Received: 24 August 2022 | Revised: 23 May 2023 | Accepted: 1 June 2023

DOI: 10.1002/jgc4.1739

National Society of Genetic Counselors WILEY

ORIGINAL ARTICLE

Lived experiences of undergoing regular tumor screening in patients with multiple endocrine neoplasia types 1 and 2 (MEN1/MEN2)

Mirthe Jasmijn Klein Haneveld[1,2] | Gerlof Dirk Valk[1] | Rachel Sara van Leeuwaarde[1]

[1]Department of Endocrine Oncology, University Medical Center Utrecht, Utrecht, The Netherlands

[2]Emma Children's Hospital, Amsterdam UMC, University of Amsterdam, Amsterdam, The Netherlands

Correspondence
Mirthe Jasmijn Klein Haneveld, Emma Children's Hospital, Amsterdam UMC, University of Amsterdam, Amsterdam, The Netherlands.
Email: m.j.kleinhaneveld@amsterdamumc.nl

Rachel Sara van Leeuwaarde, Department of Endocrine Oncology, University Medical Center Utrecht, Utrecht, The Netherlands.
Email: r.vanleeuwaarde@umcutrecht.nl

Abstract

Targeted screening programs for individuals with an increased risk for cancer have become increasingly available. Patients with multiple endocrine neoplasia (MEN), rare genetic conditions associated with the development of tumors in the endocrine glands, undergo intensive surveillance from an early age. Quantitative research has shown that patients with MEN experience fear of disease occurrence in themselves and their family members. However, little is known about the role that intensive, lifelong screening plays in the lives of individuals. This study investigates the lived experiences of patients with MEN undergoing regular tumor screening through an interpretative phenomenological analysis of interviews with 12 patients with MEN1, MEN2A, or MEN2B syndrome. Four experiential group themes are identified: *coming to the foreground/fading into the background*, *relating to uncertainty*, *experiencing control*, and *familial context*. Screening is characterized as an ambiguous experience that brings MEN to the foreground and may both exacerbate MEN-related uncertainty as well as provide a sense of control over the disease. The experience of undergoing screening is strongly influenced by the familial context, as participants care for and are cared for by family members and understand their disease through familial experiences. Good care according to patients with MEN includes providing family-centered care, addressing the impact on daily functioning and the meaning of illness, support in the interpretation of physical complaints, facilitation of patient experiences of control, and careful attunement to patient needs within a good doctor–patient relationship.

KEYWORDS
lived experience, MEN1, MEN2, multiple endocrine neoplasia, psychosocial, risk perception, screening

1 | INTRODUCTION

Screening programs for individuals at elevated risk of developing cancer have become increasingly available due to expanding genetic knowledge. Such targeted screening programs can allow for early tumor detection and reduce morbidity and mortality. Yet, the associated social and psychological burden may be considerable. In rare, familial tumor predisposition syndromes, evidence-based

weighing of risks against benefits of screening is particularly challenging. Moreover, there is still a paucity of knowledge regarding the lived experiences of individuals undergoing lifelong screening because of a genetic predisposition to tumor development (Heinsen et al., 2021; Werner-Lin et al., 2022).

MEN syndromes provide an example of the challenges invoked by a need for lifelong screening. The MEN syndromes are rare, autosomal dominant conditions, associated with the development of benign and malignant tumors of various endocrine glands. Since the discovery of the genetic causes of MEN1 and MEN2 in the 1990s, care for MEN syndromes has improved drastically and intensive surveillance has become the cornerstone of care (de Laat et al., 2018; Ramundo et al., 2011; van Leeuwaarde et al., 2016). Considering the high penetrance of MEN syndromes and evidence for improved survival with regular follow-up, the need for screening is widely accepted. However, establishing screening guidelines for MEN is not straightforward (Newey & Newell-Price, 2022; van Treijen et al., 2018). Robust evidence for the initiation and frequency of specific investigations is lacking. Increasingly sensitive biochemical measurements and imaging modalities contribute to the diagnosis of manifestations at an early stage; yet, this also leads to incidental findings and a high chance of detection of tumors that may have an indolent course and do not require any intervention. Risk stratification for some tumor types is challenging; it remains impossible to prevent all adverse outcomes despite the provision of optimal care according to current standards. Finally, the economic, psychological, and social burdens of MEN surveillance have hardly been investigated.

Quantitative research has shown that patients with MEN experience fear of disease occurrence, which may relate to experiences with family members who have MEN (Correa et al., 2019; van Leeuwaarde et al., 2018). Strikingly, patients with MEN1 who know that they have a (pituitary) tumor report a poorer quality of life in comparison with patients who are not aware of having a tumor (van Leeuwaarde et al., 2021). In addition, patients who estimate their risk of developing a tumor to be higher report more anxiety (van Leeuwaarde et al., 2018). These findings raise the question of what constitutes good care for patients with MEN undergoing surveillance.

Qualitative research can provide insight into patient experiences in order to optimize screening programs accordingly and develop adequate supportive care. The available qualitative data on patient experiences with MEN remains scarce, based on anecdotal evidence or research conducted over 15 years ago (Giarelli, 2003; Grey & Winter, 2018; Strømsvik et al., 2007). For patients with MEN, being at risk for tumor growth as a mutation carrier, having a tumor, and living past treatment for a tumor, as well as being the next of kin of family members in all of these situations, may occur simultaneously. This highlights the importance of considering the patient's perspective in screening programs and providing adequate supportive care. Therefore, this study aims to describe the lived experiences of undergoing screening for MEN syndromes.

What is known about this topic

Patients with MEN experience fear of disease occurrence associated with impaired quality of life, in which the role of screening remains poorly understood.

What this article adds to the topic

In-depth analysis of patient experiences provides an understanding of the meaning of screening as a source of both uncertainty and control in the lives of patients with MEN, allowing for the development of adequate supportive care.

1.1 | Further context of MEN screening

The prevalence of MEN1 is estimated to be approximately 3–20/100.000; the prevalence of MEN2 differs across populations, with estimates ranging from 13–24 and 1–2/1.000.000 for MEN2A and MEN2B, respectively (Brandi et al., 2021; Mathiesen et al., 2022).

MEN type 1 is characterized principally by primary hyperparathyroidism (lifetime prevalence >95%), pituitary adenomas (50%–65%), and duodenal and pancreatic neuroendocrine tumors (NETs, >80%); other manifestations include adrenocortical tumors; bronchial, gastric, and thymic NETs; tumors of the skin, subcutaneous tissue, and smooth muscle; and breast cancer in female patients (Pieterman et al., 2021). Many MEN1-associated tumors are benign but may require resection because of hormone production and/or mass effects; meanwhile, malignancy, in particular metastases from duodenal and pancreatic NETs, remains an important cause of death. By age 20 and 40, respectively, 50% and 95% of patients with MEN1 will have developed at least one disease manifestation (Brandi et al., 2021). For patients with MEN1, intensive clinical, biochemical, and radiological surveillance commencing in childhood has become the cornerstone of care. Screening is recommended from the age of 5 years onward; as no predictions of age-related penetrance based on genotype can be made, it has not yet been possible to individualize screening programs.

MEN type 2A is associated with very high penetrance of medullary thyroid carcinoma (90%), as well as an increased risk of pheochromocytoma (20%–50%) and primary hyperparathyroidism (10%–35%), depending on the underlying *RET* mutation; MEN type 2B is associated with full penetrance of medullary thyroid carcinoma (100%), in addition to pheochromocytoma (50%) and cutaneous, musculoskeletal, and gastrointestinal manifestations that may present in infancy (Mathiesen et al., 2022). For MEN2, care consists of prophylactic thyroidectomy and biochemical surveillance for subsequent manifestations, initiated depending on the underlying *RET* mutation (Mathiesen et al., 2022). Thyroidectomy is often performed before the age of 4 years, after which patients require lifelong thyroid hormone replacement therapy.

2 | METHODS

This study employs interpretative phenomenological analysis (IPA), a qualitative method of analysis that focuses on how people make sense of complex life experiences (Smith et al., 2022). IPA has origins in psychology and is theoretically grounded in hermeneutics, phenomenology, and idiographic approaches. The method is specifically suited to investigate the similarities and differences in the lived experiences of individuals who share a complex and emotionally charged life experience, such as undergoing tumor screening; IPA has been used successfully in other studies on lived experiences of cancer (Le Boutillier et al., 2022; Maguire et al., 2014; McGeechan et al., 2018). We closely followed the recommendations published by Smith et al. (2022) in the most recent edition of their guide to IPA. In line with the idiographic approach, which aims to understand particular phenomena in their particular context, study samples are selected purposively in IPA. They are typically small and homogeneous to allow for detailed case-by-case analysis, in which patterns of convergence and divergence can be understood in context. Sample size, according to Smith et al. (2022), depends on "the degree of commitment to the case study level of analysis and reporting; the richness of individual cases; and the organizational constraints one is operating under" (p. 46). Accordingly, for the purposes of this study, we stopped the recruitment at 12 participants.

2.1 | Participants

Twelve Dutch adults undergoing screening for MEN syndromes were purposively recruited through the Dutch patient advocacy group (Belangengroep MEN) and the outpatient clinic for Endocrine Oncology at the UMC Utrecht using an information leaflet. Six patients with MEN1, four with MEN2A, one with MEN2B, and one participant receiving follow-up based on family history were included. Participants represented a variety of age groups, employment statuses, and diagnosis and disease characteristics, as summarized in Table 1. Almost all the participants had developed disease manifestations and undergone MEN-related surgery at the time of the research.

TABLE 1 Participant characteristics.

Characteristics	*n*
Gender	
Male	4
Female	8
Age	
<20	1
20–30	3
30–40	2
40–50	2
50–60	2
60–70	2
Employment status	
Working	5
Not working for health-related reasons	2
Student/in school	3
Retired	2
Diagnosis	
MEN1	6
MEN2A	4
MEN2B	1
Other[a]	1
Age at MEN diagnosis	
<18 years	5
>18 years	6
N.A.[a]	1
Type of diagnosis	
Index patient	5
Presymptomatic genetic testing	6
N.A.[a]	1
Previous MEN-related surgery	
Yes	11
No	1
Metastasized disease	
Yes	2
No	10

[a]One participant has not received genetic testing but undergoes screening based on family history.

2.2 | Data collection

Data were collected through semi-structured interviews lasting approximately 1 h. Interviews were conducted by the first author: a female researcher trained as a medical doctor and care ethicist, who did not have any current or previous treatment relationship with the participants. The researcher introduced herself through a personal letter included in the information leaflet. An interview guide (Table S1) was used flexibly while leaving space for participant deviations. Open-ended questions were asked about life with MEN in general, screening investigations, physician appointments, information provision, and unmet needs. In accordance with participant preferences, interviews were conducted either live at the UMC Utrecht or digitally through Microsoft Teams. Eleven interviews were conducted digitally and one interview was conducted live; reasons for participating digitally included minimizing the risk of contracting COVID-19 and a preference for participating from home due to energy considerations. During one interview, the participant's partner was present at the participant's request; this participant later confirmed that the interview did represent their personal views and experiences accurately. All the other interviews were conducted individually. Interviews were audio-recorded and

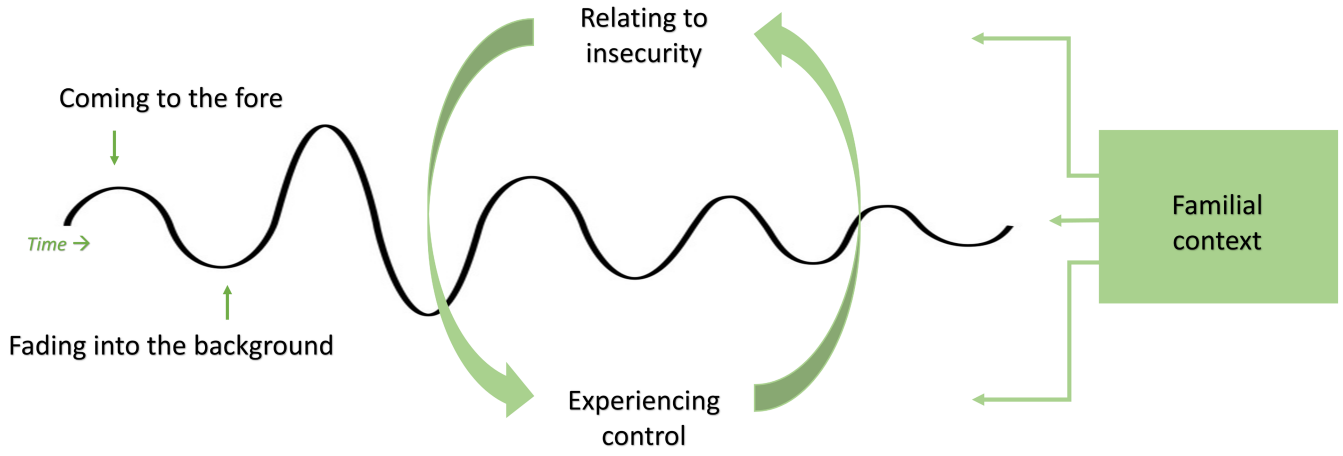

FIGURE 1 Visualization of group experiential themes.

transcribed verbatim. No repeat interviews were carried out, but the participants were able to contact the researcher in case there was anything they wanted to share.

2.3 | Data analysis

Data analysis was conducted following the seven phases of Smith's IPA: (1) immersion in the data of one participant through reading and rereading; (2) preliminary noting to examine content and language use on an exploratory level; (3) construction of 20–40 personal experiential statements per interview, reflecting interpretation of the participant's words; (4) searching for connections and relationships between these experiential statements; (5) naming and organizing clusters of experiential statements in personal experiential themes; (6) subsequent analysis of the following participant according to these steps; and (7) comparing personal experiential themes and statements across cases to identify experiential group themes while maintaining differences (Smith et al., 2022). ATLAS.ti 9 Windows was used for all stages of the coding process. Data analysis was conducted by the first author; the interpretation of the data and (group) experiential themes were discussed between the first and third authors, who both had full access to the data.

Member check was carried out by sending all the participants a narrative summary of their interview as well as an overview of the four group experiential themes. Nine participants responded, of which six stated that no changes needed to be made; three participants responded with minor factual corrections to the description of the individual interview and/or an additional observation with regard to differences in care between hospitals. Finally, results were presented for discussion on the patient organizations' annual contact day.

2.4 | Ethics statement

On March 22, 2022, METC NedMec declared that this research does not fall under the Dutch Medical Research Involving Human Subjects Act (WMO). All the participants provided written informed consent after a full written and verbal explanation of the study and time for consideration. Participants were free to leave the study at any time for any reason without any consequences. Confidentiality is preserved through the use of pseudonyms and the presentation of demographic characteristics at the group level only.

3 | RESULTS

The lived experiences of 12 patients with MEN syndrome with regard to screening are characterized by four experiential group themes: *coming to the foreground/fading into the background*, *relating to uncertainty*, *experiencing control*, and *familial context*.

These themes are visualized in relation to each other in Figure 1. Screening is characterized as an ambiguous experience. On the one hand, screening brings MEN to the foreground as it provides a confrontation with uncertainty: about the body, medical care, the future, and the underlying uncertainty of existence. On the other hand, screening is described and used as a way to maintain control over disease, allowing MEN to fade into the background. The familial context shapes how participants experience having MEN and undergoing screening, as participants are in caring relationships with family members and understand their disease through these experiences. There is ambiguity in experiences both within and between the four themes; below, the similarities and differences between the personal lived experiences are described narratively and through the use of citations.

3.1 | Theme 1: Coming to the foreground/fading into the background

Participants experience MEN coming to the foreground and fading into the background over time. Both screening and life events affect the dominance of MEN in the participants' lives.

3.1.1 | 1A. Influence of screening

Many participants describe how having MEN comes to the foreground around (semi-)annual screening visits to the hospital. They mention, for example, paying more attention to physical complaints, listing questions for the physician, worrying about possible results, and feeling uncomfortable during this period. When the appointments are over again, MEN can temporarily disappear into the background and take up a smaller place in their thoughts, feelings, and daily activities. One participant describes hospital visits as '*peak moments*' that involve a confrontation with the reality of having MEN: "[When] I go to the MRI or (…) blood test I am very aware that I do indeed have a disease and that something could be wrong. And then I allow myself to think about, what if (…) they do find something (…) that shouldn't be there? (…) The moment I am back in the car to go home, I feel like I am not a patient anymore, it is over again" (P3).

3.1.2 | 1B. Influence of life events

Life events are described as impacting this temporal movement, which in turn influences how participants experience undergoing screening. Several participants describe that MEN comes to the foreground of their thoughts when they experience illness due to MEN-related disease manifestations themselves or are confronted with serious illness or death of loved ones: "[I went] almost whistling to [the appointments], like, it's fine. And then my sister (…) was not doing well anymore and that was the first realization that I thought, oh, you actually don't know what your blood values will be and one year is not like the next" (P9).

In addition, changed responsibilities bring MEN to the fore. For example, some participants describe that the desire to have children or the start of a family influence their experience of undergoing screening: "I experienced way more tension from [the appointments] (…) because of becoming a mother and feeling responsible for my children, because I [had] this fear of, oh, help, my children may soon have no mother" (P2).

After a period in which MEN is in the foreground, MEN may also disappear into the background. Some participants experience that the impact of MEN decreases with time after surgery or after a long period of stable results, which may affect their perception of screening: "I've been stable for so long that a higher result is not immediately (…) a drama to me, it's just like, well, a little higher this year" (P8). Other participants describe the fading into the background of MEN more as an active process, in which they have learned to decrease the impact of the disease: "I've learned to keep it in the background, to not let it be the biggest thing in my life, so to speak" (P10).

3.2 | Theme 2: Relating to insecurity

Screening may contribute to experiences of insecurity due to confrontation with the risk of MEN-related illness. Participants describe different sources of insecurity: the body, medical care, and the future. Some participants cope with their experiences of insecurity by relating to the underlying uncertainty of existence.

3.2.1 | 2A. The body

Patients report the experience of an unreliable body that cannot simply be trusted. This uncertainty manifests itself in worrying about the body, a loss of trust, and a vigilant attitude. Several participants describe fear when they experience physical complaints. Because MEN-related tumors can cause various and nonspecific symptoms, any physical sensation may raise the question of whether it could be related to MEN: "Someone else might think, I have slept badly or something, but (…) with me there might be something really wrong" (P2). This is associated with an awareness of tumor risk and an absence of trust in the functioning of one's body: "At any moment, your body may just make a switch [snaps fingers] in one of your organs and it goes wrong again" (P11).

The experience of an uncertain body is also expressed in an active attitude of vigilance. Many participants pay close attention to changes they notice in their bodies as potential symptoms of MEN-related tumors: "I usually make that link when I feel agitated, (…) because that is often a symptom" (P7). Some participants monitor their health using, for example, blood pressure monitors or additional medical check-ups: "If I'm tired, I think, let's keep an eye on it, right? What kind of fatigue is it? What other symptoms do I notice? Oh, maybe I'll have my thyroid rechecked" (P9).

Several participants mention situations in which insecurity about their body was exacerbated by screening or other healthcare situations. Waiting – specifically in the waiting room at the hospital, but also the longer periods of waiting for follow-up tests or treatments – is described by multiple participants as reinforcing feelings of insecurity. Others describe being confronted with their dysfunctional body when something goes wrong during hospitalization, for example, when medication is not delivered on time or nurses are not available: "It's the frustration that your body doesn't do what you want. Yeah, well, then when all kinds of things get added on, it adds up." (P6). It is important to participants that healthcare workers recognize the position of uncertainty and vulnerability they are in: "As a patient, you feel a little vulnerable, at least in my case. You want to be understood" (P11).

3.2.2 | 2B. Medical care

Undergoing screening is complicated by the experience of medical care as uncertain, as MEN is rare and remains not fully understood. Participants experience that information, diagnostic tests, and treatments change over time: "[Now] we are going to operate if a tumor (…) gets bigger than two centimeters, (…), and three years ago it was three centimeters, then I'm like, okay, nice discussion,

am I going to participate in that?" (P1). On the one hand, they hope that care will (further) improve in the future through scientific research; on the other hand, awareness of the uncertainty and variability of medical care may be challenging when treatment decisions must be made. Getting conflicting information, at various times or from different healthcare providers, can be a source of insecurity. Some participants report a 'what if' feeling when a certain study or treatment that became standard practice later had not been performed in the past, followed by a poor outcome: "Over the [years] we have been misled many, many times. Yes, I think that is really part of (…) MEN, that you don't really know where you stand, one time you walk this path, and the other time you walk another path. Yeah, it might be because it's still all new, huh?" (P8). Other participants describe a lack of trust in healthcare professionals following errors in the medical care for themselves or their relatives. For example, one participant describes how the pressure to watch over care to avoid medical errors adds to pre-existing distress: "You already have other things actually on your mind than to keep going after things like that, so to speak, (…) you really have to watch over your own body" (P7).

3.2.3 | 2C. The future

Participants relate to the risk of certain disease manifestations in the future, such as the occurrence of metastasis or the need for invasive surgery, for example, removal of the adrenal glands. Through screening examinations, several participants are aware of tumors in their bodies, which do not currently require treatment, but may do so in the future: "You know it's there and every time (…) it seems to get a few centimeters closer and maybe that's putting it too strongly, but you get a bit of an oppressive feeling of oh yes, now it's bigger again, eh? What's it going to mean, the next surgery, huh? I'm already in bad health" (P4). Having an uncertain future perspective makes participants experience life differently compared to others and weighs into the life choices that participants make, for example, when it comes to moving houses, moving abroad for work, traveling, or having children. Sometimes, previous pursuits are no longer possible, leading to experiences of loss. At the same time, the uncertain future motivates participants to enjoy the life that is currently there. Several participants describe gratitude for and happiness brought by relationships with others and increased enjoyment of activities they can participate in: "Ever since, after every result, no matter what kind, like you only have one week left to live or whatever, but we always go out to eat. We enjoy life" (P7).

3.2.4 | 2D. Existence

Various participants discuss the insecurity they experience in relation to the uncertainty that is fundamental to human existence: "Some situations in your life, they happen to you. Some people are unlucky, and some people are lucky" (P1). This may serve as a way of coping by putting things into perspective. For example, one participant describes not wanting to give too much weight to having MEN: "Look, the people around me who don't have MEN are all going to die one day too (…) Should I experience life differently because I happen to have something which I am sure that will go wrong one day?" (P5).

3.3 | Theme 3: Experiencing control

In contrast to the experiences of insecurity described above, screening may also contribute to experiences of control. Control over disease, over one's own body, and over one's life are identified as central themes in participants' lived experiences.

3.3.1 | 3A. Control over disease

Both results of specific examinations and participation in screening in general can provide a sense of control over the disease. Undergoing an examination, such as a scan or taking blood samples, can provide a sense of security: "It gives me a lot of peace of mind that even if I don't feel my symptoms, I can always take blood samples, so I can always check if it's okay" (P3). Receiving a result gives a temporary perspective, allowing worries about MEN to fade into the background.

In addition, many participants experience participating in the screening program as a whole as a way of having control over their disease. Even with a negative outcome, such as the detection of a new tumor, screening can offer an experience of control: some participants describe that this knowledge gives them 'preparation time' for eventual surgery; for others, it helps to know that immediate action will be taken if needed. In this way, screening increases the chances of not becoming ill; being under surveillance in a hospital thus evokes trust: "That's what I use (…) to calm down: (…) I get checked so often, if there is something [wrong], then we have the time to do something" (P11).

3.3.2 | 3B. Control over the body

All participants strongly value experiencing control over their bodies in some way; this is expressed in relation to counseling, disease management, and lifestyle choices.

Several participants highlight the importance of control over medical and genetic information. This is described both in the context of having the right to know ("It's my body and I want to know what they observe and what that means" (P5)) and the right not to know ("It's important that [the doctors] check every time to see if you want to [receive genetic testing] and why (…) but it's also important that they remain neutral, without pushing [you]" (P12)).

Control over one's body also manifests relating to the management of disease manifestations. Most participants describe that it is

important to them to have a say in decision-making about medication use, surgery, and/or scheduling of follow-up appointments: "[If] I do have control over, when something happens to my body, how I want to solve it, I still have the idea that I have a kind of power over my own illness" (P3).

Finally, multiple participants mention lifestyle choices as a way to maintain control over one's body, for example through managing one's diet, physical activity, and rest: "The life I lead now I can only lead because I am incredibly strict in what I do" (P6). One individual participant describes a sense of control through the possibility of a self-chosen end of life in case of severe disease manifestations: "I have also been able to obtain a quantity of [toxic agent] in a certain way (…) That gives me a lot of peace of mind" (P1).

It is important to the participants that healthcare is provided in a way that allows for their own ways of experiencing control. In practice, this means that hospital appointments are scheduled in accordance with one's daily schedule and that self-management of medication is continued during hospitalization, for example. Moreover, the manner in which participants are approached by health care providers is experienced as significant: "Medically trained I am of course not equal to the doctor, but as a human being I felt that I was approached as an equal (…) I'm not an expert, but I do know my own body" (P5).

3.3.3 | 3C. Control over the impact on one's life

Several participants control the impact of MEN on their lives in their handling of screening and their handling of social interactions.

As opposed to the active role in controlling one's disease as described above, a few participants describe distancing to alleviate the burden of screening, for example, by not looking into their online medical file or minimizing the information they look up regarding their disease; "I try to hold off as much as possible (…) I've had enough misery already. I trust this doctor, I've been with him for so many years, right? If he says, we'll do an MRI of that, we'll do an MRI" (P4). Other participants report that they control the impact of MEN in the way they discuss their disease in social interactions: "[My disease] does determine my life in a certain sense and limits my going out, but that doesn't necessarily have to [limit] quality [of life], so I try to radiate that to those around me, that my life has so much quality, so don't worry about me" (P5).

3.4 | Theme 4: Familial context

For many participants, having MEN plays a role in their family relationships; conversely, the way family members deal with MEN influences how participants themselves experience and understand MEN. As such, the familial context shapes both experiences of uncertainty and control and influences the extent to which MEN comes to the foreground in an individual's experiences. The familial context is expressed in relation to caring for and about family and understanding illness through the family.

3.4.1 | 4A. Caring for and about family

Often, family members have an active involvement in each other's care, including emotional support, practical support such as assisting in contacts with health care providers, and concrete physical acts of care. Many participants experience contact with family members who also have MEN as valuable, as outsiders frequently do not understand what having MEN entails: "My mother is going through the same process, (…) undergoing the same operations, taking the same medications et cetera, so you can support each other very well" (P4). For some participants, concerns about family members are more important than one's own health. Feelings of guilt around passing on the disease are described as well: "My grandmother does feel a little guilty, actually, because she is the beginning of MEN in the family" (P12).

In addition to concerns for existing family members, participants describe care for potential children to whom they might pass on MEN. In addition to the decision to have children and whether to use pre-implantation genetic diagnosis, considerations also involve the way in which participants deal with their condition as parents: "I also wouldn't [want], when I have children later on, and they have MEN (…), that they have some kind of example from me of, you just have to run and fly and you're never allowed to think about what impact it has" (P9).

3.4.2 | 4B. Understanding illness through the family

The familial context also plays a role in how MEN is understood and experienced. First, familial experiences influence the emotional impact of having MEN and undergoing screening: "Before I was twelve, I went to maybe six, seven funerals, so that also does something in my head probably, that (…) sometimes I can react very heavily to something when actually it might not even be that bad" (P4).

Second, the way family members relate to having MEN and undergoing screening is often shared in families. Several participants describe being raised with a certain attitude through the way MEN was discussed or handled in the family. For example, one participant explains: "My grandfather grew [old] with this, (…) so we were raised with the idea of, developments go on, if you just have regular check-ups, they'll catch it in time, so you can grow old with it just fine" (P2). Another participant describes the feeling of having to stand up for oneself as acquired from parental experiences: "My parents [fought] for a very long time until they finally knew what I had. And I think I took that over a little bit (…) that you have to make yourself heard because otherwise, it can just end badly." (P6).

Finally, participants often compare themselves to other family members with MEN when it comes to, for example, receiving the diagnosis, the course of an operation, or the chances of developing serious illness. These comparisons may both increase and decrease worries about one's own health. For some, confrontation with illness of family members results in awareness of the risk of developing

disease manifestations themselves: "My sister was quite young [when she developed a tumor], much younger than my grandmother and mother. So, at the time (…), I was like, this can also happen to me" (P12). On the other hand, there are also participants for whom their own illness has considerably less impact in relation to the illness of a loved one: "[My lab result] doesn't mean anything anymore because you can see it in proportion, right?" (P8).

4 | DISCUSSION

This study describes lived experiences of undergoing screening for MEN syndromes through an IPA of interviews with 12 patients with MEN in The Netherlands. Four experiential group themes are described: *coming to the foreground/fading into the background*, *relating to uncertainty*, *experiencing control*, and *familial context*. Overall, this study highlights the complex and nuanced ways in which individuals experience tumor screening. Recommendations for supportive care for individuals undergoing MEN screening, in line with these lived experiences, are described in Table 2.

Participants' experiences in our study differ from those in existing qualitative studies on the MEN population in some respects, possibly due to the increasing availability of genetic testing and changes in screening technologies. Giarelli's (2003) study on 12 patients with MEN2A in the United States described experiences with surveillance as rhythmic and repetitive, with similar themes including vigilance over one's and family members' bodies and negotiating control over the disease. However, the genetic nature of MEN2A was absent from patient narratives (Giarelli, 2003). Strømsvik et al. (2007) described the experiences of 29 Swedish patients with MEN1, which partly align with our findings, such as uncertainty about the future, coming to terms with the condition, and the impact of MEN on daily activities. The familial context was not as prominent in their study, potentially due to the study population and timeframe: only 22% of patients were mutation-positive and 31% were aged <50 years (Strømsvik et al., 2007). In our study, the majority of participants are under 50 years old and half of them commenced screening as minors, in line with current-day clinical practice with presymptomatic screening from early childhood as the cornerstone of care.

The temporal movement in the lived experiences of our participants reflects the rhythmic movement of threat coming to the fore and then being reintegrated into participants' daily lives, as described by Giarelli (2003). Previous quantitative research on patients with MEN has suggested that patients tend to employ cognitive avoidance as a coping mechanism, as reflected by high scores on measures of this strategy, which may indicate a preference to avoid thinking or talking about the disease outside of medical settings (Correa et al., 2019; Rodrigues et al., 2017). In our study, experiences of insecurity bring MEN to the forefront of participants' thoughts and feelings, while experiences of control provide a foothold for MEN to fade into the background. As such, this study extends upon the description of 'surveillance life' by Heinsen et al. (2021) in healthy mutation carriers with Lynch syndrome: the relevance of 'living with chronic risk' fluctuates throughout life, creating 'genetically at risk' chronicities that take form as individuals come to terms with a disease that possibly awaits them. As opposed to these healthy mutation carriers, nearly all the participants in the current study had already developed disease manifestations and underwent surgery for MEN-related tumors. In this context, the experience of living with risk in MEN syndromes is shaped by both the nature and consequences of the medical condition itself, as well as individual and family experiences of illness.

The lived experiences show that screening may evoke both feelings of insecurity and control. The feelings of insecurity may explain the high level of fear of disease occurrence measured in Dutch patients with MEN1, particularly in those who already developed a higher number of disease manifestations (van Leeuwaarde et al., 2018). Our participants describe the body, the future, and medical care as sources of insecurity. This finding reflects previous phenomenological accounts of severe or chronic illness leading to *bodily doubt*, including a loss of faith in one's body (Carel, 2013). The diffuse tumor risk in MEN makes the entire body subject to scrutiny, similar to what has been described in patients with Li-Fraumeni syndrome (Werner-Lin et al., 2022). Previous qualitative research suggests that medical technology, such as surveillance imaging, may exacerbate insecurity by objectifying the body and making it feel fragmented (Griffiths et al., 2010; Reventlow et al., 2006; Werner-Lin et al., 2022). For example, technical information from osteoporosis scans and mammograms was described to lead to uncertainty rather than empowerment and to decrease attention to lived bodily experiences (Griffiths et al., 2010; Reventlow et al., 2006). These findings underline the importance of supporting patients with MEN in interpreting any symptoms they may experience; adequate information provision about screening results, without ignoring the patients' own experience of symptoms; and careful attention to the impact on daily functioning and meaning of illness, with additional psychosocial support if necessary.

In contrast to exacerbating insecurity, screening was shown to offer a sense of grip in our study. Participants believe it is important to be well-informed and allowed to make decisions about their bodies. Gaining a sense of control over disease through screening may relate to 'fighting spirit', which has been described as a prominent coping mechanism in patients with MEN2 and is associated with adherence to investigational procedures (Correa et al., 2019; Rodrigues et al., 2017). A broader notion of 'being in control' over one's life and situation is described by Heinsen et al. (2021) in individuals with

TABLE 2 Recommendations for good care for patients with MEN undergoing surveillance.

1. Providing family-centered care
2. Addressing the impact on daily functioning and meaning of illness
3. Supporting patients in interpreting symptoms
4. Facilitating patient experiences of control
5. Establishing a positive doctor–patient relationship

Lynch syndrome undergoing regular colonoscopies. Participants employed coping strategies ranging from positive attitudes to avoidance to facilitate living with chronic risk of cancer; where screening provides an ambiguous sense of control, some participants attempted to maintain agency by exerting influence on specific aspects of the screening procedures (Heinsen et al., 2021). In our study, this sense of 'being in control' is described in relation to genetic counseling, disease management, lifestyle choices, and coping strategies. As maintaining control provides a foothold for MEN to fade into the background, patient experiences of control should be facilitated.

The close interrelationship of participant experiences of screening with the familial context substantiates previous quantitative research on MEN1 that demonstrated that patients experience more fear of disease occurrence for their family members than for themselves (van Leeuwaarde et al., 2018). Our study finds that families develop specific ways of relating to having MEN, bearing the risk of tumor growth, and undergoing screening, which carry over to the individual patient. This is in line with previous qualitative research describing how disease-specific knowledge develops in families with various other inherited disorders (Jenkins et al., 2013; Kasparian et al., 2015; Petersen et al., 2014; Werner-Lin et al., 2022, Wilsnack et al., 2021). Wilsnack et al. (2021) discuss these findings in light of social identity theory: families living with Li-Fraumeni syndrome derived a sense of group identity through sharing of disease experiences, in which family identity may serve as a buffer to mediate distress. Kasparian et al. (2015), however, highlight that the impact of Von Hippel–Lindau disease on family functioning and relationships varies between families, in which both strengthened bonds and distancing due to isolation, grief, and guilt are described. Taken together, these studies point to the importance of the familial context as a support system, as a source of emotional distress, and as shaping disease knowledge and attitudes, supporting the need for family-centered care.

4.1 | Study limitations and recommendations for future research

This study provides a detailed account of the experiences of a small group of Dutch adults undergoing screening for MEN syndrome. The in-depth interviews focused on screening, case-by-case analysis of individual experiences, and relative homogeneity of our participants contribute to the information power of this study (Malterud et al., 2016). However, several characteristics of our study population need to be considered to assess the transferability to other contexts. Our recruitment strategy resulted in a group of involved participants, who all underwent regular surveillance in academic hospitals and of whom a majority was a member of the patient advocacy group. The textual, Dutch-language and partly digital recruitment and data collection may have excluded patients with low literacy or from minority populations. As such, the study participants may not be representative of the MEN patient population as a whole.

Nearly, all the participants had developed disease manifestations and had undergone MEN-related surgery at the time of the interview. The transferability of findings to the group of young mutation carriers who have not yet developed clinical manifestations may be limited. Follow-up research that pays attention to the experiences of children and teenagers may contribute to better supportive care for families in which one or multiple child(ren) have MEN syndrome.

Moreover, the close interconnectedness between patients with MEN and their families underpins the relevance of both individual- and family-focused research; it would be relevant to extend the concept of Family Quality of Life (FQoL) to MEN and other familial tumor predisposition syndromes (Boelsma et al., 2017).

The use of video interviews may have limited observation of behavior and body language. In future studies, observations such as shadowing may allow for the inclusion of participants for whom verbalizing their experience is not easy and provide further insights into patients' lived experiences (van der Meide et al., 2013).

Finally, through the focus on patient experiences, the perspectives of physicians and the impact of physician–patient interactions remain out of view, whereas care occurs in the interaction between caregiver and care receiver. Drawing on the themes that characterize screening for patients, it would be of interest to examine how clinicians deal with uncertainty, as well as how physician attitudes and behaviors influence decision-making in MEN care (Heath, 2014).

4.2 | Practice implications

Family-centered care can be provided by acknowledging the impact of both family experiences on the individual patient and the patient's illness on their relatives, and by considering family preferences in assigning physicians and scheduling appointments. An unmet need for psychological and social support can be met by involving, for example, medical social workers, nursing specialists, spiritual caregivers, or medical psychologists. Such care is complementary to, but not a replacement for, attention to the lived experience by the primary caregiver. Research into oncologist communication shows that simple conversational techniques can create space for the patient's lived experience, such as making eye contact and confirming or verbalizing the patient's experience (van Meurs et al., 2022). To provide support in interpreting physical symptoms, it is recommended to establish a clear, low-threshold point of contact in case of questions, such as a specialized nurse; to allow for communication between the primary physician and other involved (primary care) physicians; and to pay careful attention to seemingly medically irrelevant problems in consultations. Patient experiences of control could be facilitated through shared decision-making and documenting management decisions made by the patient and their primary physician in the patient file in case of (planned) admissions. Establishing a positive doctor–patient relationship is a prerequisite for implementing all aforementioned recommendations. This relationship enables healthcare providers to tailor information and decision-making to align with patient preferences, as well as facilitate open discussions about the emotional and social consequences of having MEN for the individual

and their family. Physical appointments with sufficient time to discuss personal topics are considered important to establish a good doctor–patient relationship and should therefore be facilitated in the organizational context of the hospital (Hamington, 2012).

5 | CONCLUSION

Interpretative-phenomenological analysis of in-depth interviews with 12 patients with MEN shows that screening is experienced as a source of both uncertainty due to and control over disease. Whereas experiences of uncertainty bring MEN to the forefront of participants' thoughts and feelings, experiences of control provide a foothold for MEN to fade into the background. The familial context of MEN syndromes strongly influences how screening is understood and experienced. Adapting care to the lived experiences of patients with MEN, therefore, involves providing family-centered care; addressing the impact on daily functioning and the meaning of illness; support in the interpretation of physical complaints; facilitation of patient experiences of control; and careful attunement to patient needs within a good doctor–patient relationship.

AUTHOR CONTRIBUTIONS

MK: conceptualization, participant recruitment, data collection, data analysis, interpretation and discussion of results, initial manuscript. GV: interpretation and discussion of results, manuscript revision. RvL: conceptualization, participant recruitment, interpretation and discussion of results, manuscript revision. Authors MK and RvL confirm that they had full access to all the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis. All the authors gave final approval of this version to be published and agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

ACKNOWLEDGMENTS

The research presented in the paper was conducted to fulfill the degree requirements of the Master Care Ethics and Policy at the University of Humanistic Studies of the first author. As part of the University of Humanistic Studies thesis process, university teachers Dr. Susanne van den Hooff and Dr. Vivianne Baur made valuable comments on the research proposal and the research process. We thank Rachel Giles for reviewing and editing the language of this article. Finally, we would like to express our gratitude to the board of the Belangengroep MEN for their contribution to participant recruitment and for the organization of the annual patient contact day during which study findings were presented, as well as to all the participants who contributed to this study. No financial support was received for this study. Jehannine Austin served as action editor on this paper.

CONFLICT OF INTEREST STATEMENT

Author Mirthe J. Klein Haneveld, Author Gerlof D. Valk, and Author Rachel S. van Leeuwaarde declare that they have no conflict of interest.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy restrictions in order to preserve the confidentiality of participants, as study data consist of personal accounts that may be traced back to participants.

ETHICS STATEMENT

Human Studies and Informed Consent: On March 22, 2022, METC NedMec, the medical ethical committee of the UMC Utrecht, declared that this research does not fall under the Dutch Medical Research Involving Human Subjects Act (WMO). The research protocol has been approved in line with the requirements of the Ethics Review Committee of the University of Humanistic Studies. Written informed consent was obtained from all the participants.

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

ORCID

Mirthe Jasmijn Klein Haneveld https://orcid.org/0000-0002-0453-2608

Gerlof Dirk Valk https://orcid.org/0000-0001-5841-8344

REFERENCES

Boelsma, F., Caubo-Damen, I., Schippers, A., Dane, M., & Abma, T. A. (2017). Rethinking FQoL: The dynamic interplay between individual and family quality of life. *Journal of Policy and Practice in Intellectual Disabilities*, *14*(1), 31–38. https://doi.org/10.1111/jppi.12224

Brandi, M. L., Agarwal, S. K., Perrier, N. D., Lines, K. E., Valk, G. D., & Thakker, R. V. (2021). Multiple endocrine neoplasia type 1: Latest insights. *Endocrine Reviews*, *42*(2), 133–170. https://doi.org/10.1210/endrev/bnaa031

Carel, H. (2013). Bodily doubt. *Journal of Consciousness Studies*, *20*(7–8), 178–197.

Correa, F. A., Farias, E. C., Castroneves, L. A., Lourenço, D. M., & Hoff, A. O. (2019). Quality of life and coping in multiple endocrine neoplasia type 2. *Journal of the Endocrine Society*, *3*(6), 1167–1174. https://doi.org/10.1210/js.2018-00371

de Laat, J. M., van Leeuwaarde, R. S., & Valk, G. D. (2018). The importance of an early and accurate MEN1 diagnosis. *Frontiers in Endocrinology*, *9*, 533. https://doi.org/10.3389/fendo.2018.00533

Giarelli, E. (2003). Bringing threat to the fore: Participating in lifelong surveillance for genetic risk of cancer. *Oncology Nursing Forum*, *30*(6), 945–955. https://doi.org/10.1188/03.ONF.945-955

Grey, J., & Winter, K. (2018). Patient quality of life and prognosis in multiple endocrine neoplasia type 2. *Endocrine-Related Cancer*, *25*(2), T69–T77. https://doi.org/10.1530/ERC-17-0335

Griffiths, F., Bendelow, G., Green, E., & Palmer, J. (2010). Screening for breast cancer: Medicalization, visualization and the embodied experience. *Health*, *14*(6), 653–668. https://doi.org/10.1177/1363459310361599

Hamington, M. (2012). Care ethics and corporeal inquiry in patient relations. *International Journal of Feminist Approaches to Bioethics*, *5*(1), 52. https://doi.org/10.2979/intjfemappbio.5.1.52

Heath, I. (2014). Role of fear in overdiagnosis and overtreatment. *BMJ*, *347*(2), g6123. https://doi.org/10.1136/bmj.g6123

Heinsen, L. L., Wahlberg, A., & Petersen, H. V. (2021). Surveillance life and the shaping of 'genetically at risk' chronicities in Denmark. *Anthropology & Medicine*, *1–16*, 29–44. https://doi.org/10.1080/13648470.2021.1893654

Jenkins, N., Lawton, J., Douglas, M., & Hallowell, N. (2013). Interembodiment and the experience of genetic testing for familial hypercholesterolaemia. *Sociology of Health & Illness*, *35*(4), 529–543. https://doi.org/10.1111/j.1467-9566.2012.01510.x

Kasparian, N. A., Rutstein, A., Sansom-Daly, U. M., Mireskandari, S., Tyler, J., Duffy, J., & Tucker, K. M. (2015). Through the looking glass: An exploratory study of the lived experiences and unmet needs of families affected by Von Hippel–Lindau disease. *European Journal of Human Genetics*, *23*(1), 34–40. https://doi.org/10.1038/ejhg.2014.44

Le Boutillier, C., Urch, C., King, A., Barry, C., Mansfield, L., & Archer, S. (2022). 'Still living with it even though it's gone': Using interpretive phenomenological analysis to explore shared experiences of living with and beyond breast, prostate, and colorectal cancer. *European Journal of Oncology Nursing*, *56*, 102067. https://doi.org/10.1016/j.ejon.2021.102067

Maguire, R., Stoddart, K., Flowers, P., McPhelim, J., & Kearney, N. (2014). An interpretative phenomenological analysis of the lived experience of multiple concurrent symptoms in patients with lung cancer: A contribution to the study of symptom clusters. *European Journal of Oncology Nursing*, *18*(3), 310–315. https://doi.org/10.1016/j.ejon.2014.02.004

Malterud, K., Siersma, V. D., & Guassora, A. D. (2016). Sample size in qualitative interview studies: Guided by information power. *Qualitative Health Research*, *26*(13), 1753–1760. https://doi.org/10.1177/1049732315617444

Mathiesen, J. S., Effraimidis, G., Rossing, M., Rasmussen, Å. K., Hoejberg, L., Bastholt, L., Godballe, C., Oturai, P., & Feldt-Rasmussen, U. (2022). Multiple endocrine neoplasia type 2: A review. *Seminars in Cancer Biology*, *79*, 163–179. https://doi.org/10.1016/j.semcancer.2021.03.035

McGeechan, G. J., McPherson, K. E., & Roberts, K. (2018). An interpretative phenomenological analysis of the experience of living with colorectal cancer as a chronic illness. *Journal of Clinical Nursing*, *27*(15–16), 3148–3156. https://doi.org/10.1111/jocn.14509

Newey, P. J., & Newell-Price, J. (2022). MEN1 surveillance guidelines: Time to (re)think? *Journal of the Endocrine Society*, *6*(2), bvac001. https://doi.org/10.1210/jendso/bvac001

Petersen, H. V., Nilbert, M., Bernstein, I., & Carlsson, C. (2014). Balancing life with an increased risk of cancer: Lived experiences in healthy individuals with Lynch syndrome. *Journal of Genetic Counseling*, *23*(5), 778–784. https://doi.org/10.1007/s10897-013-9682-3

Pieterman, C. R. C., van Leeuwaarde, R. S., van den Broek, M. F. M., van Nesselrooij, B. P. M., & Valk, G. D. (2021). Multiple endocrine neoplasia type 1. In K. R. Feingold (Eds.), *Endotext*. MDText.com, Inc.

Ramundo, V., Milone, F., Severino, R., Savastano, S., di Somma, C., Vuolo, L., de Luca, L., Lombardi, G., Colao, A., & Faggiano, A. (2011). Clinical and prognostic implications of the genetic diagnosis of hereditary NET syndromes in asymptomatic patients. *Hormone and Metabolic Research*, *43*(11), 794–800. https://doi.org/10.1055/s-0031-1286324

Reventlow, S. D., Hvas, L., & Malterud, K. (2006). Making the invisible body visible. Bone scans, osteoporosis and women's bodily experiences. *Social Science & Medicine*, *62*(11), 2720–2731. https://doi.org/10.1016/j.socscimed.2005.11.009

Rodrigues, K. C., Toledo, R. A., Coutinho, F. L., Nunes, A. B., Maciel, R. M. B., Hoff, A. O., Tavares, M. C., Toledo, S. P. A., & Lourenço, D. M., Jr. (2017). Assessment of depression, anxiety, quality of life, and coping in long-standing multiple endocrine neoplasia type 2 patients. *Thyroid*, *27*(5), 693–706. https://doi.org/10.1089/thy.2016.0148

Smith, J. A., Flowers, P., & Larkin, M. (2022). *Interpretative phenomenological analysis: Theory, method and research* (2nd ed.). SAGE.

Strømsvik, N., Nordin, K., Berglund, G., Engebretsen, L. F., Hansson, M. G., & Gjengedal, E. (2007). Living with multiple endocrine neoplasia type 1: Decent care - insufficient medical and genetic information. A qualitative study of MEN1 patients in a Swedish hospital. *Journal of Genetic Counseling*, *16*(1), 105–117. https://doi.org/10.1007/s10897-006-9047-2

van der Meide, H., Leget, C., & Olthuis, G. (2013). Giving voice to vulnerable people: The value of shadowing for phenomenological healthcare research. *Medicine, Health Care and Philosophy*, *16*(4), 731–737. https://doi.org/10.1007/s11019-012-9456-y

van Leeuwaarde, R. S., Pieterman, C. R. C., Bleiker, E. M. A., Dekkers, O. M., van der Horst-Schrivers, A. N., Hermus, A. R., de Herder, W. W., Drent, M. L., Bisschop, P. H., Havekes, B., Vriens, M. R., & Valk, G. D. (2018). High fear of disease occurrence is associated with low quality of life in patients with multiple endocrine neoplasia type 1: Results from the Dutch MEN1 study group. *The Journal of Clinical Endocrinology and Metabolism*, *103*(6), 2354–2361. https://doi.org/10.1210/jc.2018-00259

van Leeuwaarde, R. S., Pieterman, C. R. C., May, A. M., Dekkers, O. M., van der Horst-Schrivers, A. N. A., Hermus, A. R., de Herder, W. W., Drent, M. L., Bisschop, P. H., Havekes, B., Vriens, M. R., & Valk, G. D. (2021). Health-related quality of life in patients with multiple endocrine neoplasia type 1. *Neuroendocrinology*, *111*(3), 288–296. https://doi.org/10.1159/000508374

van Leeuwaarde, R. S., van Nesselrooij, B. P. M., Hermus, A. R., Dekkers, O. M., de Herder, W. W., van der Horst-Schrivers, A. N., Drent, M. L., Bisschop, P. H., Havekes, B., Vriens, M. R., de Laat, J. M., Pieterman, C. R., & Valk, G. D. (2016). Impact of delay in diagnosis in outcomes in MEN1: Results from the Dutch MEN1 study group. *The Journal of Clinical Endocrinology & Metabolism*, *101*(3), 1159–1165. https://doi.org/10.1210/jc.2015-3766

van Meurs, J., Stommel, W., Leget, C., van de Geer, J., Kuip, E., Vissers, K., Engels, Y., & Wichmann, A. (2022). Oncologist responses to advanced cancer patients' lived illness experiences and effects: An applied conversation analysis study. *BMC Palliative Care*, *21*(1), 37. https://doi.org/10.1186/s12904-022-00917-4

van Treijen, M. J. C., van Beek, D.-J., van Leeuwaarde, R. S., Vriens, M. R., & Valk, G. D. (2018). Diagnosing nonfunctional pancreatic NETs in MEN1: The evidence base. *Journal of the Endocrine Society*, *2*(9), 1067–1088. https://doi.org/10.1210/js.2018-00087

Werner-Lin, A., Forbes Shepherd, R., Young, J. L., Wilsnack, C., Merrill, S. L., Greene, M. H., & Khincha, P. P. (2022). Embodied risk for families with Li-Fraumeni syndrome: Like electricity through my body. *Social Science & Medicine*, *301*, 114905. https://doi.org/10.1016/j.socscimed.2022.114905

Wilsnack, C., Young, J. L., Merrill, S. L., Groner, V., Loud, J. T., Bremer, R. C., Greene, M. H., Khincha, P. P., & Werner-Lin, A. (2021). Family identity and roles in the context of Li-Fraumeni syndrome: "No one's like us mutants". *Health & Social Work*, *46*(4), 299–307. https://doi.org/10.1093/hsw/hlab032

SUPPORTING INFORMATION

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

How to cite this article: Klein Haneveld, M. J., Valk, G. D., & van Leeuwaarde, R. S. (2024). Lived experiences of undergoing regular tumor screening in patients with multiple endocrine neoplasia types 1 and 2 (MEN1/MEN2). *Journal of Genetic Counseling*, *33*, 402–412. https://doi.org/10.1002/jgc4.1739