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ORIGINAL ARTICLE

Assessing the relationship between patient preferences for recontact after *BRCA1* or *BRCA2* genetic testing and their monitoring coping style in a Norwegian sample

Randi Marlene Dahle Ommundsen[1,2] | Nina Strømsvik[3,4] | Anniken Hamang[1]

[1]Department of Medical Genetics, St. Olav's Hospital, Trondheim University Hospital, Trondheim, Norway

[2]Department of Global Health and Primary Care, University of Bergen, Bergen, Norway

[3]Faculty of Health and Social Sciences, Department of Health and Caring Sciences, Western Norway University of Applied Sciences, Bergen, Norway

[4]Department of Medical Genetics, Northern Norway Familial Cancer Center, University Hospital of North-Norway, Tromsø, Norway

Correspondence
Randi Marlene Dahle Ommundsen, Department of Medical Genetics, St. Olav's Hospital, Trondheim University Hospital, Trondheim, Norway.
Email: randi.marlene.dahle@gmail.com

Abstract

Recontacting former patients regarding new genetic information is currently not standard care but might be implemented in the future. Little information is available on the implications of this practice from the point of view of former patients. The aim of this study was to investigate preferences for recontact when new genetic information becomes available among patients tested for BRCA pathogenic variants. We further wanted to investigate whether having a high or low information-seeking coping style (monitoring) impacts preferences. Preferences for recontact were assessed using a self-constructed questionnaire. The Threatening Medical Situations Inventory (TMSI) was used to measure monitoring coping style. The questionnaires were sent to 500 randomly selected patients who had previously been tested for BRCA pathogenic variants within the time frame 2001–2014 at one genetic clinic in Norway. We received 323 completed questionnaires. Most respondents wanted to be recontacted with advances in genetic medicine (81.1%) and to receive highly personalized updates. Genetic counselors/geneticists were believed to be most responsible for recontact. There was a significant relationship between being a high monitor and wanting recontact to learn about own cancer risk and receive ongoing support. Patients have a high interest in being recontacted. The findings indicated a tendency for high monitors to prefer more detailed and personalized information.

KEYWORDS

communication, genetic testing, monitoring coping style, patient preferences, psychosocial, recontact

1 | INTRODUCTION

Ongoing advances in cancer genetics lead to new opportunities for genetic testing, early disease detection, and potential interventions and therapies. This raises important issues regarding communication of such information from the genetic clinic to former patients by recontacting them.

Previously, genetic testing was limited to *BRCA1* and *BRCA2* regarding hereditary breast- and ovarian cancer. However, panel testing has become increasingly available in recent years, leaving testing for only *BRCA1/2* outdated by today's standards (Hooker et al., 2017). Pathogenic variants in other high and moderate penetrant genes may also be causing increased risk for breast- and ovarian cancer, often in addition to cancer in other organs (Buys et al., 2017;

Couch et al., 2017; Hauke et al., 2018; Lu et al., 2019). Patients who previously tested negative for pathogenic variants in *BRCA1* and *BRCA2* may therefore benefit from being tested by multiple-gene panels (Buys et al., 2017; Hauke et al., 2018). Additional genetic testing of earlier patients would in Norway require recontact since consent from the patient must be obtained prior to new testing.

Recontacting former patients about advances in medical genetics is not yet standard of care, but is taking place in various settings on an ad hoc basis (Mueller et al., 2019; Sirchia et al., 2018). In Norway, restrictive legislation was introduced in 1994 protecting persons from genetic discrimination (Act relating to human medical use of biotechnology of 2003). Genetic counseling was mandated prior to and following predictive testing. The same law also included restrictions in contacting family members who had not approached genetic counseling themselves. As a result, a perceived barrier of uncertainty regarding recontacting patients was established (Hamang et al., 2009).

Among genetic counselors, there is little consensus about how to approach recontacting to offer updated genetic testing to patients (Mueller et al., 2019). However, previous research demonstrates that most patients appreciate the possibility of being recontacted regarding new genetic information (Carrieri et al., 2017; Griffin et al., 2007; Otten et al., 2015; Romero Arenas et al., 2018).

A theoretical model relevant to the decision outcomes relating to patients' preferences for recontact is the Monitoring Process Model (MPM) (Miller et al., 1995; Schwartz et al., 1995). According to this model, individuals are characterized as high (HM) or low monitors (LM) based on how they encode or construe potentially life-threatening stressors. "Monitoring" is defined as a cognitive coping style characterized by the tendency to seek information about threats (Miller, 1995). Individuals high on the monitoring dimension scan for and amplify threatening cues in health information and worry about these threats or risks for extended periods of time, whereas LMs distract from and downgrade threatening information (Miller, 1995). HMs tend to desire more voluminous and detailed information in cancer-related and other medical contexts than LMs (Miller, 1995). The MPM is shown to be of great relevance to medical settings because of its possible impact on symptom reporting, preventive behavior, patient delay and the effects of information provision (Miller et al., 1989; Schwartz et al., 1995; Steptoe & O'Sullivan, 1986).

Previous studies have found high monitoring to be related to a desire for more detailed information (Ong et al., 1999; Parker et al., 2001; Sie et al., 2013), a preference to participate in medical decision making, more question asking, and dominance (Ong et al., 1999), and less satisfaction with information received during the consultation (Timmermans et al., 2007). At the same time, HMs were found to be more likely to report decisional conflict regarding genetic testing (Sie et al., 2013). With this in mind, it is plausible to assume that monitoring coping style might have an effect on patients' preferences for recontact. Thus, it may be useful to explore the extent to which monitoring tendencies influence information preferences regarding recontact.

The published literature describing patients' perspective on recontacting is limited, and patient perspective is identified as important for making progress in the discussion regarding recontacting (Mueller et al., 2019; Otten et al., 2015). We therefore aimed to investigate preferences for recontact among BRCA-tested patients. In addition, we aimed to examine differences in preferences between patients with high and low information-seeking coping style (HM and LM).

The research questions are as follows: (1) What are BRCA-tested patient preferences for recontact when new genetic information becomes available? (2) Are there any differences between preferences for recontact between HMs and LMs?

2 | METHODS

2.1 | Participants

The study was carried out at one University Hospital in mid-Norway. The data collection was completed in 2017. BRCA testing has been offered at this hospital since 2001. Inclusion criteria were: (a) being 18 years or older, (b) having been tested for a BRCA pathogenic variant between 2001 and 2014, (c) having been seen by a genetic counselor or medical geneticist, and (d) having an address registered in Norway. Patients with positive, negative, and uninformative test result were included, and they were not stratified by their personal or familial history of cancer. Totally, 2086 patients were tested for BRCA pathogenic variants in the time frame 2001–2014, and 558 were randomly selected by using the random-sample function in Excel. Electronic medical records of the 558 selected patients were reviewed for further reasons for exclusion: death ($n = 52$) or unknown address ($n = 6$). Excluded patients were replaced with an equivalent number of patients from the population that also met the inclusion criteria, resulting in a final sample of 500 patients.

2.2 | Instrumentation

2.2.1 | Demographics and preferences for genetic testing

To survey patient preferences for recontact, we created a questionnaire. Some of the questions were inspired by Griffin et al. (2007), in addition to the clinical experience of members of the research team. The questionnaire consisted of the following parts:

1. *Personal background*: Eleven questions assessed the patients' demographic and medical characteristics. Sociodemographic variables included age, gender, marital status, children, and education level. We also collected information such as *reason for genetic counseling* and *genetic test result*.
2. *Responsibility for recontact*: Patients were asked to rank whom among the following they believed was primarily responsible for

keeping patients updated regarding new genetic information: patient, primary care physician, cancer specialist, genetic counselor/geneticist.

3. *Preferences for recontact*: Respondents were provided with a list of possible reasons for wanting recontact and not wanting recontact, and were asked to check alternatives that applied. In addition, we asked about preferred method for and frequency of recontact, and what information should be provided at first recontact. To these questions respondents were given alternatives and asked to select one alternative for each question.
4. *Contact with the genetic clinic*: Patients were asked whether they had searched for genetic information or recontacted the clinic after testing, and whether they were encouraged to recontact the clinic if changes occurred in their personal or their family's cancer history.
5. *Contact with primary care physician and oncologist*: Patients were asked about the frequency of visit to their primary care physician and/or oncologist, whether they discussed their genetic test result with their primary care physician and/or oncologist, and whether they thought their primary care physician and/or oncologist were sufficiently knowledgeable about hereditary breast- and ovarian cancer.
6. *Interest in new genetic testing*: Those who received a VUS or a negative test result were asked if they were interested in new genetic testing and, if so, whether they would like to be recontacted prior to a new test and/or recontacted only if something of relevance was found.

For most questions, respondents were asked to select among predefined alternatives, but there was also space for comments. Prior to completing the questionnaire, feedback was solicited from genetic counselors at the hospital, one user representative, and others. Survey questions and format were refined based on comments and feedback.

2.2.2 | The threatening medical situations inventory (TMSI)

Monitoring coping style was measured using a Norwegian translation of the Threatening Medical Situations Inventory (TMSI). TMSI is a questionnaire based on Miller's general concepts of *monitoring* and *blunting* (Miller, 1987), and developed by van Zuuren et al. (1996) to measure coping styles specifically for the domain of medical threat. TMSI provides descriptions of four hypothetical medical threatening situations: "vague suspicious headache," "sudden appendicitis operation," "being diagnosed as hypertensive," and "choosing for uncertain heart surgery." These situations diverge with respect to two important stress parameters: controllability and predictability.

Three monitoring (seeking information) and three blunting (seeking distraction) alternatives in random order follow each TMSI scenario. Each alternative includes a five-point Likert-scale (1="not at all applicable to me" to 5="strongly applicable to me").

2.3 | Procedures

The 500 randomly selected patients received a questionnaire in the mail along with a letter explaining the nature and purpose of the study. A consent form for participation and two return envelopes, one for the questionnaire and one for the consent form, were included in the letter to ensure anonymity. To increase participation, one reminder was sent to participants who had not returned the survey after one month. Patients were given the opportunity to contact a genetic counselor if they had questions regarding the study. Ethical approval was obtained from The Norwegian Ethical Committee in November 2015 (2015/1747).

2.4 | Data analysis

All data used in this study are self-reported and gathered through the survey, except data on whether the patient had a diagnostic or a predictive genetic test, which were exclusively collected from the patients' medical journal. The questionnaire responses were manually punched into a data file. A data cleaning process was developed and performed on data from the survey. Questions that were answered improperly were discarded for those participants. Missing values were replaced by the individual's average score for the TMSI questionnaire if 75% or more of the items on the monitoring subscale were filled in by the respondent (Pieterse et al., 2005).

Total monitoring scores are obtained by summarizing the relevant items (range: 12–60) (van Zuuren et al., 1996). Higher scores indicate a higher tendency to actively search for information in case of a medical threat. The respondents were categorized as HM or LM on the basis of whether they scored above or below the median of the sum score (Nordin et al., 2002; Steptoe & O'Sullivan, 1986; Timmermans et al., 2007). Respondents scoring 38 or lower were categorized as LM, while respondents scoring 39 or higher were categorized as HM.

Descriptive analyses were performed for sociodemographic and medical variables and for responses from the questionnaire addressing preferences for recontact. In addition, responses from the questionnaire about preferences for recontact were tested with correlation analysis in-between monitoring coping style (HM versus LM). As the variables were nominal or dichotomous, the Pearson's chi-squared test was used to investigate relationships between variables. Groups with less than five responses were excluded from the comparison because of too low numbers to find statistical significance. The probability level for statistical significance testing was set at 0.05 (two-sided).

Cronbach's alpha was computed to determine the internal consistency reliability for the TMSI questionnaire used in the study. A Cronbach`s alpha above 0.70 is acceptable, while 0.80 or greater is preferred (Cortina, 1993). Data were analyzed using IBM SPSS for Windows, Version 23.0 (2015).

3 | RESULTS

3.1 | Respondent characteristics

In this study, the participation rate was 65.2% (326/500). Reasons for not participating in the study were not obtained.

Sample characteristics are presented in Table 1. A chi-square goodness-of-fit test indicated that there were no significant differences between the sample and population on the variables gender, genetic test result, and type of test (diagnostic/predictive).

TABLE 1 Sample characteristics

	n = 326	%
Gender		
Female	283	86.8
Male	43	13.2
Mean age (s.d.)	55 (12.6)	
Mean year of genetic testing (s.d.)	2010 (3.3)	
Education level		
Junior high school	35	10.7
High school	135	41.4
University/advanced level	152	46.6
Living arrangements		
With spouse/cohabitant	166	50.9
With spouse/cohabitant and child(ren)	88	27.0
Alone with child(ren)	13	4.0
Alone	54	16.6
With other	4	1.2
Children	302	92.6
Reason for genetic counseling *(Multiple response)*		
Personal history of cancer	128	39.3
Cancer in the family	160	49.1
Personal risk of cancer	40	12.3
Relatives risk of cancer	60	18.4
Known mutation in the family	63	19.3
Referral *(Multiple response)*		
By primary care physician	80	24.7
By cancer specialist	110	34.0
Self-referred through relatives	113	34.9
Other	29	9.0
Result of genetic test		
Positive	55	16.9
Negative	263	80.7
VUS	6	1.8
Don't remember	2	0.6
Genetic test		
Diagnostic	142	43.6
Predictive	181	55.5
No data	3	0.9

Following genetic testing, 10.2% had searched for genetic information regarding HBOC (mainly on the internet), and only 5.6% had recontacted the genetic clinic for genetic information. Nearly all of the respondents (96,6%) had informed family, friends, and others about their genetic test result, whereas only 22,9% recalled that they during genetic counseling had been instructed to recontact the genetic clinic in cases of new personal or familial cancers.

The median score for the monitoring scale was 38 (range 12–60). Using the median as cut-off between high and low monitors, 52,6% (163/310) were classified as LM, while 47.7% (147/310) were classified as HM. Sixteen participants were excluded from the monitoring analysis due to three or more missing monitoring values on the TMSI. The distribution of the scores on the monitoring scale is shown in Figure 1. We obtained a Cronbach's alpha of 0.82 for the monitoring scale.

The proportion of women was significantly higher in the high monitor group than in the low monitor group (91.8% versus. 82.2%, $p = .012$). No other significant demographic differences between high and low monitors were found.

3.2 | Responsibility for recontact

Respondents believed that the primary responsibility for keeping the patient updated belonged to the genetic counselor/geneticist (43.6%), followed by the primary care physician (20.9%), then the patients themselves (12.6%), and the cancer specialist (12.0%). Eleven percent (36/326) did not respond. There was no significant association between monitoring coping style and perceived responsibility of the patient, primary care physician, cancer specialist, and genetic counselor ($p = .30, .60, .40, .09$, respectively).

3.3 | Preferences for recontact

The majority of respondents wanted to be recontacted when new genetic information was available (81.1%). Three respondents (0.9%) did not answer the question. While a greater percentage of HMs (86.3%) wanted to be recontacted compared to LMs (80.4%), no statistically significant difference was found ($p = .21$).

Respondents were asked how often they would prefer to be recontacted if routines for recontact were implemented in genetic clinics. Results are presented in Figure 2. The option "when there is new genetic information that directly affects them" was preferred by both HMs (58%) and LMs (70%). However, a significant difference between LMs and HMs was found ($p = .003$).

Of the 302 respondents (156 LM and 146 HM) who answered the question about preferred method for recontact, both LMs (50.6%) and HMs (55.5%) preferred personalized letter. General letters were more highly preferred among LMs (24.4%) compared to HMs (13.7%), while newsletter on email was slightly more preferred

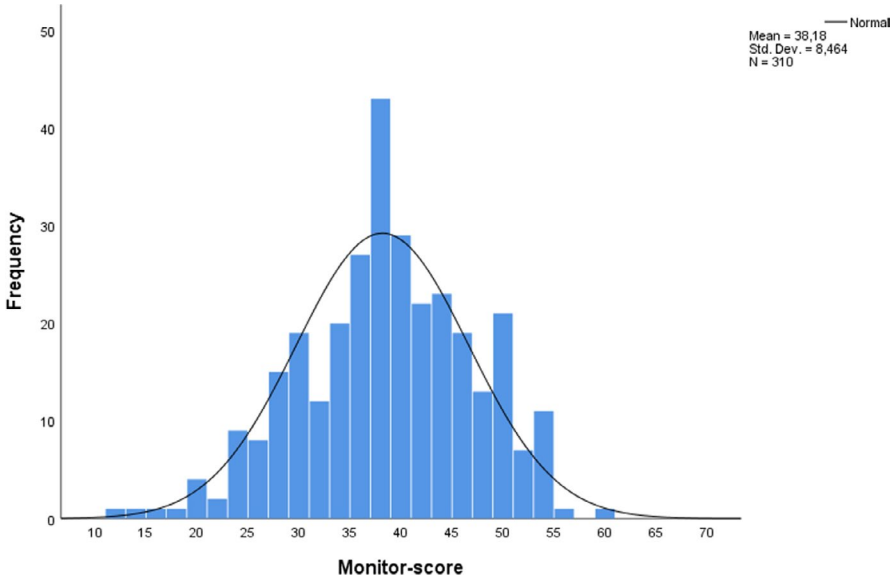

FIGURE 1 Distribution of scores on the monitoring scale of the Threatening Medical Situations Inventory (TMSI)

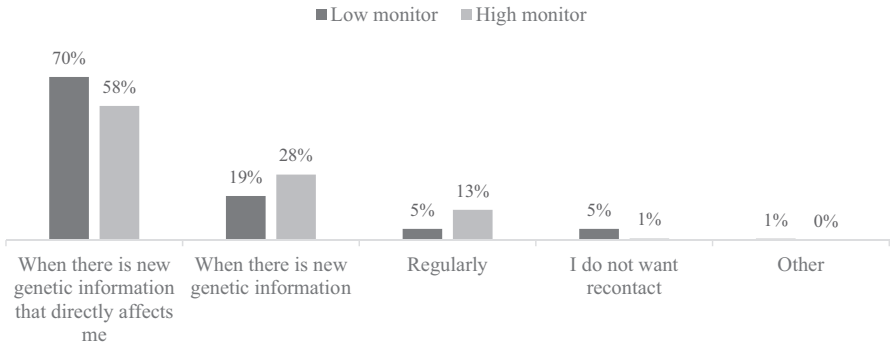

FIGURE 2 How often participants would prefer being recontacted. Responses of low monitors ($n = 162$) and high monitors ($n = 145$). $p = .003$

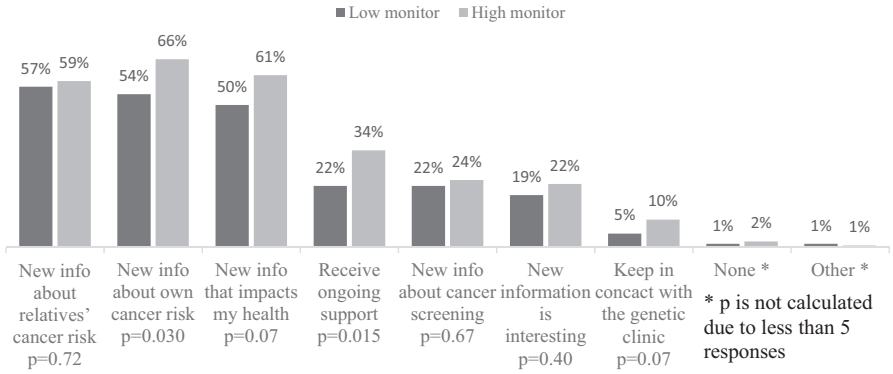

FIGURE 3 Reasons for wanting recontact. Responses of low monitors ($n = 142$) and high monitors ($n = 160$)

among HMs (18.5%) compared to LMs (16.0%). A slightly higher proportion of HMs (11.0%) compared to LMs (4.5%) preferred receiving a phone call. Updated webpages and media were the least preferred methods for both LMs (3.2% and 1.3%, respectively) and HMs (1.4% and 0.0%, respectively). There was an association between monitoring coping style and preferred method for recontact ($p = .032$).

3.4 | Reasons for and against recontact

The most frequent reasons for wanting recontact for both groups were: information about personal cancer risk and cancer risk relevant for relatives, and impact on one's health (Figure 3). The question was not answered by 3.7% (12/326). Statistically significant differences between the two groups were found for the following: "receiving ongoing support" ($p = .015$) and "to receive information about own cancer risk" ($p = .030$).

The majority of respondents reported that there were no reasons for not wanting to be recontacted, followed by "a waste of time if the information is not relevant to me" and "recontact could make me anxious" (Figure 4). No statistical difference was found regarding reasons for not wanting recontact. The question was not answered by 30.7% (100/326).

Most of the respondents (86.5%) replied that patients should be asked at the initial consultation whether they wanted recontact in

the future, whereas only 1.5% said the patient should not be asked. The question was not answered by 0.3% (1/326). There was no significant difference between HMs and LMs ($p = .320$).

To the question regarding recontact in the future, 4.1% (11/266) answered that they under no circumstances wanted to be contacted again. There was no significant difference between HMs and LMs ($p = .45$).

3.5 | New testing

Among those having received a negative test result or a VUS (270/326), the majority wanted new genetic testing if it was available and relevant for them (71.5%). This includes both respondents tested for a known pathogenic variant in the family and initial proband screening with no reportable pathogenic variant identified. Furthermore, more than half of those (63.1%, 154/244) preferred being recontacted prior to new genetic testing, and they would only like to be recontacted if the results of genetic testing had some relevance for them (64.8%, 158/244). No statistically significant difference was found when comparing HMs and LMs ($p = .33$, 0.17, 0.71, respectively).

4 | DISCUSSION

The main result in this study was that most patients previously tested for BRCA pathogenic variants have a high interest in recontact when there is new genetic information. The high interest in being recontacted was not significantly different between HMs and LMs, but there were smaller significant differences regarding reasons for recontact and method of recontact. Patients assigned the highest degree of responsibility for recontact to genetic counselors/geneticist.

In this study, patients showed a high interest in being recontacted. This is consistent with previous research exploring views of patients in clinical genetics (Carrieri et al., 2017; Dheensa et al., 2017; Griffin et al., 2007; Rasmussen et al., 2019; Romero Arenas et al., 2018). The preferred method for recontact in our study was personal letters containing information relevant to them, which is also found in other studies (Griffin et al., 2007; Rasmussen et al., 2019).

Although most patients indicated that they wanted to be recontacted, some respondents also reported negative attitudes toward recontact, which is in line with other studies (Carrieri et al., 2017; Griffin et al., 2007; Romero Arenas et al., 2018). These studies found that recontact could bring up bad memories or be a waste of time, and that new information could be upsetting, which indicates that recontact can be experienced as stressful for some patients. The potential for negative psychosocial consequences, such as increased anxiety, stress, and negative effects on self-image and family relations, has been cited as a major drawback to recontacting patients (Fitzpatrick et al., 1999; Otten et al., 2015).

At the same time, more than 50% of the sample in our study replied they had no reasons for not wanting recontact. Only a minority of respondents indicated reasons for not wanting recontact, such as believing that recontact would be stressful or bring back "bad memories." Similar results were found by Griffin et al. (2007). In an interview with 16 men with Lynch syndrome who were recontacted with information about a potentially increased risk for prostate cancer, participants reported a low level of emotional distress about being recontacted, and recontact was seen as desirable (Rasmussen et al., 2019). We found that more respondents reported reasons for not wanting recontact than there were respondents who actually did not want recontact. This indicates that patients might have some negative thoughts regarding recontact, but the benefit of recontact outweighs their reasons for not wanting recontact.

In this study, respondents assigned the highest degree of responsibility for recontact to genetic counselors/geneticist, and the least responsibility to themselves. In several studies, patients give a higher responsibility for recontact to health care professionals than to themselves (Carrieri et al., 2017; Griffin et al., 2007; Romero Arenas et al., 2018). One reason for this may be that patients do not know where to look for, or how to interpret, new information, and might find seeking information distressing (Dheensa et al., 2017). In contrast, genetic providers are found to assign a higher degree of responsibility for recontact to the patient than they assign to themselves (Fitzpatrick et al., 1999; Kausmeyer et al., 2006; Mueller et al., 2019). Accordingly, there seems to be a gap between who patients and genetic providers view as primarily responsible for recontact.

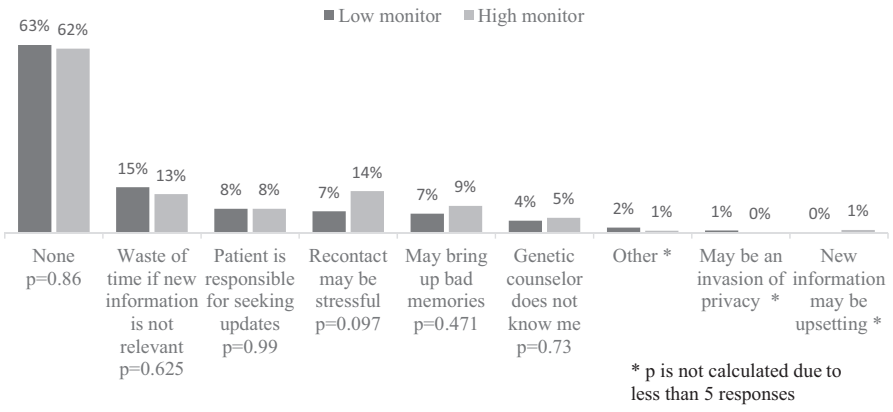

FIGURE 4 Reasons for not wanting recontact. Responses of low monitors ($n = 133$) and high monitors ($n = 106$)

A possible reason for genetic counselors' high assignment of responsibility to the patient may be grounded in the central principles of genetic counseling, which recognize that the patient will play an integral role in the counseling process (Fraser, 1974). Since patients in genetic counseling settings are given a reasonable degree of responsibility, including the obligation to provide appropriate information, it may seem reasonable that the long-standing concept of responsibility shared by the patient and the geneticist/genetic counselor should equally apply to recontact (Mao, 1999).

In addition, practical reasons like time management issues, appropriate systems to retrieve appropriate patients for recontact, and not enough personnel to do the job are cited in the literature as reasons for why genetic counselors/geneticists are not recontacting patients (Mueller et al., 2019; Otten et al., 2015; Sirchia et al., 2018). This may also influence the counselors' preferences.

Several authors propose initiating a discussion with the patient about responsibility for recontact during the consultation to clarify any gaps in expectations and to record patient preferences regarding recontact (Hunter et al., 2001; Murray et al., 2011). In our study, being asked at the consultation whether they would want to be recontacted in the future was preferred by the majority of respondents, and the preference did not differ between any of the compared groups.

4.1 | Monitoring coping style

Further analyses of the results indicated a tendency for HMs to show more interest in personalized information and less interest in general information than LMs. Several studies have found a relationship between monitoring coping style and information preferences. Ong et al. (1999) found monitoring coping style to be related to a preference for detailed information and participation in medical decision making among cancer patients. Meulenkamp et al. (2010) investigated research participants' information preferences with regard to receiving genetic research results from biobanks and found monitoring coping style to be positively associated with a preference for more information. It has also previously been shown that HMs tend to desire more voluminous information in cancer-related and other medical contexts (Miller, 1995).

HMs are described as perceiving their risk to be higher, to experience more intrusive ideation, to encode threats as catastrophic, and generally to be more distressed than LMs (Miller et al., 1994; Schwartz et al., 1995). We only briefly addressed possibly negative consequences of recontact and did not find HMs to report recontact as being more stressful or bring back bad memories. Overall, both HMs and LMs reported few reasons for not wanting recontact.

Miller et al. (1988) found that HMs desired a less active role in medical care and proposed that patients' information-seeking was not initiated for its instrumental value but in order to reduce uncertainty and anxiety. Shiloh et al. (1999) showed that HMs were interested in threat-relevant information (predictive genetic testing) for both problem- and emotion-focused functions, while LMs were interested only in the instrumental, controlling function. We found a tendency for HMs to be more interested in recontact for the reason of keeping contact with the clinic ($p = .07$) and receiving ongoing support ($p = .015$) compared to LMs. In addition, HMs were more interested in being recontacted regularly, whether there were new findings or not. LMs showed higher interest in being recontacted only in situations where new genetic information was generated that specifically pertained to them. It is unclear from our findings, but it is possible that HMs are more interested in recontact also for its emotional values compared to LMs because they were more interested in regular contact regardless of new findings. It may also just be that HMs are information seekers who also want to be informed that there is no new information available.

Because of their threat-related vigilance and information-seeking style, HMs are described as being especially likely to opt for predictive genetic testing for cancer (Schwartz et al., 1995; Shiloh et al., 1999). However, in our study interest in new genetic testing was not found to be significantly different between HMs and LMs. Both groups showed high interest in new genetic testing. Wakefield et al. (2007) also found that among individuals considering genetic testing for cancer risk, the majority (92%) was interested in new tests; there was, however, no difference between HMs and LMs.

Our results indicate that having a high monitoring coping style is of less importance to patients' preferences for recontact. An explanation for finding only small differences might be that being recontacted is not thought of as creating a stressful situation (Rasmussen et al., 2019; Romero et al., 2018), and HMs and LMs would therefore not differ much in their preferences. Miller et al. (1994) found that the tendency of HMs to be interested in testing is found to be pronounced in certain situations, for example, in situations where they are more likely to exaggerate the severity and seriousness of the threat for both themselves and relatives. Recontact about new cancer risk information can cause little emotional distress to patients when the information is seen as actionable (Rasmussen et al., 2019).

The results from this study contribute to a small body of growing research on patients' perspectives on recontact.

4.2 | Study strength and limitations

The design of this study has the same limitations as all cross-sectional designs regarding control, causality, and generalizability.

The questionnaire addressing demographics and patient preferences has not been validated.

Prior research has reported the blunting scale to have poorer psychometric properties compared to the monitoring scale (Ong et al., 1999). In this study, only the monitoring subscale was used in the analyses, which is consistent with the aim of this study and other studies (Pieterse et al., 2005; Schwartz et al., 1995; Shiloh et al., 1999).

The reliability and validity of TMSI have been considered as satisfactory (van Zuuren et al., 1996). TMSI is found to have good internal

consistency when used on individuals with a significant family history of cancer (Wakefield, Homewood, et al., 2007) and individuals with a personal history of cancer (Ong et al., 1999).

Information about non-respondents was not obtained, and the non-respondents may be different from the respondents. Based on available information about the study population (gender, test-result, and diagnostic/predictive test), the sample was representative. Our study participants had a higher education level than the general population, with 47.5% having higher education compared to 31.4% in the general Norwegian population (Statistics Norway, 2020). Because education is associated with higher information preferences (Protière et al., 2012), our results may be slightly over-representative. At the same time, it has previously been reported that the education level of patients attending familial cancer clinics tend to be higher than the general population (Wakefield, Meiser, et al., 2007).

Respondents were only recruited from one of four genetic clinics in Norway, and the sample might accordingly be biased by different practices and routines at these clinics compared to other clinics. Furthermore, it may be that participants in this survey have an interest in genetic- and health-related issues in general, given that they are willing to contribute to the study, and may therefore also over-represent the information preferences of the general population of patients tested for BRCA pathogenic variants at Norwegian genetic clinics.

Furthermore, some differences in responses between groups might be due to a low number of responses in some of the variables being compared. It is also possible that personal or familial history of cancer would significantly impact the findings. Since that information was not collected, analyzing for correlation between cancer history and responses of HM and LM was not performed. A higher missing value score on some of the questions may reflect confusion or lack of an appropriate response for respondents to select. However, most participants completed the questionnaire appropriately, and our questionnaire seemed relevant, as suggested by the satisfactory response rate. We chose a commonly used measure for coping style, the TMSI questionnaire, which is well established and validated (van Zuuren et al., 1996).

The patient population surveyed in our study included only individuals tested for *BRCA*1/2 and some caution must be exercised in generalizing the results to other patient groups.

4.3 | Practice implications

The results from this study can aid in the development of recontacting strategies and help make progress in the discussion of recontact. Furthermore, it may be useful for achieving better communication with patients regarding recontact. Patients should be informed that changes in family health issues should be reported to the genetic clinic. A minority of the participants did report possible negative consequences of being recontacted, and this is important to bear in mind if systematic recontact is implemented.

Providing personalized letters, which was the preferred method in this study, could possibly be highly time-consuming and thus an obstacle to recontacting patients among genetic counselors. It would, however, be possible to send a brief letter informing patients that updated genetic information is available and requesting them to call the clinic for further information. In that way, patients with high information preferences are given the opportunity to request more detailed information, while those with lower information preferences can receive more general information.

This study allows for better understanding of how recontacting patients with new information can be achieved using the TMSI. Furthermore, this study also gives some initial reassurance that coping styles should not be perceived as barriers to recontacting patients and individualizing information based on patient preferences and coping styles may be achieved.

4.4 | Research recommendations

This is the first study addressing patient preferences for recontact in Norway. Our findings reflect the preferences among patients tested at one genetic clinic. It would be useful to examine this topic at several sites and especially at clinics that practice recontact, as they might have different perspectives on the subject.

This study aimed to determine differences in attitudes and preferences based on monitoring coping style. Investigating additional potential modifiers of preferences for recontact such as age, personal and familial cancer history, marital status, educational level, and availability of social support is required for a more comprehensive understanding of the topic. As information preferences are not static, future investigations could also explore changes in preferences for recontact over time. In addition, studies investigating psychosocial aspects of recontact may be focused on more extensively. Addressing patient expectations and attitudes toward recontact, for example, in a qualitative approach, might give further insight into experiences and concerns regarding the recontacting process. In future studies, it would be interesting to explore how established routines and systems may contribute to enhance recontacting. It would also be worthwhile to address the potential workload the implementation of such routines will generate.

In our study, we did not examine perceived stress. Further research is therefore needed in order to draw conclusions about the extent to which patients would make use of their monitoring coping style in an event of recontact.

Investigating patients seen for other genetic reasons than *BRCA*1/2 should be further explored in future research.

5 | CONCLUSIONS

In this study, we found a high preference for recontact regarding new genetic information among patients previously tested for BRCA pathogenic variants. Respondents preferred highly personalized

updates and reported few reasons for not wanting recontact. Patients were found to assign the highest degree of responsibility for recontact to genetic counselors/geneticists, and the least degree of responsibility to themselves.

The findings indicated a tendency for HMs to prefer more detailed and personalized information.

AUTHOR CONTRIBUTIONS

Randi Marlene Dahle Ommundsen designed and administered the study. She collected, plotted, analyzed and interpreted the data, and wrote the original draft of the article. She confirm that she 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. Nina Strømsvik was substantially involved in interpreting the data and revising it critically for important intellectual content. Anniken Hamang was substantially involved in designing the study, collecting, analyzing, and interpreting data. She revised the work critically for important intellectual content. All of 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.

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COMPLIANCE WITH ETHICAL STANDARDS

CONFLICT OF INTEREST

Randi Marlene Dahle Ommundsen, Nina Strømsvik, and Anniken Hamang declare that they have no conflict of interest.

HUMAN STUDIES AND INFORMED CONSENT

All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000. Informed consent was obtained from all patients for being included in the study.

ANIMAL STUDIES

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

DATA SHARING AND DATA AVAILABILITY

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 or ethical restrictions.

ORCID

Randi Marlene Dahle Ommundsen https://orcid.org/0000-0001-6722-789X

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