Psychosocial issues of individuals undergoing surveillance for increased risk of melanoma and pancreatic cancer due to a germline CDKN2A variant: a focus group study

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ORIGINAL ARTICLE

Psychosocial issues of individuals undergoing surveillance for increased risk of melanoma and pancreatic cancer due to a germline CDKN2A variant: A focus group study

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Abstract

Individuals with a germline *CDKN2A* pathogenic variant (PV) are at high risk of developing melanoma and pancreatic cancer and are therefore offered surveillance. The potential advantages and disadvantages associated with genetic testing and surveillance are discussed during medical counseling, although little is known about the associated psychosocial factors that are relevant to this population. This study sought to provide a qualitative exploration of psychosocial factors related to genetic testing and participation in skin and pancreatic surveillance in (potential) carriers of a *CDKN2A* PV. Fifteen individuals—both at-risk individuals and confirmed variant carriers—participated in one of the three online focus groups. Pre-defined discussion topics, including genetic testing, cancer surveillance, influence on lifestyle and family planning, were discussed. Patients reported that important reasons to engage in genetic testing included the possibility to participate in surveillance to gain control over their cancer risk and to get clarification on the potential carrier status of their children. We observed considerable differences in risk perception and experienced burden of surveillance. Knowledge of the PV has had a positive influence on lifestyle factors and altered attitudes toward life in some. Most participants were not aware of preimplantation genetic testing. This focus group study provided insight into a variety of psychosocial themes related to (potential) carriership of a *CDKN2A* PV. Future efforts should focus on identifying those who may benefit from additional psychosocial support, development of a centralized source of information, and assessing the knowledge, needs, and timing of counseling for family planning.

KEYWORDS
counseling, genetic testing, hereditary cancer, psychosocial, risk perception, surveillance

1 | INTRODUCTION

Hereditary melanoma is an autosomal dominant inherited disorder caused by *CDKN2A* variants. Carriers of a germline pathogenic variant (PV) in *CDKN2A* are at an estimated 70% lifetime risk of melanoma and a 20% lifetime risk of pancreatic cancer (Klatte, Boekestijn, et al., 2022; Klatte, Wallace, et al., 2022). In these individuals, age of onset for melanoma can be as early as the second decade of life. A specific founder variant (c.225_243del, p.Ala76Cysfs*64; RefSeq NM_000077.4) in the *CDKN2A* gene named *p16-Leiden* is identified as the most common cause of hereditary melanoma in the Netherlands (Gruis et al., 1995).

The Leiden University Medical Center (LUMC) has organized a skin and pancreatic surveillance program for carriers and kindreds of a germline *CDKN2A* PV (Klatte, Boekestijn, et al., 2022; Klatte, Wallace, et al., 2022; Vasen et al., 2016). For proven carriers, skin surveillance by a dermatologist is offered every 6 months starting at the age of 12 years (Figure 1), which has been shown to result in earlier detection of melanomas (van der Rhee et al., 2011). In addition, pancreatic surveillance is offered, which consists of annual magnetic resonance imaging (MRI) and optionally endoscopic ultrasound (EUS) starting at the age of 40 years or 10 years younger than youngest affected blood relative. Because of the limited insight into the risk–benefit ratio of pancreatic surveillance, this is still offered in research setting and only to individuals with a proven PV. An important prerequisite for pancreatic surveillance is that the PV is confirmed by genetic testing. Due to the autosomal dominant inheritance pattern of the syndrome, first-degree relatives of *CDKN2A* PV carriers—henceforth referred to as *risk carriers*—are at a 50% risk of harboring the PV. Both first- and second-degree relatives are offered skin surveillance once a year unless genetic testing confirms carrier status, or a melanoma is diagnosed. Presymptomatic genetic testing is an option from young adulthood.

Prior to participation in pancreatic surveillance, individuals are counseled about potential advantages and disadvantages of this screening. Potential advantages are earlier detection of lesions with a higher resectability rate and improved chances of survival (Klatte et al., 2023). Disadvantages include physical burden, such as claustrophobia during MRI examinations, stress for examinations, awaiting results or abnormal findings, finding abnormalities of uncertain nature, and the potential of false-positive outcomes with undergoing major surgery. Providing risk management education is another part of counseling. Individuals are strongly encouraged to quit smoking, as smoking conveys a strongly increased risk of oropharyngeal cancer, pancreatic cancer, and other tumor types in carriers of a germline PV in *CDKN2A* (Helgadottir et al., 2014; Potjer et al., 2015). Moreover, individuals are recommended to limit sun exposure and use sunscreen to decrease melanoma risk.

In general, individuals at risk of hereditary melanoma show a positive attitude toward genetic testing (Bränström et al., 2012; Kasparian et al., 2009). Although skin surveillance may be continued without confirmation of the PV, individuals must determine if they want to engage in genetic testing for subsequent participation in pancreatic surveillance, which can be complex. Potentially, apart from the abovementioned (dis)advantages, many other, more personal aspects may play a significant role for risk carriers in the decision-making process. A study conducted in 2008 in families with the specific *p16-Leiden* PV, on average 48 years old, found an uptake of genetic testing of 41% (de Snoo et al., 2008). Motivators for seeking genetic counseling included the desire for certainty and learning about the risk of passing on the PV to their children. A more recent Norwegian study among families with hereditary melanoma showed a higher uptake of 66% for genetic counseling, with a significant proportion (93%) of PV carriers undergoing skin surveillance (Levin & Mæhle, 2017). Additionally, a study from the United States found no evidence of negative psychological or behavioral effects among individuals who received *CDKN2A* test results. However, this study focused solely on the risk of melanoma and did not consider the increased risk of pancreatic cancer (Christensen et al., 2011). There is currently no literature on uptake of pancreatic surveillance among *CDKN2A* PV carriers. One of the factors that may cause at-risk individuals to postpone or even refrain from testing are concerns about discrimination in obtaining insurance and mortgages. In the Netherlands, individuals seeking a mortgage can or sometimes are required to have additional life insurance, and carrying a hereditary cancer syndrome can be a barrier to obtaining insurance. However, insurers are only allowed to ask questions about hereditary (cancer) syndromes for a life insurance and disability insurance above a certain amount (currently € 328.131,-, and € 47.578,-, respectively). However, this is not the case for all insurers, and fortunately, for basic health insurance, insurers are obliged to accept everyone.

Next to concerns about insurance, carriers may experience doubts toward having biological children due to their risk of cancer-related mortality at an early age and the risk of cancer in their offspring (Donnelly et al., 2013; Douma et al., 2010). Technologies such as prenatal diagnosis and preimplantation genetic testing (PGT) may be attractive options to prevent passing of cancer

What is known about this topic

Individuals with a germline *CDKN2A* pathogenic variant are at increased risk of developing melanoma and pancreatic cancer, and are therefore offered surveillance. The advantages and disadvantages associated with genetic testing and surveillance are discussed during medical counseling, but the psychosocial factors that are relevant to this population are not well understood.

What this paper adds to the topic

This paper explores the psychosocial factors related to genetic testing and surveillance in individuals with a germline *CDKN2A* pathogenic variant and provides insight into areas to improve care.

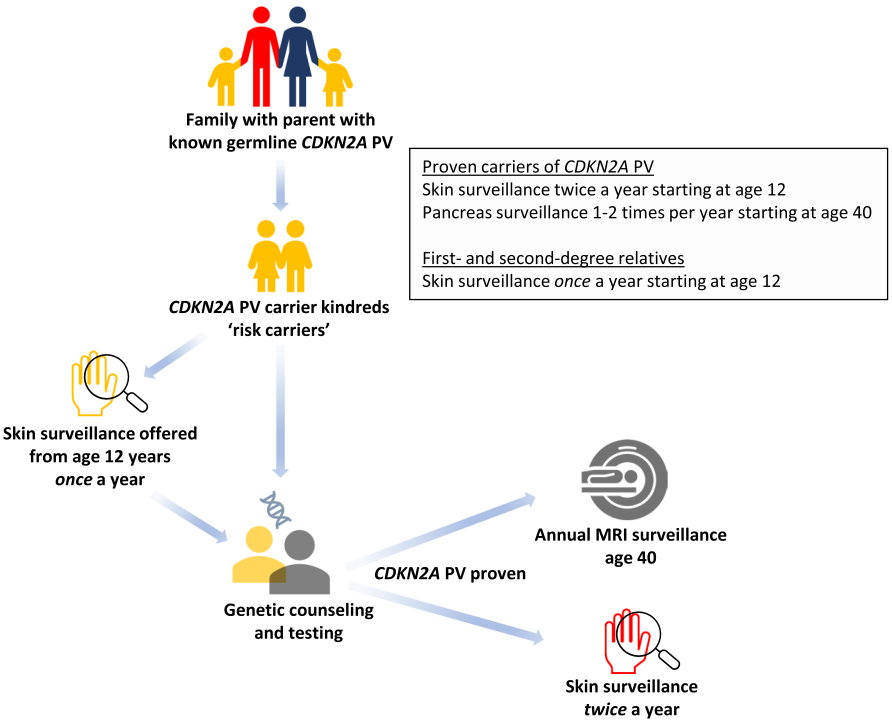

FIGURE 1 Overview of organization of genetic testing, skin and pancreatic surveillance for carriers of a germline *CDKN2A* PV in the LUMC. Kindreds of families with a parent with a known *CDKN2A* PV ("risk carriers") are offered skin surveillance once a year starting from the age of 12 years. These individuals are at 50% risk of harboring the PV. When these individuals test positive for the *CDKN2A* PV, skin surveillance is intensified to twice a year, and pancreatic surveillance may be initiated starting from age 40 years.

susceptibility to offspring. PGT is a technique used in combination with in vitro fertilization to screen embryos for genetic disorders before they are implanted into the uterus. However, for *CDKN2A* this is still seldom used in the Netherlands (PGD Nederland Jaarverslag, 2019).

Gaining more understanding of personal psychosocial aspects associated with genetic testing and surveillance participation may provide important insights to ensure adequate guidance for risk carriers during the counseling process and surveillance participation. In addition, more awareness of factors influencing the desire to have children could potentially open future discussions on PGT.

In this study, we therefore aimed to provide a qualitative assessment of psychosocial factors that are relevant for individuals at 50% risk or proven carriers of a germline *CDKN2A* PV.

2 | METHODS

2.1 | Study design and participants

This was a qualitative study conducted between February 2021 and July 2021 at the LUMC in Leiden, The Netherlands. Three online focus groups were conducted involving individuals enrolled in skin and/or pancreatic surveillance. Phenomenology was chosen as the methodological framework to explore the subjective experiences and perspectives of participants, allowing for an in-depth understanding of their experiences and the meaning they give to their (potential) carriership and increased cancer risk (Brocki & Wearden, 2006). To ascertain a diversity of viewpoints, we purposively aimed to include individuals with a variety in medical and family history and an equal distribution of males and females in each group. Candidates were invited by a member of the study team (DK) through an invitation letter, face-to-face, or via telephone to participate. We included four to eight participants in each group. Inclusion criteria included Dutch-speaking and ≥18 years. For the first focus group, we invited individuals who were at risk of carrying a *CDKN2A* PV and were participating in skin surveillance but had not undergone genetic testing (risk carriers). For the second focus group, we recruited individuals with a proven *CDKN2A* PV who participated in pancreatic surveillance less than 5 years. Lastly, for the third group we invited individuals with a proven *CDKN2A* PV who had been enrolled in pancreatic surveillance for 5–10 years. All participants had received an information letter, explaining the background and reasons for the study. They were required to provide written informed consent prior to participation. The study was approved by the Institutional Review Board of Leiden University Medical Center (MEC P21.006).

2.2 | Content and procedure

A set of discussion topics with open-ended questions were developed using input from literature and experiences from the study team (DK, SH, RvD, MvL, EB). The focus group was not pilot-tested, although discussion topics and questions were reviewed by experts from the Dutch National Hereditary Information Center (Erfocentrum: https://erfelijkheid.nl/). Discussion topics included behavior and attitudes toward genetic testing, attitudes toward skin and pancreatic surveillance, provision of information, influence of a genetic predisposition on life and lifestyle, and family planning (Figure 2). Focus groups lasted one and a half hours and were conducted online via a secure video platform. They were led by a female investigator with extensive experience in conducting qualitative

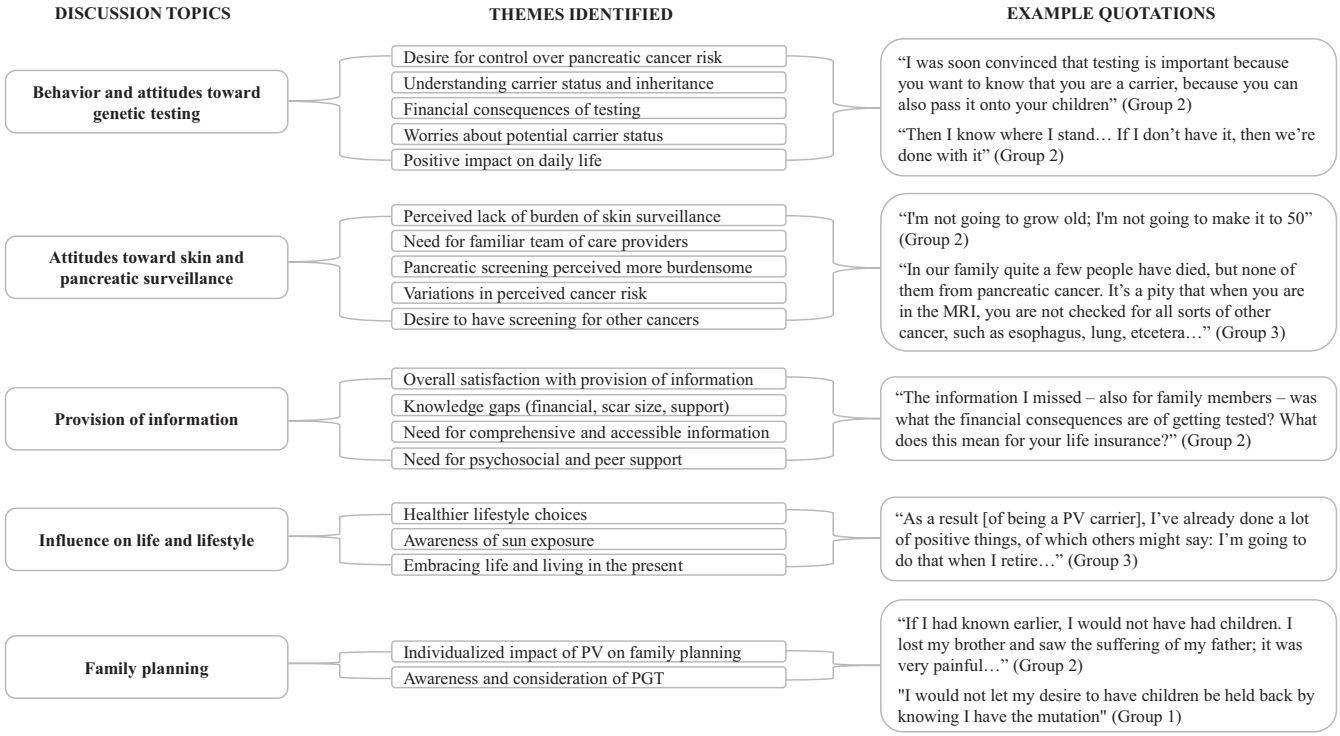

FIGURE 2 Overview of the focus group discussion topics with themes identified, including example quotations.

research (EB). EB is psychologist and a professor at the Department of Clinical Genetics and has a special interest in the quality of life of individuals with or at increased risk of cancer. Prior to the focus groups, participants were requested to complete a short socio-demographic questionnaire (Appendix S1), which in addition included questions regarding personal and family history of melanoma and pancreatic cancer.

2.3 | Data collection and analyses

Three video- and audiotaped focus groups were transcribed. In addition, field notes were made during the focus groups. All focus group transcripts were reviewed by two authors (DK and AO). Transcripts were assessed carefully and quotes relevant to the discussion topics were filtered. A coding tree was not used in the data analysis process. Instead, thematic analysis was used to identify overarching themes within the aforementioned pre-defined discussion topics. The identified themes were discussed with the last author (EB), and subsequently with the study team to assess credibility. In this study, transcripts were not returned to participants for comment and/or correction due to logistical constraints and to minimize participant burden. Consolidated criteria for reporting qualitative research (COREQ) guidelines were used to structure the research design, analysis, and reporting of findings and are provided in the Appendix S2 (Dossett et al., 2021; Tong et al., 2007). Data were managed, and demographic data were analyzed using Microsoft Excel (version 2102).

3 | RESULTS

Fifteen individuals, seven women and eight men, participated in one of the three focus groups (duration 84–94 min). Seventeen invited individuals refused to participate, for which the most significant reason was their unavailability during the scheduled focus group. One individual declined participation because this was expected to be emotionally burdensome. Participants were aged between 22 and 70 years. The first focus group consisted of four risk carriers (age 22–34 years; three females). Group two encompassed five carriers (age 36–66 years; two females). Lastly, group three (age 49–70 years; two females) included six carriers. In total, nine (60%) out of fifteen individuals had a personal history of melanoma and none a history of pancreatic cancer, although one individual underwent a partial pancreatic resection for which appeared to be a benign lesion. Twelve (80%) had a first-degree relative with melanoma and five (33%) a first-degree relative with pancreatic cancer (Table 1).

3.1 | Behavior and attitudes toward genetic testing

Within the discussion topic of behavior and attitudes toward genetic testing, several themes emerged from the participants' perspectives. An overview of the focus group discussion topics with themes identified, including example quotations is shown in Figure 2. A commonly reported reason for considering genetic testing was the desire to gain control over pancreatic cancer risk through surveillance. They recognized the importance of genetic testing to understand

TABLE 1 Characteristics of the study population ($N = 15$).

	Participants ($N = 15$)
Age, median (range), years	49 (27–70)
Female	7 (47)
Marital status[a]	
Married	5 (36)
Relationship	7 (50)
Single	2 (14)
Religious[a]	6 (43)
White	15 (100)
Living with partner or family	12 (80)
Number of children	
Zero	5 (33)
One	0 (0)
Two or three	10 (67)
Highest educational level[a]	
High school	2 (14)
Higher professional education (HBO)	6 (43)
University	4 (29)
Other	2 (14)
Personal history of melanoma	9 (60)
Personal history of pancreatic cancer	0 (0)
First-degree relative with melanoma	12 (80)
Second-degree relative with melanoma	8 (53)
First-degree relative with pancreatic cancer	5 (33)
Second-degree relative with pancreatic cancer	8 (53)

Note: All data—except for age—are numbers with proportion of total; *n* (%).
[a]Proportion was based on 14 individuals; data from one participant were not obtained.

their carrier status and the potential to pass it on to their children. Participants who had not undergone genetic testing expressed a preference to wait until the age of 40, as pancreatic surveillance could be initiated from that age. Waiting was also influenced by potential financial consequences, such as difficulties in obtaining a mortgage and disability insurance, which were mentioned as reasons for postponing testing, including for some children of carriers. Interestingly, some individuals were unaware of the potential mortgage-related consequences.

> Before I start having children or before I'm 40 and eligible for the scans, it [genetic testing] only has negative consequences.
>
> (Group 1)

In addition, a risk carrier (Group 1) expressed the fear that knowing their potential carrier status would cause more worry than living with the current uncertainty, leading to a decision to delay genetic testing. Another individual expressed a preference to continue skin surveillance, even if their genetic test results were negative.

Regarding the impact of carrier status on daily life, most participants mentioned that it had a positive consequence of prompting them to make the most out of each day and influencing their daily choices. This highlights the transformative effect of carrier status on their outlook and decision-making processes.

3.2 | Attitudes toward skin surveillance

In terms of attitudes toward skin surveillance, several themes were identified from the participants' responses. Firstly, most individuals did not perceive regular skin checks as burdensome, despite a significant proportion of them having a personal history of melanoma. Moreover, there was not a substantial fear of melanoma expressed by the participants. Multiple participants mentioned the positive aspect of taking "total body pictures" as part of the skin surveillance process, although not everyone had experienced this practice. Furthermore, one patient who had a history of more than 19 melanomas mentioned becoming accustomed to the excisions associated with the surveillance.

> Lie down, cutting, and leave again.
>
> (Group 3)

Participants consistently expressed a need for a familiar team of care providers. The alternating physicians in skin surveillance were often mentioned as a disadvantage, as it created a feeling among some participants that they had to stay on top of the screenings themselves. However, contrasting views emerged, with some individuals being comfortable with alternating providers due to their perception that the information was effectively transferred between physicians.

Interestingly, one participant highlighted the lack of a guarantee that all abnormalities would be diagnosed in the early stages, which was experienced as troubling by other group members. This discrepancy in perspectives further contributed to the range of attitudes within the group regarding skin surveillance.

> Maybe it is I, but when something is found during an inspection, you assume that it's not too late.
>
> (Group 1)

3.3 | Attitudes toward pancreatic surveillance

In the context of the discussion topic on attitudes toward pancreatic surveillance, a variety of themes were uncovered from the participants' discussions. Overall, pancreatic surveillance was perceived as more burdensome compared to skin surveillance. The fear of abnormalities in the pancreas was a significant concern among several participants, reflecting the heightened anxiety associated with this specific form of surveillance. The uncertainty surrounding the outcome of pancreatic scans was highlighted, with participants

expressing the feeling of going into the scan as a healthy individual but being unaware of the results.

> You go in the scan healthy, but yo' don't know what the outcome is.
>
> (Group 2)

There were variations among individuals in their perception of their risk of pancreatic cancer and the level of burden associated with screening. Some participants felt a relatively low perceived risk, which allowed them to approach pancreatic surveillance in a relaxed manner. On the other hand, one participant expressed a pessimistic view, expressing doubts about reaching an older age and not expecting to make it past age 50.

> I'm not going to grow old; I'm not going to make it to 50.
>
> (Group 2)

While the screening examinations themselves were generally not considered burdensome, some participants found the period between the examination and receiving the results to be stressful. This waiting period contributed to increased stress levels, as noted by one participant who mentioned the noticeable increase in stress several months before the MRI scan.

Additionally, some participants expressed the desire to have screening for other types of cancer as well, beyond just pancreatic cancer. They felt it would be beneficial to undergo comprehensive screenings for various cancers during the surveillance process, such as esophageal and lung cancer.

These themes collectively demonstrate the apprehension and concerns associated with pancreatic surveillance, the variability in individuals' perceived risk and burden, the emotional impact of the waiting period, and the expressed desire for broader cancer screenings within the surveillance program.

3.4 | Provision of information

Overall, participants expressed satisfaction with the provision of information, particularly highlighting the thoroughness of care provided by the Department of Clinical Genetics. However, discrepancies were noted in the information received by participants regarding genetic testing and surveillance. For instance, some individuals mentioned missing information about other cancer risks in addition to the risk of pancreatic cancer and melanoma. Furthermore, only a few participants were aware of the possibility of receiving psychosocial care, indicating a lack of information dissemination on this aspect.

Interestingly, younger participants mentioned receiving information about genetic testing and surveillance primarily from family members. Many of these younger individuals expressed a preference to receive this information at a younger age or desired guidance on where to find reliable information.

> An example of…: "A lot of the information I hear now [in this focus group] I got through my mother or are new to me. I would have liked to have known earlier… But at 16 perhaps it would have been too young, then maybe it would have been quite a blow…".
>
> (Group 1)

One knowledge gap we identified was concerning the financial consequences of a positive test result, with significant variations in participants' understanding of these matters. One other knowledge gap related to the larger-than-expected size of scars after resection of melanoma, a sentiment that was affirmed by another group member.

In general, the participants expressed a need for annual "information days" and a central source of information to stay updated on developments in research, treatment, and screening. They also viewed peer support days as valuable opportunities to connect with fellow carriers of a PV, highlighting the importance of social support within the community. These themes collectively underscore the participants' desire for comprehensive and accessible information, ongoing updates, and opportunities for peer interaction.

3.5 | Influence on life and lifestyle

Various themes emerged from the participants' discussions on the influence of being a PV carrier on lifestyle. The knowledge of being a carrier had a significant impact on participants' lifestyle choices, leading to healthier behaviors. Many individuals mentioned quitting smoking, losing weight, and moderating their alcohol consumption as direct results of their PV status.

When it came to the risk of melanoma, participants demonstrated a heightened awareness and mindfulness of sun exposure. They actively limited their exposure time and made consistent use of sunscreen, considering it a responsibility to safeguard their bodies. Interestingly, there was a prevalent sentiment among participants that living each day to the fullest and enjoying life in the present moment was important. This outlook emphasized the participants' desire to embrace life while maintaining a proactive approach to their health and well-being. These themes collectively highlight the positive effect of PV carrier status on participants' lifestyle choices, particularly in relation to smoking, weight management, alcohol consumption, sun exposure, and their overall appreciation for the present.

> When I got children, I was like, we must enjoy it, because now we are still here… Also, for that reason it is important to be as healthy as possible, because you have that responsibility towards your partner and children as well.
>
> (Group 3)

3.6 | Family planning

Participants expressed diverse viewpoints in the discussion topic on family planning, It was observed that most participants already had children before undergoing genetic testing. The responses regarding having children varied among the participants. Some individuals mentioned feeling relieved that their decision to have children was not dependent on the results of genetic testing. For them, the knowledge of being a carrier of a PV did not impact their existing family planning choices. However, one participant mentioned that they had already been uncertain about having children and that discovering their PV status solidified their decision not to have children. Another expressed that in retrospect he would have decided not to have children.

Furthermore, it was noted that while most younger individuals were aware of PGT, this knowledge was not widespread among the groups with older individuals. However, when PGT was explained, it was viewed as a potential option by participants in these groups. This indicates that PGT may be seen as a valuable consideration for family planning when the concept is introduced to individuals who were previously unfamiliar with it.

> If that would have been possible, that would have been a good option. However, for me personally, it doesn't fit well with my values to have an influence on that, so therefore that is not important to me.
>
> (Group 1)

The themes that emerge from these discussions highlight the complex and individualized nature of decisions related to family planning in the context of being a PV carrier. Participants' feelings of relief, uncertainty, and the consideration of options such as PGT underscore the range of perspectives and decision-making processes involved in this topic.

4 | DISCUSSION

This study aimed to obtain insight into the psychosocial factors associated with genetic testing and participation in skin and pancreatic surveillance of individuals at risk or carrying a *CDKN2A* PV. A qualitative approach allowed exploration of a variety of themes which provided insight into the impact and consequences of (potentially) carrying a PV putting individuals at high risk of melanoma and pancreatic cancer. These results highlight potential areas for improvement of care and themes that warrant further study.

4.1 | Behavior and attitudes toward genetic testing

Important reasons to engage in genetic testing were to gain control over the risk of pancreatic cancer through the surveillance participation and to clarify the potential risk of their children. Psychological outcomes of testing among individuals with a known *CDKN2A* PV have previously been described in the literature. In a qualitative study among members of families with a *CDKN2A* PV, concerns about the carrier status of their children were commonly expressed (Bergenmar et al., 2009). Similarly, a study among Australian families by Kasparian et al. (2009) reported comparable reasons to engage in genetic testing, such as learning about the risk of their children (82%), and that it may help to take preventive measures to reduce one's own cancer risk (77%). In contrast, in their study, a negative consequence that testing could lead to insurance discrimination was affirmed in a minority of individuals, although this was raised as an important concern by multiple participants in our study. This is in general an overestimated concern, since in practice only a minority of individuals will experience potential negative consequences. In our center, the potential impact of a PV status on insurance and mortgage is discussed with individuals during genetic counseling. We should consider offering this information to risk carriers at an earlier age, which could mitigate potential concerns and allow younger individuals to make an informed choice regarding genetic testing and potential financial consequences earlier.

4.2 | Attitudes toward skin and pancreatic surveillance

Some individuals mentioned that the high risk of pancreatic cancer and the associated surveillance was experienced as burdensome, while for others the risk of developing pancreatic cancer was perceived as small. So far, from research specifically focusing on individuals with *CDKN2A* PV it is not evident that the knowledge of carrier status induces distress or worry about pancreatic cancer or melanoma (Aspinwall et al., 2013; Christensen et al., 2011; Zhu et al., 2018). Studies found that overall, the emotional impact of annual pancreatic cancer surveillance itself may be acceptable, as surveillance seemed not to influence psychological well-being (Harinck et al., 2011; Konings et al., 2015; Paiella et al., 2020). Distress was however more prominent in younger individuals and appeared to be related to lower levels of coping abilities (Paiella et al., 2020). Moreover, a factor that appears associated with cancer worries is having a family member affected by pancreatic cancer at a young age (Konings et al., 2017). Intensified surveillance seems to increase cancer worries only temporarily, without affecting general pathological anxiety or depression (Overbeek et al., 2020). Regarding risk of melanoma, individuals did not evidently express a great fear of occurrence, which is consistent with an earlier study in this cohort, in which most patients did not report elevated fear (Hinnen et al., 2021). However, occurrence of melanoma in the preceding year was associated with reporting elevated fear.

A variety of factors may influence the perceived risk of developing cancer in patients with a hereditary predisposition (Tilburt et al., 2011). A family history of cancer is a well-known factor associated with an increased perceived risk, which has also been

demonstrated in individuals participating in annual pancreatic cancer surveillance (Konings et al., 2017). Moreover, in those at increased risk of colorectal cancer, it appeared that individuals who were younger experienced a greater perceived risk of developing cancer (Rimes et al., 2006). In addition, certain cognitive factors, such as belief that cancer is less preventable, have previously been associated with a higher perceived risk of disease (Codori et al., 2005). Most likely, there is a variety within our population in how individuals perceive their risk and experience burden of surveillance. It is therefore relevant to differentiate who should be offered additional care. Possibly, regular administration of a cancer worry scale (CWS) or the more specific Psychosocial Aspects of Hereditary Cancer (PAHC) questionnaire around screening intervals may help to identify those who may benefit from psychological support (Custers et al., 2014; Eijzenga et al., 2014).

4.3 | Provision of information

A noteworthy observation is differences in the extent of information obtained by participants on genetic testing and surveillance. Adequate provision of information is essential to help individuals increase their knowledge, increase their sense of control, and simultaneously decrease uncertainty (Dean et al., 2017; Dean & Davidson, 2018). One study conducted in *BRCA* PV carriers found that information needs may change over time and that it is important to receive the right type of information at the right time (Dean et al., 2017). We observed a need for a centralized source of information, which ideally would be tailored to the distinct phases of life individuals are in. For example, (simplified) counseling for skin surveillance might be offered at the start of surveillance at age 12, while information on options for genetic testing and consequences for pancreatic surveillance are offered starting from 18 years.

4.4 | Influence on life and lifestyle

For several participants, it appeared that knowledge of the PV had a positive impact on their lifestyle, including smoking cessation. Although genetic counseling often mostly focuses on preventive strategies through for example imaging, risk management education plays another important role in prevention of cancer (Daly et al., 2021). Carriers of a *CDKN2A* PV appear to be particularly susceptible for tobacco smoke, which has been associated with a more increased risk of pancreatic cancer, but also other malignancies such as oropharyngeal cancer (Potjer et al., 2015). This underlines that active lifestyle interventions such as referral to smoking cessation clinics should be an integral part of our and other cancer surveillance programs. In our study, individuals also mentioned to be mindful about sun exposure. It did not emerge whether this and other lifestyle changes were directly a consequence of counseling or start of skin surveillance. Genetic test results for *CDKN2A* have previously been reported to be informative and motivating for personal sun protection efforts, which may in consequence lead to the reduction of sun exposure (Aspinwall et al., 2018; Stump et al., 2020).

4.5 | Family planning

In general, professional societies recommend engaging in genetic testing not earlier than the age at which interventions are believed to be helpful (American Society of Clinical Oncology, 2003; Botkin et al., 2015). In our medical center, a large proportion of individuals engage with genetic testing around the age of 40, because at this age pancreatic cancer surveillance can be initiated. However, a study by Stump et al. (2018) demonstrated that minors who underwent genetic testing for *CDKN2A* reported improved sun-protective behavior without experiencing psychological distress. Therefore, it is important for us to investigate the potential advantages of providing genetic counseling and testing at an earlier age within our population.

As a consequence of testing around the age of 40, most parents who were interviewed in this study already had children at the time they underwent genetic testing. It was mentioned by some that they were happy that it could not have influenced their decision to have children. Assisted reproductive technologies such as PGT were known to a minority of the participants. One study carried out in the Netherlands among Von Hippel–Lindau and Li-Fraumeni syndrome families found that more than one-third expressed a positive attitude toward PGT (Lammens et al., 2009), which was found higher (52%) in individuals with Peutz-Jeghers syndrome (van Lier et al., 2012). Importantly, early studies indicated that carriers of a hereditary cancer PV often did not have previous information about prenatal diagnostic tests or PGT (Douma et al., 2010; Quinn et al., 2010). Further research is needed to assess the current knowledge on PGT and needs for more extensive counseling on family planning within this specific population.

4.6 | Study strengths and limitations

This study is unique in that it involved participants in different phases of life and investigated a broad variety of psychosocial themes. One limitation of using predefined discussion topics in our focus group study is that it may restrict the exploration of new or unexpected topics that emerge during the discussions. However, to mitigate this this limitation, we balanced the use of predefined topics with an openness to explore emergent themes that arose during the focus group discussions, allowing for flexibility and adaptability in capturing the different perspectives and new discussion topics fully. It is important to acknowledge that data saturation was not explicitly targeted in our study design due to resource and time constraints. However, we believe we succeeded in gathering diverse perspectives and a deeper understanding of the psychosocial aspects of relevance to this population. Because this study was conducted in a relatively small, specific population from a single institution, and

we used purposive sampling to recruit individuals for this study, the generalizability of our findings is limited. Furthermore, since the study participants were already enrolled in skin and/or pancreatic cancer surveillance, the extrapolation of findings to non-participating individuals may be limited. Nonetheless, for this growing cohort of *CDKN2A* PV carriers and risk carriers in our center, our findings will have a direct impact in how care will be provided in the future. Moreover, some of our findings may have relevance to other hereditary cancer syndromes that require surveillance.

5 | CONCLUSION

In conclusion, our results provide insight into a variety of psychosocial aspects regarding genetic testing, skin and pancreatic surveillance in (potential) carriers of a *CDKN2A* PV. An important reason to undergo genetic testing and participate in surveillance was to gain control over ones' cancer risk. There appeared to be variety in how individuals perceived their risk and experienced burden of surveillance. This warrants further exploration to discern who may benefit from additional psychosocial support. Additionally, we should work toward a centralized source of information covering relevant themes, including cancer surveillance, influence of lifestyle, and family planning. A larger, quantitative study among proven carriers and risk carriers is currently being conducted and will indicate areas where there is the most need for improvement of care.

6 | PRACTICE IMPLICATIONS

Regular administration of a psychosocial questionnaire could aid in identifying individuals participating in surveillance who may benefit from psychological support. Furthermore, attention should be given to concerns surrounding occupation and life insurance during genetic testing counseling. Active lifestyle interventions should be an integral part of cancer surveillance programs. To provide comprehensive information, a centralized (online) source should offer guidance on genetic testing, skin and pancreatic surveillance, and related themes, including family planning. Finally, further research is recommended to evaluate the knowledge and requirements of counseling for family planning, which should include reproductive options such as preimplantation genetic testing.

AUTHOR CONTRIBUTIONS

Derk Klatte: Conceptualization, Methodology, Data collection, Formal analysis, Investigation, Writing—Original draft. **Anke Onnekink**: Formal analysis, Investigation, Writing—Review & editing. **Chris Hinnen**: Conceptualization, Writing—Review & editing. **Remco van Doorn**: Conceptualization, Writing—Review & editing. **Thomas Potjer**: Conceptualization, Writing—Review & editing. **Monique van Leerdam**: Conceptualization, Methodology, Supervision, Writing—Review & editing. **Eveline Bleiker**: Conceptualization, Methodology, Data collection, Investigation, Supervision, Writing—Review & editing. Author Derk Klatte confirms that she had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis. All the authors gave final approval of this version of the manuscript to be published.

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CONFLICT OF INTEREST STATEMENT

The authors declare that they have no conflicts of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are not shared due to privacy or ethical considerations.

ETHICS STATEMENT

Human Studies an Informed Consent: This study was approved by the Institutional Review Board of Leiden University Medical Center (MEC P21.006). All participants gave their informed consent prior to their inclusion in the study.

Animal Studies: No non-human animal studies were carried out by the authors for this article.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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