Mapping Users' Experience of a Family History and Genetic Risk Algorithm Tool in Primary Care

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Keywords

Family history · Primary care · Qualitative methodology

Abstract

Introduction: The development of a family history (FH) questionnaire (FHQ) provides an insight into a patient's familiarity of a trait and helps to identify individuals at increased risk of disease. A critical aspect of developing a new tool is exploring users' experience. **Objective:** The objective of this study was to examine users' experience, obstacles and challenges, and their views and concerns in the applicability of a new tool for determining genetic risk in Slovenia's primary care. **Methods:** We used a qualitative approach. The participants completed a risk assessment software questionnaire that calculates users' likelihood of developing familial diseases. Audio-taped semi-structured telephone interviews were conducted to evaluate their experience. There were 21 participants, and analyses using the constant comparative method were employed. **Results:** We identified 3 main themes: obstacles/key issues, suggestions for improvements, and coping. The participants were poorly satisfied with the clarity of instructions, technical usability problems, and issues with the entry of relatives' data. They expressed

satisfaction with some of the characteristics of the FHQ (e.g., straightforward and friendly format, easy entry, and comprehension). They suggested simpler language, that the disease risk should be targeted toward the disease, that the FHQ should include patient-specific recommendations, and that it should be part of the electronic medical records. When discussing what would they do with the results of the FHQ, the participants used different coping strategies: active (e.g., seeking information) or passive (e.g., avoidance). **Discussion/Conclusion:** User experience was shown to be a synthesis of obstacles, overcoming them with suggestions for improvements, and exploration of various coping mechanisms that may emerge from dealing with the stressor of "being at risk."

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Introduction

Family history (FH) has an important role in family practice. It provides insight into a patient's family background and helps to identify patients at higher risk of developing diseases that "run in the family" [1], including cardiovascular diseases [2, 3], various types of cancer [4,

5], and diabetes [6], among others [7]. Collecting data on FH and providing patient-specific recommendations is a key and integral part of a proactive approach to patient care; most importantly, it represents the basis of implementing cost-effective strategies for preventing and reducing the risk of disease in the population [7].

FH tools allow the data to be collected and managed systematically. Patients can provide the required information themselves, either at home or in the waiting room at the physician's office [8]. This gives the patient more time to collect the correct information from their relatives, and at the same time, it decreases the burden of collecting the data for physicians [1, 9, 10]. Thus, the physician can focus on interpreting the information, rather than collecting it [11].

There are currently no FH tools available to physicians or their patients in Slovenia to determine their risk level for a broader group of common diseases with possible genetic etiology [12]. In 2019, Selič et al. [12] presented a protocol for the first genetic tool, based on risk assessment software. It is an electronic Web-based application intended to be used in primary prevention by family physicians. Patients enter their data on their FH, and the application provides a risk assessment for developing familial disease according to the disease's presence in the patient's family. The tool can calculate 3 levels of risk (average, medium, or high), based solely on a 3-generational FH.

A critical aspect of developing a new tool is exploring users' experience [13, 14]. It is imperative to be aware of any potential obstacles and problems that users may experience [14, 15]. Previous studies exploring user experience have reported that time-consuming history questionnaires (FH questionnaire [FHQ]) [9, 14], technical usability issues related to the use of the computer [16, 17], difficult-to-understand medical terminology being included in the FHQ [17], and being unable to retrieve information needed to complete the FHQ (e.g., less relevant diseases in relatives and relative's age when diagnosed) appeared to be the most important obstacles [10, 18, 19]. Users also had concerns with the safety of the data, specifically about the privacy and confidentiality of the information entered in their FHQ [9, 17].

The development of a new FHQ is sought to provide clinicians with more detailed and systematic information about the risk associated with their patients' FH. The following study will assess the user experience described above, the obstacles and challenges, and users' views and concerns in the applicability of a new tool for determining genetic risk in Slovenia's primary care.

Table 1. Characteristics of participants ($n = 21$)

Characteristics	N (%)
Age, years	
25–30	11 (52)
31–39	4 (19)
40–59	6 (29)
Gender	
Male	8 (38)
Female	13 (62)
Marital status	
Single	5 (24)
Partnered	16 (76)
Education	
1 = high school	5 (24)
2 = college/university	14 (66)
3 = MS, PhD, MD	2 (10)
Working status	
Student	6 (29)
Full-time employed	14 (66)
Unemployed	1 (5)

Materials and Methods

This study was approved by the National Medical Ethics Committee at the Ministry of Health of the Republic of Slovenia. It was in accordance with the Ethical Principles for Medical Research Involving Human Subjects and the Declaration of Helsinki and with the Consolidated Criteria for Reporting Qualitative Research checklist.

Participants and Procedure

This study is part of a research project, “The Development of an Algorithm for Determining Genetic Risk at the Primary Healthcare Level: a New Tool for Primary Prevention (ID L7-9414)” [12], and was conducted between April and September 2021. The exclusion criteria were not having internet access, age below 18 years, not speaking the Slovene language, an inability to understand the instructions, and signs of mental disorder or cognitive deterioration that could lead to distorted interview results. We initially included 22 participants, but one decided to decline the participation due to his worsening clinical status (tumor progression). Thus, 21 participants were included in the interviews (see Table 1 for participants' characteristics). Based on data and thematic saturation in qualitative research and the sample size used, at least 10 interviews are usually appropriate for diversity sampling [20].

The interviewer working on this project recruited participants by sending an email to a group of students on a psychology program at the University of Primorska and their parents. As soon as the participant had consented to the study, the interview began. A female psychology student with a bachelor's degree (K.K.) conducted interviews under the supervision of a principal investigator (P.S.) with a PhD and extensive experience in qualitative research. Every effort was made toward no conscious or unintended bias on the part of the interviewers in regard to the subjects' age, profession, or sexual orientation. The interview process was discussed

Table 2. Questions for an open-ended interview

No.	Question
1	Did you find the application understandable? Did you understand what application required from you? Did you understand the instruction of application?
2	Did you find the application useful? Did you find the application practical?
3	Was entering data in the application easy? Did you have problems with entering data in the application? If yes, which ones?
4	Do you find it useful to complete the Web application at home and take the results to your personal doctor?
5	Do you find it useful for your personal physician to incorporate the results of an online application into your medical treatment?/Do you find it useful for your doctor to consider the results of the Web application in your treatment?
6	Would you like to know the results of your risk even though you are healthy for once?/Would you like to know your risk of developing the disease?
7	Based on the results obtained, would you decide on treatment, even if it is only information about the increased risk?/Would you decide for treatment if you have information that your risk of developing the disease is increased?
8	Would you change your lifestyle based on the results?/Would you decide to make a lifestyle change if it would help reduce your risk of developing the disease?

among researchers (K.K., P.S.-Z., and Š.M.) after conducting 3 interviews to ensure that the gathered data showed sufficiently meaningful descriptions. The participants were not offered any financial compensation for the completion of the FH or the interviews; they were informed about the study and knew that they could withdraw their participation at any time. Due to the COVID-19 pandemic, telephone interviews were used to collect the data. Each interview lasted 20–30 min and was audio recorded.

Data Collection

Risk Assessment Software

The participants completed a software application that was available through a website provided by email. A Web application-based algorithm with an aim for determining the risk level for selected monogenic and polygenic diseases was developed as part of a research project, “The Development of an Algorithm for Determining Genetic Risk at the Primary Healthcare Level: a New Tool for Primary Prevention (ID L7-9414)” [12].

In this study, we used a test version in which we reviewed the experiences of the potential users. Based on the reported experiences and a review of the results, the second/upgraded version of this application will be prepared by geneticists. The risk assessment software has an implemented algorithm, which calculates the likelihood that a person will develop a familial disease based on the presence of medical conditions in their relatives. This application calculated the risk for familial diseases based on a 3-generation FH and classified the subjects in 3 risk groups: low, medium, and high. For each group, risk-based recommendations followed (genetic counseling in high-risk groups and patient monitoring by the medical team in medium- and low-risk groups). The risk level is based on the generation of the relatives affected by the disease, the onset of the disease in the relatives, and the number of relatives affected [12]. An algorithm based on the modified Scheuner method [21] was developed to determine the familial risk of cardiovascular diseases, hypertension, diabetes, cancer, neurological, mental, and

sensory diseases, and other diseases present in the family with a possible genetic etiology.

Navigation flow follows 4 sections presented in the software. Each section is presented on a separate page. The user clicks on the option presented on the page. If the user cannot find the given answer, each question has an option “other” in which users can write personalized answers. The first section captures personal data (gender, number of abortions if women, number of siblings, having a twin, height, weight, and presence of the current diseases), second section captures data on the structure and size of the 3-generation family, third section captures data on the relatives’ diseases, and the fourth section captures the description of the risk of a familial genetic predisposition.

There are no public health tools or electronic applications available to doctors or the lay public in Slovenia to determine the risk level for specific diseases with genetic etiology. Application [12] determines genetic risk for all diseases that could have a genetic component, not just for specific ones. Given that this tool is in its pilot version, further description will be provided as the algorithm undergoes through its test phase.

Telephone Interviews

The data were collected by semi-structured telephone interviews. The questions were based on a review of the previous articles (see Introduction) [9, 13–17]. The open-ended interviews explored 3 main topics (see Table 2 for specific questions): understanding and usefulness (e.g., how was your understanding of the software?); challenges and obstacles (e.g., what challenges did you have when using the FHQ?); and users’ views on choices related to the consequences of a potential increased risk identified by the software (e.g., how would you feel about knowing your disease risk?). It allowed the users to elicit a description of their experience and to clarify their responses and enabled the interviewer to immediately respond to the answers and thus explore issues and gain clarity.

Table 3. Main theme, obstacles/key issues, and its subthemes

Theme 1: obstacles/key issues (number of quotes)		
Unclear instructions	Technical usability problems	Issues with relatives' data entry
Disease categorization (9)	Data not stored in real time (7)	Data entry too complicated (3)
The need for unified data (3)	Time remaining for completion not shown (2)	Data not accurate (9)
Uncertainty about the death of relatives (9)		
Confusion over the entry of relatives' data (7)		

Table 4. Main theme suggestions for improvements and its subthemes

Theme 2: suggestions for improvements (number of quotes)
No need for modification:
Straightforward and friendly format (8)
Easy entry (8)
Easy to understand (3)
Clear overall instructions (5)
Useful and relevant (6)
Satisfying completion time (5)
Language should be simpler (5)
Disease risk should be targeted towards the disease (11)
It should include patient-specific recommendations (9)
It should be part of the EMR (6)
EMR, electronic medical records.

Data Analysis

After data collection, the interviews were transcribed and analyzed manually. The process of data analysis occurred in 3 phases using the constant comparative method [22]. This methodological approach follows a process of inductive coding, comparison of the observed sub-themes, and a constant verification of the analysis of the qualitative data. As a consequence, the patterns found are gradually revealed and refined throughout the process [23]. In the first phase, a primary analysis by inductive coding was performed. In the second phase, subthemes were explored through a series of steps from assigning quotations to codes, summarizing the description of the codes to each subtheme, establishing the boundaries of the subthemes, and finally finding the appropriate themes. This process was repeated so that the themes, which emerged from the interviews, were used to inform further analysis of the transcribed data. The data analysis was discussed on a weekly basis. The third phase of the data analysis involved confirmation of the themes and categories by all the authors of the article.

Results

The collected data were organized into 3 sublevels: code(s), subtheme(s), and main theme(s). We identified 3 main themes, 10 subthemes, and 21 codes emerging from 215 quotes. The identified themes were as following:

Table 5. Main theme, coping, and its subthemes

Theme 3: coping (number of quotes)	
Active coping	Passive coping
Seeking information (5)	Avoidance (2)
Attending screening programs (11)	Rationalization (2)
Changing health behavior (10)	Minimalization (4)
	Complaining/venting feelings (3)

(1) obstacles/key issues, (2) suggestions for improvements, and (3) coping. Here, we present the data using quotations that were selected as examples of the codes representing subthemes and themes. In Tables 3–5, the numbers in brackets represent the number of quotes identified under each code.

Obstacles/Key Issues

This theme contains 3 subthemes: unclear instructions, technical usability problems, and issues with relatives' data entry (Table 3). Within this theme, the participants universally thought that the instructions were not clear enough (Table 3). When completing the FHQ, the participants were confused about where to put certain diseases and how to categorize the data (U4: “I couldn’t find where to put Alzheimer’s disease, so I just put it under Dementia”); they expressed the need for more unified instructions (U6: “There are different categorizations in the original table and in the application”); they did not know whether to include dead relatives or not (N1: “I didn’t think it was clear enough whether should I add relatives that were alive or dead”); and thought that the entry of relatives' data was at times very confusing (U21: “I didn’t know what to answer to ‘How many grandfathers did your mother have’? How it can be 15 or 16? That was very confusing”).

The participants also had technical usability issues; specifically, they observed that the information was not stored when completing the assessment (U2: “I made 2 mistakes and wanted to go back, and then it threw me on to the first page and I had to start over from the begin-

ning”); and not showing the time remaining for completion (U6: “Usually in questionnaires you have how much time there is left for completion up in the right corner. That was missing”).

Issues with the entry of relatives’ data were seen as an obstacle. They thought that the data entry was not clear (U10: “The list of brothers and sisters is not transparent. I don’t think my father would be able to complete something like this. It’s just too complicated”) or accurate enough (U7: “One of my relatives had asthma. Because he has died, we cannot ask him when the asthma started, how long it persisted and what the trajectory of the disease was”).

Suggestions for Improvements

The participants were satisfied (Table 4) with how straightforward and friendly the format was (U4: “The application was very straightforward. I especially liked the first page when you give information – very clear and nothing chaotic about it”) and with the easy entry of the data (U3: “It was very easy to include the data”). They thought the application was easy to understand (U17: “The application was very easy to understand, made for an average user”); that the instructions were clear overall (U1: “If I didn’t understand something, I would read it again and then I got it”); and that the application was useful and relevant (U7: “It was very useful, especially for the diseases that run in the family”). The participants were satisfied with the completion time (U4: “I liked that it was short and easy and afterward you got something out of it”).

They had some suggestions for improvements, including that the language should be simpler (U5: “You have to dive deep to understand some of the expressions. There is a lot of medical terminology that is hard to understand – maybe some of the wording should be made simpler”); that the risk of a particular disease should be better specified (U6: “Definitely I would want more information than just saying that I’m at high risk. For what disease?”); that the application should include patient-specific recommendations (U7: “It would be very valuable if the application included information on what should I do after receiving a high risk result”); and that it should be part of the electronic medical records (EMRs) (U7: “I would want this data to be included in the EMRs, so that all specialists are able to see the results”).

Coping

The participants used different coping strategies when discussing what would they do with the results. Their answers were categorized into 2 subthemes (Table 5): active coping and passive coping.

When asked what would they do if they found that they were at high risk of developing a disease, the participants using active coping would seek information (U4: “I would definitely call my doctor to get more information”); attend screening programs (U7: “If there was a serious problem, I would attend an additional screening test”); or change their health behaviors (U6: “If someone had told me that I had an increased risk for that disease, and that eating healthily or exercising more would decrease that risk, I would definitely do it”).

Others used passive coping to deal with the stressor of potentially being at high risk. These participants would use avoidance (U1: “I wouldn’t use the application to tell me what my risk of developing the disorder is. Everyone who smokes know that they are going to get cancer. I don’t need an application for that”); rationalization (U14: “I wouldn’t want to burden the health system additionally with my issues”); minimalization (U2: “I solve my issues when they come. Why earlier? I wouldn’t be worried unless I became sick. I wouldn’t even change my lifestyle. Living in fear and prevention is not it. It is not living”); and venting feelings (U10: “At the end... I really don’t like it that the risk is colored red. It is... I mean it can make you feel a bit of distress”).

Discussion/Conclusion

Summary of Findings

The aim of this study was to explore users’ experience after completing a risk assessment software questionnaire. Three main themes were generated from 217 quotations taken from the participants’ interviews: obstacles/key issues (unclear instructions, technical usability problems, and issues with the entry of relatives’ data); suggestions for improvements (language should be simpler, disease risk should be targeted toward the disease, and it should include patient-specific recommendations and be part of the EMR); and coping (active and passive coping). In this study, all 3 themes will be important for the future development of the software; however, the final theme (coping) also has clinical implications.

Comparison with the Existing Literature

Web-based software has become a critical element of collecting FH, supporting the quality of the users’ experience and reducing the time burden of clinicians, since the information can be completed at home. One of the aims of investigating the users’ experience was to explore the obstacles and key issues reported by the users (Fig. 1).

Obstacles/key issues	Suggestions for improvements	Coping
<ul style="list-style-type: none"> - Unclear instructions (the need for unified data) - Technical usability problems (data not stored in real time) - Issues with relatives' data entry (data not accurate) 	<ul style="list-style-type: none"> - Simpler language - Disease risk should be targeted towards the disease (not general risk) - Including patient-specific recommendations - Should part of the EMR 	<p>Ways of coping with FH risk-based result:</p> <ul style="list-style-type: none"> - Active (seeking information, attending screening programs) - Passive (avoidance, minimalization)

Fig. 1. Mapping users' experience.

To understand users' experience, we first need to understand what kind of FH tools exist. FH tools can be characterized as generic (i.e., identification of multiple diseases) [24, 25] or disease-specific (i.e., one disease or disease group) [26, 27]. Tools can be pedigree-oriented (i.e., a complete overview of family members and their diseases) [28, 29] or disease-oriented (i.e., presence/absence of the disease in the family) [30, 31]. Tools can be completed by the patient [32] or clinician [33]. It can be paper- [34] or electronic-based [35] and can include risk assessment [36] and (evidence-based) recommendations [37]. The tool explored in this study intends to be generic, electronic, pedigree-oriented, completed by the patient with included risk assessment, and evidence-based recommendations.

Based on reviewing previous FH tools, there is no tool that would "fit every user" [11, 13, 28, 37–45]. Even in more popular tools such as Health Heritage®, users' experiences results showed that only 63% found the information easy to understand [46]. Therefore, it is more important to understand users' needs and try to implement the majority of problems that would fit the majority of users.

Unclear instructions, technical usability issues, and issues with data entry emerged as 3 key issues, which require examination in more depth. Our participants had trouble knowing which group of diseases a certain disease belongs to (e.g., "I could not find where to put Alzheimer's disease, so I just put it under Dementia). Obstacles can also arise due to the use of complex medical terms that are generally incomprehensible to the layperson [47]. One example shown in another study [48] is the use of the term hypertension, which is more commonly called high blood pressure. Users have a need for additional description, in addition to the given name or a group of diseases. It is widely believed that communication between the clinician and the patient depends on the patients' lay model of the disease [49]. It is therefore crucial that the instructions are

made for laypeople and to make sure that the users understand every part of the FH completion; the instructions must be clear, understandable, and unified throughout. Users have a need for additional descriptions in addition to the given name or group of diseases [48]. An important barrier is listing accurate description of the relatives' age. This plays an important role in calculating reliable familial risk [10]. Namely, age at diagnosis is especially important in identifying those individuals at high risk for developing oncological or cardiovascular diseases [10].

In this study, we observed that older users report more technical usability issues. Minimal skills in the use of computer technology were associated with increased time consumption for data entry, which posed an additional barrier to users [50]. Participants reported technical difficulties, such as difficulties in entering data on relatives' illnesses and their subsequent editing [51]. The visual appearance of the tool also played an important role in the user experience [52, 53]. Too much information provided, disorganized text, insufficient font, and difficulty understanding the presented content discouraged users from using the online tool [14, 53, 54]. In one study, 26% of people needed help to complete an online genetic risk assessment tool, of which 77% were over 60 years of age [18]. The lack of skills required to use a computer, especially in older individuals, poses an important barrier to implementing online tools into clinical practice [55].

One of the key obstacles in the previous studies was the time required to complete it [9, 14]. Although our participants were satisfied with the completion time (Table 3), it is necessary for the software to have the ability to save the data before moving to the next question and to show the time remaining for completion. This will give the users better control of where they are with their completion time and reassurance that the questionnaire can be halted at any time and the data will not be lost.

Our participants were concerned about the reliability of the entered data on the diseases of deceased or less well-

known relatives (Table 3). As reported in the previous studies [50, 56], when participants do not have information on the cause of death, they are faced with a dilemma of how to enter the missing data into the software. The lack of information on the FH deterred some participants from using the software as they felt that the data entered would not be sufficiently valid or reliable [56]. Unfortunately, the lack of information in the collected data presents a problem in re-cording a comprehensive and reliable FH [7, 9, 16].

The participants in our study liked how straightforward and friendly the format was, the data entry, the understandability, the overall instructions, and how useful and relevant it was, and they were satisfied with its completion time (Table 4). They also had the opportunity to respond to which suggestions they would use to overcome the reported obstacles. Besides the suggestion that the language should be simpler (as discussed above), the participants suggested that the disease risk should be specific to a particular disease, that the software should include patient-specific recommendations, and that it needs to be included in the EMR.

Previous studies have shown that interest in using the FH tool is driven by the users' perception of how valuable the information is [14]. Therefore, it is necessary for the users to know which disease they have a higher risk of developing. It is also necessary to provide personalized information about risk factors (i.e., patient-specific recommendations). This can motivate users to implement health-related preventive behaviors that can protect against disease development [52, 57]. In doing this, the patient-specific recommendations need to be clear and unambiguous [58].

The participants in this study expressed a wish that the FH would be implemented in their records (Table 4). One study reported that interest would be much higher if patients received the information from their clinician or from their family, with the intention that this information would assist in their medical help or treatment [42]. Although there are many available tools for collecting FH, there is little chance that patients would use a tool by themselves unless encouraged to do so by their personal clinician [13, 59].

The participants in this study would use different coping mechanisms if faced with "being at risk" (Table 5). Some participants would seek information, attend screening programs, and change their behaviors. They would use active coping, which refers to those coping efforts that are characterized by an attempt to deal with a situation (problem-oriented strategies). Active coping is believed to be an adaptive way of dealing with problems and a key component of resilience, managing health problems, and

improving quality of life [60]. Other participants would use passive coping; specifically, they would either avoid or deny the stressor by using various defense mechanisms (e.g., avoidance, rationalization, minimalization, and complaining/venting feelings) [61].

Other studies have identified numerous avoidance or denial strategies when looking for reasons why people would not want to complete the FH despite the invitation of their clinician [14, 59, 62, 63]: lack of time, inappropriate timing of the invitation, forgetting that they received the invitation, lack of emotional readiness for getting FH information, fear of receiving the information, not knowing why completing FH is important, lack of interest, not knowing how the information would benefit them in future, and so on. Although completing the FH and finding the information does not have long-term psychological consequences, as reported by a systematic review [64], patients with high-risk outcomes may experience acute anxiety and worry related to their health [65]. Thus, employing interventions for those who are avoiding or denying their disease risk should be a priority.

Strengths and Limitations of the Study

When developing a new tool, it is critical to explore users' experience. The strength of this study is that we have identified some potential obstacles and found suggestions to improve the risk assessment software, which will help us further in developing it. Importantly, we have recognized different coping mechanisms that pose significant clinical implications. With open-ended questions, the participants had more control over the collected data. Although the results came from a rich amount of data, which allowed us to organize the information into meaningful patterns and themes, it was inevitable that the results would be a reflection of the authors' perspective. To decrease the probability of potential bias, we standardized the procedures, methods, and strategies across every interview. Additionally, we provided detailed information about our participants to increase the transparency of our findings.

One of the limitations of our study is the bias of the sample with respect to age. Our participants were students and their partners, aged 18–26 years or their parents/parents' partners, aged 36–59 years. Even in those 2 groups, we observed differences in their application experiences. For example, younger users reported less problems (FH was easier to understand, less time-consuming, and more useful). Participants aged 60 years or over were excluded from the study, so it is not known what their user experience would be. One study reported that 23% of the participants over 60 years were not

able to use the computer which granted them the use of the software [17]. Based on data gathered from the Statistical Office of the Republic of Slovenia, 44% of individuals aged 56–74 years have not used the Internet at least once in their lifetimes [66], making Web-based software in Slovenia an even more challenging prospect. There also some patients who might not be comfortable using a computer or access to the Internet, which may prevent them from using online tools to determine genetic risk.

As with any other qualitative study, our limitation was the lack of objective measures, limiting the reliability and validity. Furthermore, our findings cannot be generalized beyond the sample that participated in this study.

Conclusions and Clinical Implications

Experience with risk assessment software was shown to be a synthesis of obstacles, overcoming them with suggestions for improvements, and an exploration of various coping mechanisms that may emerge from dealing with the stressor of “being at risk.” A potential next step (in consultation with information technologists and geneticists) would be to apply the findings of this study to the risk assessment software. Next, a validation study evaluating whether the software is valid and useful by testing analytical and clinical validity and clinical utility is required. Additional studies should be oriented to exploring further how to address the passive coping mechanisms that are very likely the core of the reason why patients refuse to either complete the FH or engage in preventive behaviors.

This study is also an important step for Slovenia because currently there are no public health tools or electronic applications available to doctors or the lay public in Slovenia to determine the risk level for diseases with genetic etiology. Although the present risk assessment software [12] does not significantly differ from other existing tools, users all over the world experience similar problems when using technology that is driving digital health. Users’ experiences explored here might help other FH tools. Importantly, a “coping mechanism” that emerged from this study should be addressed with caution in any further genetic consultations.

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Statement of Ethics

The participants gave their written informed consent to participate in this study. The study was approved by the National Medical Ethics Committee at the Ministry of Health from the Republic of Slovenia (No. 0120-544/2016/3).

Conflict of Interest Statement

The authors have no conflicts of interest to declare.

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Author Contributions

P.S.Z. and K.K. conceived this study and developed the interviews. All the authors revised the manuscript and approved its final version. Š.M. contributed to the data analysis and wrote the first draft of the manuscript; K.K. conducted the interviews and the data analysis and contributed to the first draft of the manuscript; Z.K.K. contributed to the data analysis and revised the manuscript; and P.S.Z. supervised the whole process, contributed to the data analysis, and revised the manuscript.

Data Availability Statement

The majority of the data generated and analyzed during this study are included in this article. Questions about raw data of the taken interviews can be directed to the corresponding author.

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