellors (e.g. clinical geneticists, genetic counsellors, and social workers), experts in health communication and medical decision-making, psychologists, and the intended end-users of the decision aid, i.e. persons having a genetic predisposition to cancer and their partners who are planning to have children, to guide the development of the decision aid and to optimize its reach. After we developed and evaluated the online decision aid, we conducted an explorative study on opportunities for continued implementation (**Chapter 6**) because many (proven) effective decision aids are often infrequently used in daily practice following trial periods.¹³ By conducting this study we intended to maximize the impact of the decision aid by increasing the awareness and reach of the decision aid, facilitating its implementation, and optimizing the sustained use of the decision aid after finalizing this project. To further increase the awareness of the tool, the outcomes of our studies have been, and will be, published in scientific medical journals and presented at national and international scientific conferences, meetings of involved professionals (e.g. presentations at department meetings) and at patient organization meetings.

Based on the results of the study described in **Chapter 6**, we strive to structurally implement the decision aid in the reproductive counselling of persons having a genetic predisposition to cancer and their partners who are planning to have children. The decision aid will be freely available on the Internet enabling all healthcare providers, patients and relatives of patients to use the decision aid without costs. This will facilitate the overall reach of the tool, also among couples who will never visit the Clinical Genetic Department. We will strive to incorporate the decision aid on commonly used websites such as patient organization websites and the national PGD website (<http://www.PGDNederland.nl>). Also, the link to the decision aid will be included in the standard report that counselees receive after consultation. In this way,

referral to the decision aid can be relatively easily incorporated in daily practice of healthcare providers. The possibility for referral to the decision aid by general practitioners, gynecologists and/or midwives, which will aid to further increase of the reach and thereby the impact of the decision aid, needs to be explored. Further development of the decision aid, technical maintenance, and keeping it continuously up-to-date, requires recourses. To cover these costs we could consider submitting an application for an implementation grant (e.g. Dutch Cancer Society).

The decision aid will serve both healthcare providers (e.g. clinical geneticists and social workers) and patients. Healthcare providers may benefit from the decision aid as it could contribute to an improvement of the reproductive decision quality among their patients.¹⁴ If the decision aid is used by the couple before scheduled counseling, healthcare providers do not have to explain all elements of each reproductive option in detail. Patients will be better informed, which may lead to more interactive consultations and more time to discuss psychological issues and couples' motives and considerations. In this way, patients will benefit from the decision aid by enabling them to make a more informed reproductive decision. Supporting couples in making an informed reproductive decision will probably reduce feelings of doubt and uncertainty and may lessen the negative psychological impact of decision-making on couples' daily life and wellbeing. Furthermore, as a substantial part of carrier couples are not aware of their reproductive options,¹⁵ timely introduction to the decision aid by healthcare providers during preconception care and reproductive counseling is expected to result in an overall higher awareness of reproductive options among carrier couples. More couples will be able to make a well thought-out decision regarding their reproductive options, preventing regret or hard feelings afterwards.¹

The content of the tool is currently being adapted to other hereditary conditions for which reproductive techniques are available in the Netherlands. With this continued development, we aim to facilitate informed reproductive decision-making among the entire patient group and therewith further increase the impact of the decision aid. Furthermore, we are exploring the possibilities for translation and adaptation of the content of the decision aid to facilitate international application of the tool.

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