Patients’ expectations of preventive measures of medical institutions during the SARS-CoV-2 pandemic in Germany in women with an increased risk of breast and ovarian cancer: a cross-sectional, web-based survey

Roxana Schwab, Annika Droste, Kathrin Stewen, Walburgis Brenner, Marcus Schmidt, Annette Hasenburg

ABSTRACT

Objectives To identify patient-approved contingency measures for protection of patients and healthcare workers (HCWs) from COVID-19 infection and to use these findings to improve staff’s preparedness to cope with the course of this pandemic or similar situations.

Methods (design, setting, participants, interventions) We conducted a cross-sectional, web-based survey of women with an increased risk of breast or ovarian cancer, regardless of whether they had experienced an active malignant disease during the pandemic. A self-reported questionnaire, developed for this study, was used to assess expectations and opinions about preventive measures within medical institutions.

Results Sixty-four (71.9%) of the 89 potential participants responded to at least one question regarding contingency measures within medical institutions. Approximately 37% of the respondents preferred having information about their facility’s hygiene protocols before appointment; 57.8% of the respondents endorsed regular SARS-CoV-2 testing of patients prior to medical appointments and 95.3% endorsed regular testing of HCWs. Additionally, 84.4% of the respondents supported HCWs’ use of surgical masks and 68.8% supported HCWs’ use of masks with greater protection. Notably, 75.0% of the respondents advocated for the presence of a significant other during medical consultations; 71.9% approved the use of telemedicine and 93.8% endorsed changes in appointment practices to enable social distancing. No significant associations were found between respondents’ sociodemographic, disease-specific or pandemic-specific factors and their opinions on hygiene precautions.

Conclusions Patients at high risk of infection or severe course of COVID-19 approve strict contingency measures designed to lower the transmission of COVID-19 in medical facilities. Moreover, vulnerable groups may profit from contingency plans in healthcare facilities in order to follow preventive measures, avoid diagnostic delay or avoid worsening of pre-existing conditions. However, they also value the presence of a significant other during medical consultations and procedures.

STRENGTHS AND LIMITATIONS OF THIS STUDY

⇒ With the design of the study (cross-sectional, web-based survey), over-representation of patients worrying about their health status and under-representation of women without online access are two possible sources of bias.

⇒ As the study was conducted during the first months of 2021 and vaccines against SARS-CoV-2 were inaccessible to a large proportion of the population at that time, we do not know whether the responses accurately depict the current state of the pandemic.

⇒ Our study identified several patient-approved contingency measures for protection of patients and healthcare workers from COVID-19 infection which are essential in terms of improving staff’s preparedness to cope with the course of this pandemic or similar situations.

INTRODUCTION

At the end of 2019, the novel SARS-CoV-2, which causes COVID-19, was first reported in China, before spreading rapidly to other countries by the beginning of 2020. The WHO declared the outbreak a ‘public health emergency of international concern’ on 30 January 2020 and a pandemic on 11 March 2020.¹

Vulnerable groups such as the aged population or patients with active cancers seem to have a greater risk of acquiring SARS-CoV-2 infection and severe COVID-19, requiring admission to intensive care units and invasive ventilation. Moreover, older persons and patients with pre-existing malignant diseases have a significantly higher risk of fatal outcomes compared with people in the general population without pre-existing medical conditions.² In order to protect...
this vulnerable population from possible infection, it is crucial to implement effective contingency plans in healthcare facilities, such as in ambulatory healthcare services, hospitals or nursing homes.3 As a pandemic is a dynamic process, measures were implemented at various time points by different countries to prevent the spread of infection among the population and to protect persons at high risk of exposure, such as healthcare workers (HCWs). In Germany, the first widespread social distancing measures were implemented by the government at the end of March 2020.1 4 As a result, healthcare facilities imposed specific safety protocols, general visitation guidelines and outpatient visitation policies in accordance with national and institutional regulations.3 Subsequently, family members and visitors were temporarily banned from joining ambulatory and hospitalised patients, with few exceptions, depending on the incidence of SARS-CoV-2 infection.

Persons with hereditary cancers, such as women at high risk of breast and ovarian cancer, require regular medical appointments. Women with mutations in breast cancer genes 1 and 2 (BRCA 1 and 2) have a cumulative risk of developing breast cancer of up to 75% by 80 years of age and a cumulative risk of developing ovarian cancer of up to 44% by the age of 80.5 Even if they do not undergo active cancer treatment or follow-up care, this group of patients requires regular medical monitoring and risk-reducing surgical interventions to prevent and detect a malignant disease at an early stage.6

**Aim of the study**

Vulnerable groups are on one hand dependent on a reliable and functioning healthcare system, and on the other are at increased risk of adverse medical outcomes related to a SARS-CoV-2 infection. To our knowledge, this is the first study to assess and identify patient-oriented and patient-approved contingency measures in persons at an increased risk of breast and ovarian cancer. Additionally, to improve preparedness for future pandemics or similar situations, it is crucial to identify if specific demographic or disease-specific factors influence the decision-making process regarding the prevention of SARS-CoV-2 transmission.

**MATERIALS AND METHODS**

**Study participants**

The target population was made up of approximately 1300 German-speaking persons at increased risk of breast and ovarian cancer being subscribed (actively or passively) at an internet platform of patient support groups for hereditary breast cancer or ovarian cancer during the period of recruitment. Recruitment was conducted via a direct link to the survey and an online invitation to participate distributed via the internet platforms of patient support groups. The survey was limited to individuals visiting the website who were aged 18 years or older and who gave electronic informed consent to participate in the study. The survey was completely anonymous to encourage honest and unbiased responses. Participants received no incentives for completion of the survey. Due to the recruitment method used in this study, it was not possible to calculate the response rates; nevertheless, we expected approximately 100 participants for this descriptive survey. Power analyses were conducted using PROC POWER, SAS V.9.4 for estimation of CI (power >99.9%; proportions 0.65–0.90; half-width CI 0.10).

**Data collection and measures**

The survey was active from 29 January to 22 February 2021. A questionnaire targeting the expectations and needs of persons with respect to hygiene measures related to the COVID-19 pandemic was developed based on a review of relevant literature.7–17 Data were collected anonymously and included participants’ self-reported sociodemographic and clinical information. The expectations and opinions of women with respect to the safety precautions of healthcare facilities and institutions for preventing the spread of the virus were assessed using the following questions:

1. Would you have liked to be informed about hygiene protocols in advance of your appointment? Yes, No, I don’t know/dos not apply.
2. Would more information about the prevailing hygiene protocols have had a positive influence on your behaviour (eg, meeting appointments)? Yes, No, I don’t know/does not apply.
3. Do you think that patients should be tested for SARS-CoV-2 infection before an ambulatory visit/appointment? Yes, No, I don’t know/does not apply.
4. Do you think that medical personnel/physicians should be tested for SARS-CoV-2 infection on a regular basis? Yes, No, I don’t know/does not apply.
5. Do you think that appointments should be scheduled in such a way to ensure that distancing rules can be strictly observed? Yes, No, I don’t know/does not apply.
6. Should a relative or a close person be allowed to accompany patients in the healthcare setting despite the COVID-19 pandemic? Yes, No, I don’t know/does not apply.
7. Do you think/agree that appointments which do not require one’s physical presence (eg, counselling appointments) should be conducted as teleconferences or video conferences during the COVID-19 pandemic? Yes, No, I don’t know/does not apply.
8. Do you think that medical personnel should at least wear a Filtering Face Piece-1 (FFP-1) mask (surgical mask) during the COVID-19 pandemic? Yes, No, I don’t know/does not apply.
9. Do you think that medical personnel should always wear a Filtering Face Piece-2 (FFP-2) mask during the COVID-19 pandemic to ensure patients’ safety? Yes, No, I don’t know/does not apply.

A full copy of the questions which were considered for the present evaluation can be found in online supplemental file 1.
Patient and public involvement

No patients were involved. Patient support groups for hereditary breast cancer or ovarian cancer supported the survey by distributing the link via their internet platforms.

Statistics

For descriptive analyses, missing data consisted of participants who did not answer the survey questions. Data were analysed using SPSS V.26.0. Descriptive statistics are expressed as mean, SD, median, IQR or proportions (%), as appropriate. We used the Mann-Whitney U test, \( \chi^2 \) test and Fisher’s exact test to analyse differences in data between the respondents and the non-respondents to the survey questions.\(^{18} \)

The Mann-Whitney U test (used for continuous variables), \( \chi^2 \) test (used for categorical variables) or Fisher’s exact test (used for categorical variables) were used as appropriate to compare differences in expectations according to demographic, disease-specific and pandemic-specific variables.\(^{18} \) P values were calculated using 95% CI and a p value <0.05 was considered statistically significant. Because the p values were not adjusted for multiple testing, all results should be interpreted as exploratory.

RESULTS

Demographic characteristics of the study group

Although 89 potential participants accessed the questionnaire (‘clicks’), 11% (9 of 89) did not answer any of the questions; 80% (64 of 80) answered at least one question pertaining to hygiene management and expectations for preventive measures, and 20% (16 of 80) did not answer any questions pertaining to preventive measures related to the pandemic. To understand the differences between respondents and non-respondents, we analysed the demographic, pandemic-specific and clinical characteristics of both groups (table 1). No significant differences were found between the two groups regarding demographic, pandemic-specific or clinical variables, except for a higher educational level of respondents compared with non-respondents.

Opinions about preventive measures

Approximately 37.5% of the respondents would have preferred to be informed about their facility’s specific hygiene protocols prior to their appointment, an equal proportion did not care to be informed and a slightly smaller proportion had no opinion on this topic (table 2). Only 20.3% of the respondents indicated that being informed about hygiene protocols would have changed their behaviour, whereas majority of the respondents either had no opinion or denied any possible influence of the information on their behaviour (table 2).

Majority of the respondents endorsed regular testing of patients for SARS-CoV-2 prior to visits to healthcare facilities. However, a much larger proportion of respondents supported regular testing of HCWs (table 2).

The proportion of respondents who endorsed changes in appointment practices to enable social distancing in medical institutions and waiting wards was also quite high. Despite social distancing requirements for visitors in medical institutions, the vast majority of respondents (75.0%) supported the possibility of being accompanied by a significant other during medical consultations, and 71.9% approved the implementation of telemedicine while 21.9% disapproved this option (table 2).

With regard to wearing protective gear, a relatively high proportion of respondents (84.4%) agreed that HCWs should wear surgical masks (not cloth masks) to stop the spread of SARS-CoV-2, compared with the much smaller proportions who did not consider surgical masks to be necessary or had no opinion on the topic. Fewer respondents (66.8%) agreed that HCWs wear masks with a higher level of protection (ie, the FFP-2 mask), while more respondents disagreed and others had no opinion (table 2).

Factors influencing decision-making related to hygiene practices during the pandemic

We examined group differences using the Mann-Whitney U test to identify subsets of patients with similar expectations and assess differences between those who had definite opinions of facilities’ hygiene management during the pandemic and answered ‘yes’ (vs ‘no’) to the questions and their counterparts. Missing data included all participants who did not answer the relevant question or did not have a definite opinion of the topic (‘do not know/does not apply’).

None of the demographic, pandemic-specific or disease-specific factors was found to have a significant influence on respondents’ opinions with respect to the hygiene measures implemented during the pandemic (all p>0.05; table 3).

DISCUSSION

Our study provides a descriptive analysis of participants’ expectations of preventive healthcare measures in medical institutions during the SARS-CoV-2 pandemic in Germany. During a pandemic, implementation of strict contingency plans in medical institutions is vital. In the beginning of the SARS-CoV-2 pandemic, in January 2020, 41% of the novel infections seemed to be hospital-acquired,\(^{19} \) fuelling the spread of the virus among the wider population. Viral transmission to patients in healthcare facilities will affect the population with a higher incidence of pre-existing medical conditions and thus with a higher risk of a severe course of the disease.\(^{20} \) Additionally, infection among HCWs could lead to shortages in qualified personnel to care for the patients, bringing the healthcare system to the brink of decompensation. Thus, adequate and effective protection of both patients and HCWs is of paramount importance.\(^{21} \)

Persons including patients with pre-existing medical conditions might be very sensitive to proper adherence to
## Table 1  Demographic and clinical characteristics of the total study sample

<table>
<thead>
<tr>
<th></th>
<th>Non-respondents</th>
<th>Respondents</th>
<th>P value (non-respondents vs respondents)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age Mean (SD)</td>
<td>46.64 (2.210)</td>
<td>42.85 (1.363)</td>
<td>0.161*</td>
</tr>
<tr>
<td>Median (IQR)</td>
<td>47.50 (40.00–54.00)</td>
<td>43.00 (33.75–51.25)</td>
<td></td>
</tr>
<tr>
<td>n=14</td>
<td></td>
<td>n=62</td>
<td></td>
</tr>
<tr>
<td><strong>Having a stable relationship</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes % of N</td>
<td>100 (14/14)</td>
<td>90.6 (58/64)</td>
<td>0.236*</td>
</tr>
<tr>
<td>No % of N</td>
<td>0 (0/14)</td>
<td>9.4 (6/64)</td>
<td></td>
</tr>
<tr>
<td><strong>Living alone</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes % of N</td>
<td>100 (16/16)</td>
<td>90.6 (58/64)</td>
<td>0.340*</td>
</tr>
<tr>
<td>No % of N</td>
<td>0 (0/16)</td>
<td>9.4 (6/64)</td>
<td></td>
</tr>
<tr>
<td><strong>Living with children &lt;18 years</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes % of n/N</td>
<td>25.0 (4/16)</td>
<td>34.4 (22/64)</td>
<td>0.474†</td>
</tr>
<tr>
<td>No % of N</td>
<td>75.0 (12/16)</td>
<td>65.6 (42/64)</td>
<td></td>
</tr>
<tr>
<td><strong>Living with persons &gt;65 years</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes % of N</td>
<td>12.5 (2/16)</td>
<td>6.2 (4/64)</td>
<td>0.399*</td>
</tr>
<tr>
<td>No % of N</td>
<td>87.5 (14/16)</td>
<td>93.8 (60/64)</td>
<td></td>
</tr>
<tr>
<td><strong>Living with a partner</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes % of N</td>
<td>62.5 (10/16)</td>
<td>60.9 (39/64)</td>
<td>0.909†</td>
</tr>
<tr>
<td>No % of N</td>
<td>37.5 (6/16)</td>
<td>39.1 (25/64)</td>
<td></td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Up to secondary level education % of N</td>
<td>84.6 (11/13)</td>
<td>48.4 (31/64)</td>
<td><strong>0.017†</strong></td>
</tr>
<tr>
<td>Tertiary level education % of N</td>
<td>15.4 (2/13)</td>
<td>51.6 (33/64)</td>
<td></td>
</tr>
<tr>
<td><strong>Did you have COVID-19?</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes % of N</td>
<td>0 (0/13)</td>
<td>4.7 (3/64)</td>
<td>0.429*</td>
</tr>
<tr>
<td>No % of N</td>
<td>100 (13/13)</td>
<td>95.3 (61/64)</td>
<td></td>
</tr>
<tr>
<td><strong>Someone in your social network has had COVID-19</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes % of N</td>
<td>23.1 (3/13)</td>
<td>28.6 (18/63)</td>
<td>0.687†</td>
</tr>
<tr>
<td>No % of N</td>
<td>76.9 (10/13)</td>
<td>71.4 (45/63)</td>
<td></td>
</tr>
<tr>
<td><strong>Reduction of social network</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Moderate reduction % of N</td>
<td>15.4 (2/13)</td>
<td>15.6 (10/64)</td>
<td>0.983†</td>
</tr>
<tr>
<td>Large reduction % of N</td>
<td>84.6 (11/13)</td>
<td>84.4 (54/64)</td>
<td></td>
</tr>
<tr>
<td><strong>Risk profiling for OC and BC</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>BRCA 1 and 2 % of N</td>
<td>76.9 (10/13)</td>
<td>70.3 (45/64)</td>
<td>0.895‡</td>
</tr>
<tr>
<td>Mutations other than BRCA 1 and 2 % of N</td>
<td>15.4 (2/13)</td>
<td>14.10 (9/64)</td>
<td></td>
</tr>
<tr>
<td>Positive family history of BC or OC % of N</td>
<td>7.7 (1/13)</td>
<td>15.6 (10/64)</td>
<td></td>
</tr>
<tr>
<td><strong>Having a history of (in situ or invasive) OC and BC</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes % of N</td>
<td>73.3 (11/15)</td>
<td>64.1 (41/64)</td>
<td>0.496†</td>
</tr>
<tr>
<td>No % of N</td>
<td>26.7 (4/15)</td>
<td>35.9 (23/64)</td>
<td></td>
</tr>
<tr>
<td><strong>Having a history of invasive BC</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes % of N</td>
<td>60 (9/15)</td>
<td>56.20 (36/64)</td>
<td>0.792†</td>
</tr>
<tr>
<td>No % of N</td>
<td>40 (6/15)</td>
<td>43.80 (28/64)</td>
<td></td>
</tr>
<tr>
<td><strong>Having a history of invasive OC</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Continued
contingency plans in medical institutions. This is understandable because the risk of severe and fatal COVID-19 is higher in the aged population and in persons with comorbidities.\(^7\)\(^{20}\)\(^{22}\) One study found that patients with cancer were 10-fold more susceptible to acquiring nosocomial infections with the SARS-CoV-2 virus than were patients without cancer.\(^7\) The observed 49% reduction in outpatient appointments for breast cancer follow-up during the pandemic\(^11\)\(^{12}\) was either a result of responses to hygiene plans or protocols within medical institutions or due to patients’ worries about becoming infected with COVID-19 while visiting healthcare facilities. Nevertheless, the implementation of appropriate contingency measures may reinforce vulnerable groups to attend necessary medical consultations, for example, during medical emergencies as well as mandatory diagnostic procedures, in order to act in an appropriate and timely manner to avoid possible harm or excess deaths due to the pandemic.\(^23\)\(^{24}\)

Accordingly, a study assessing medical outcomes during the COVID-19 pandemic in rural Japanese nursing homes did not observe an increased risk of emergencies by implementing appropriate contingency measures.\(^3\)

For reassurance, 37.5% of the participants in this study preferred to be informed of the healthcare facility’s hygiene protocols in advance of medical appointments. More interestingly, over 20% of participants stated that receiving prior information about safety protocols during the COVID-19 pandemic would have strengthened their adherence to medical appointments. Dissemination of

### Table 2

**Participants’ opinions and expectations of hygiene measures during the COVID-19 pandemic**

<table>
<thead>
<tr>
<th>Questions</th>
<th>Yes, in % of respondents (n/N)</th>
<th>No, in % of respondents (n/N)</th>
<th>I don’t know/does not apply, in % of respondents (n/N)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Would you have liked to be informed about hygiene protocols in advance of your appointment?</td>
<td>37.5 (24/64)</td>
<td>37.5 (24/64)</td>
<td>25.0 (16/64)</td>
</tr>
<tr>
<td>Would more information about the prevailing hygiene protocols have had a positive influence on your behaviour (eg, meeting appointments)?</td>
<td>20.3 (13/64)</td>
<td>31.3 (20/64)</td>
<td>48.4 (31/64)</td>
</tr>
<tr>
<td>Do you think that patients should be tested for SARS-CoV-2 infection before an ambulatory visit/appointment?</td>
<td>57.8 (37/64)</td>
<td>26.6 (17/64)</td>
<td>15.6 (10/64)</td>
</tr>
<tr>
<td>Do you think that medical personnel/physicians should be tested for SARS-CoV-2 infection on a regular basis?</td>
<td>95.3 (61/64)</td>
<td>1.6 (1/64)</td>
<td>3.1 (2/64)</td>
</tr>
<tr>
<td>Do you think that appointments should be scheduled in such a way to ensure that distancing rules can be strictly observed?</td>
<td>93.8 (60/64)</td>
<td>1.6 (1/64)</td>
<td>4.7 (3/64)</td>
</tr>
<tr>
<td>Should a relative or a close person be allowed to accompany patients in the healthcare setting despite the COVID-19 pandemic?</td>
<td>75.0 (48/64)</td>
<td>15.6 (10/64)</td>
<td>9.4 (6/64)</td>
</tr>
<tr>
<td>Do you think/agree that appointments which do not require one’s physical presence (eg, counselling appointments) should be conducted as teleconferences or video conferences during the COVID-19 pandemic?</td>
<td>71.9 (46/64)</td>
<td>21.9 (14/64)</td>
<td>6.3 (4/64)</td>
</tr>
<tr>
<td>Do you think that medical personnel should at least wear an FFP-1 mask (surgical mask) during the COVID-19 pandemic?</td>
<td>84.4 (54/64)</td>
<td>7.8 (5/64)</td>
<td>7.8 (5/64)</td>
</tr>
<tr>
<td>Do you think that medical personnel should always wear an FFP-2 mask during the COVID-19 pandemic to ensure patients’ safety?</td>
<td>68.8 (44/64)</td>
<td>18.8 (12/64)</td>
<td>12.5 (8/64)</td>
</tr>
</tbody>
</table>

FFP, Filtering Face Piece; n, number of respondents to the specific answer; N, total number of women who answered the question.
information that is valuable, transparent and proactive has been recognised previously by the WHO as an essential tool to overcome various difficulties or insecurities triggered by the pandemic.\(^1\)

Physical distancing to limit exposure to potentially infectious aerosols was widely recommended.\(^{13, 20, 21}\) Approximately 93.8% of the participants in this study expected adherence to the recommended physical distancing rules in waiting rooms. The recommended physical distancing protocol had a decisive influence on the visiting policies of medical institutions.\(^{20}\) Al-Shamsi et al.\(^{2} \) suggested that clinic attendance in outpatient settings should be limited to the patient and one visitor. Nevertheless, one of the pillars of patient-centred care has proven to be family involvement.\(^1\) One study found that up to 46% of adult patients were accompanied by family members to routine visits with their physicians.\(^1\) Family members, friends and caregivers mediate patients’ psychosocial and emotional support, encouragement, and reassurance, thereby improving the communication processes during medical visits and influencing patients’ satisfaction with physicians’ care.\(^{2, 14, 25, 26}\)

Medical appointments are an anxiety-provoking experience for patients, especially for those facing a possible or existing malignant diagnosis.\(^2\) The word ‘distress’ is mentioned by patients with cancer who were denied the option of having a family member or friend with them during medical appointments.\(^{15}\) Although the respondents in this study endorsed vigilant sanitary precautions to prevent nosocomial infections, an overwhelming proportion (75.0%) supported the possibility of being accompanied by a significant other during medical consultations, irrespective of their demographic, disease-specific or pandemic-specific characteristics. The company of a trustworthy person seemed to be clearly important for the participants of our study.

<table>
<thead>
<tr>
<th>Table 3</th>
<th>Influence of demographic, disease-specific and pandemic-specific factors on expectations regarding prevention of SARS-CoV-2 transmission</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age</td>
<td>0.441* 0.373* 0.316* 0.100* 0.102* 0.487* 0.263* 0.729* 0.821*</td>
</tr>
<tr>
<td>Stable partnership (no vs yes)</td>
<td>0.999‡ 0.508‡ 0.645‡ 0.999‡ 0.999‡ 0.999‡ 0.999‡ 0.368‡ 0.999‡</td>
</tr>
<tr>
<td>Living alone (yes vs no)</td>
<td>0.348‡ 0.508‡ 0.999‡ 0.999‡ 0.999‡ 0.577‡ 0.133‡ 0.999‡ 0.567‡</td>
</tr>
<tr>
<td>Living with children (yes vs no)</td>
<td>0.104† 0.676‡ 0.537‡ 0.999‡ 0.999‡ 0.784† 0.179‡ 0.646‡ 1.846†</td>
</tr>
<tr>
<td>Living with an elderly person (yes vs no)</td>
<td>0.999‡ 0.508‡ 0.296‡ 0.999‡ 0.999‡ 0.541‡ 0.999‡ 0.999‡ 0.999‡</td>
</tr>
<tr>
<td>Living with a partner (yes vs no)</td>
<td>0.233† 0.208† 0.824† 0.999‡ 0.999‡ 0.999‡ 0.999‡ 0.999‡ 0.999‡</td>
</tr>
<tr>
<td>Tertiary level education (yes vs no)</td>
<td>0.558† 0.717† 0.793† 0.999‡ 0.999‡ 0.542† 0.999‡ 0.244†</td>
</tr>
<tr>
<td>Having had COVID-19 (yes vs no)</td>
<td>0.999‡ 0.547‡ 0.535‡ 0.999‡ 0.999‡ 0.999‡ 0.999‡ 0.999‡ 0.522‡</td>
</tr>
<tr>
<td>Someone in their social network having COVID-19 (yes vs no)</td>
<td>0.123† 0.648‡ 0.596‡ 0.999‡ 0.999‡ 0.551† 0.982‡ 0.308‡ 0.096†</td>
</tr>
<tr>
<td>Reduction of social contact (serious and very serious reduction vs low reduction)</td>
<td>0.999‡ 0.360‡ 0.512‡ 0.999‡ 0.999‡ 0.800‡ 0.442‡ 0.577‡ 0.622†</td>
</tr>
<tr>
<td>Risk profiling for OC and BC (±family history but no mutation vs BRCA 1 and 2 vs a mutation other than BRCA)</td>
<td>0.578‡ 0.604‡ 0.263‡ 0.129‡ 0.295‡ 0.744‡ 0.793‡ 0.450‡ 0.452‡</td>
</tr>
<tr>
<td>Having a history of in situ or invasive BC or OC (yes vs no)</td>
<td>0.768† 0.930† 0.836† 0.999‡ 0.999‡ 0.163† 0.179† 0.999‡ 0.185†</td>
</tr>
<tr>
<td>History of invasive BC (yes vs no)</td>
<td>0.999‡ 0.353† 0.887‡ 0.999‡ 0.999‡ 0.249† 0.383‡ 0.639‡ 0.573†</td>
</tr>
<tr>
<td>History of invasive OC (yes vs no)</td>
<td>0.999‡ 0.999‡ 0.999‡ 0.999‡ 0.999‡ 0.999‡ 0.999‡ 0.999‡ 0.999‡</td>
</tr>
</tbody>
</table>

\(^{(1)}\) Would you have liked to be informed about hygiene protocols in advance of your appointment? (2) Would more information about the prevailing hygiene protocols have had a positive influence on your behaviour (eg, meeting appointments)? (3) Do you think that patients should be tested for SARS-CoV-2 infection before an ambulatory visit/appointment? (4) Do you think that medical personnel/physicians should be tested for SARS-CoV-2 infection on a regular basis? (5) Do you think that appointments should be scheduled in such a way to ensure that distancing rules can be strictly observed? (6) Should a relative or a close person be allowed to accompany patients in the healthcare setting despite the COVID-19 pandemic? (7) Do you think/agree that appointments which do not require one’s physical presence (eg, counselling appointments) should be conducted as teleconferences or video conferences during the COVID-19 pandemic? (8) Do you think that medical personnel should always wear an FFP-1 mask (surgical mask) during the COVID-19 pandemic? (9) Do you think that medical personnel should always wear an FFP-2 mask during the COVID-19 pandemic to ensure patients’ safety?

Significance level was set at p<0.05.

*Mann-Whitney U test.
†Fisher’s exact test, two-sided.
‡Chi-square test, two-sided.

BC, breast cancer; BRCA, breast cancer genes 1 and 2; FFP, Filtering Face Piece; OC, ovarian cancer.
Other experts have managed to attenuate the detrimental effects of the pandemic on screening and provide follow-up care for patients with cancer by implementing telemedicine appointments.1 2 6 The use of telemedicine has been described as a method for patients and physicians to stay in touch and informed while reducing physical contact.2 15 28 29 Notably, 71.9% of the participants in this study approved implementation of telemedicine whenever possible and reasonable from an oncological viewpoint in order to reduce face-to-face contact and minimise potential contact with persons infected with SARS-CoV-2, while maintaining the required standards for treatment. Telemedicine appointments would be impossible in cases requiring physical examinations or imaging procedures, but would be a good choice for offering a second opinion.11

The WHO has stated that regular and widespread testing is crucial to contain the virus and stop the pandemic.20 21 The transmission of nosocomial infections, both patient-to-patient and patient-to-healthcare personnel, has been reported previously.19 These infections occur, presumably, by transmission from asymptomatic or presymptomatic carriers or persons with mild or atypical symptoms,30 31 Precautions are essential, as 17.9%–33.3% of patients may have an asymptomatic COVID-19 infection.5 While preoperative testing has been recommended by various medical societies worldwide and testing of inpatients on their admission to the hospital has been introduced by the vast majority of healthcare facilities,31 regular testing of patients prior to ambulatory appointments to avoid nosocomial spread among HCWs or other patients was not. Interestingly, 57.8% of our study population indicated they would rather tolerate the inconvenience of repetitive testing before visiting a healthcare institution in order to feel safe and avoid exposure to potentially life-threatening infectious agents.

The protection of HCWs from COVID-19 serves both sides: maintaining medical care and protecting the vulnerable population from a possible fatal nosocomial infection with SARS-CoV-2.22 In Germany, HCWs were tested only if they were symptomatic or were eligible for the national contact-tracing programme (documented contact with an infected person without adequate personal protective equipment). Nevertheless, data from the UK showed that up to 3% of asymptomatic HCWs were infected with SARS-CoV-2.16 According to mathematical models, regular PCR-based screening of HCWs, irrespective of whether they are symptomatic or asymptomatic, could reduce their contribution to transmission by up to 33%.17 This study showed that 93% of patients strongly supported the notion of broad screening programmes for HCWs, irrespective of their demographic, disease-specific or pandemic-specific factors.

HCWs have a significantly high risk of acquiring COVID-19 based on national and international data.19 32 According to some reports, HCWs acquired COVID-19 through nosocomial transmission in up to 29% of reported cases (China, January 2020).19 Thus, effective control of the source of infection is crucial in healthcare facilities. The use of personal protective equipment by HCWs and patients in medical institutions was recommended by their national centres for disease control.21 31 33 A meta-analysis conducted by Iannone et al19 found a significant benefit of wearing masks in mitigating the transmission of SARS-CoV-2. During an infection outbreak, wearing an N95 mask or an FFP-2 respirator cuts the risk of clinical respiratory infections in half among HCWs, compared with wearing only a surgical mask.8 9 Furthermore, protection of HCWs may reduce secondary transmission of the virus and nosocomial infections. During simulation tests of the spread of SARS-CoV-2 droplets/aerosols, medical masks and cloth face coverings were 57%–58% effective in protecting others and 37%–50% effective in protecting the wearer, while the N95/FFP-2 masks were more effective in protecting others (effectivity: 86%–90%) as well as the wearer (effectivity: 96%–99%).10

Limitations

This study has several limitations due to its design (cross-sectional, web-based survey). First, an over-representation of patients worrying about their health status due to their recruitment from support groups and an under-representation of women without online access are two possible sources of bias. Nevertheless, a recent systematic review showed that Facebook-recruited samples were similarly representative as samples recruited via traditional methods.34 35 Furthermore, as the patients responded directly to the questionnaire, social desirability bias was greatly limited. Moreover, as we did not reach the expected number of participants, we potentially may have underestimated the importance of some specific demographic, disease-specific and pandemic-specific factors on expectations regarding the prevention of SARS-CoV-2 transmission, although this is unlikely.

Next, this study was conducted during the first months of 2021. In Germany, the first vaccine against COVID-19 was approved by emergency use authorisation in December 2020 (Comirnaty, BioNTech Manufacturing, Germany), followed by the emergency authorisation of two other vaccines in January 2021 (COVID-19 Vaccine Moderna, Moderna Biotech, USA; Vaxzevria, AstraZeneca Life Science, UK).36 Due to the strict criteria of eligibility for vaccinations in Germany, the COVID-19 vaccines were inaccessible to a large proportion of the population during the time we conducted the survey, even for patients at risk, such as those with active or previous oncological disorders.37 38 We did not assess participants’ vaccination status; however, we presumed that most of them were not vaccinated due to national regulations during the survey period. Thus, we do not know whether the responses accurately depict the current state of the pandemic as expectations may have changed due to the currently available vaccines.

Finally, the obtained results reflected the needs and expectations of women who were at increased risk of breast cancer and ovarian cancer during the COVID-19
pandemic and the results are not necessarily generalisable to other vulnerable groups or to other life adversities.

**Strengths**
The COVID-19 pandemic changed the way patient care is delivered. Strict measures to contain the virus were implemented swiftly by experts in infectious diseases and politicians after the onset of the pandemic. Due to the course of the pandemic, there was no possibility of assessing the needs and expectations of patients before specific hygiene measures were put in place. Our study identified several patient-approved contingency measures for protection of patients and HCWs from COVID-19 infection which are essential in terms of improving staff’s preparedness to cope with the course of this pandemic or similar situations.

The high-risk and vulnerable groups in our study seemed to approve the most vigilant and strict contingency programmes designed to lower the risk of transmission in medical facilities, irrespective of demographic, disease-specific or pandemic-specific factors. Additionally, to our knowledge, this is the first study to assess the wishes of patients with respect to being accompanied by a person of trust during medical appointments during the pandemic. The possibility of being accompanied by a close person seemed to be non-negotiable for most of the participants in the study. Thus, in addition to strict visitation policies for outpatients and rules restricting visitation for hospitalised patients, we also need innovative strategies to maintain and improve the experiences of patients during the COVID-19 pandemic, such as allowing patients to be accompanied by a person of trust provided that they comply with strict precautionary measures, for example, by providing a current negative SARS-CoV-2 test result or proof of immunisation.

As we assessed participants’ needs, fears and expectations, we followed the WHO recommendation for two-way communication with populations at risk.21 Our goal is to improve and optimise public health measures which could be implemented during the next wave of the COVID-19 pandemic or other possible pandemics.

**CONCLUSION**
In conclusion, we showed that most patients at high risk of infection or severe course of COVID-19 approve strict contingency measures such as physical distancing rules, implementation of telemedicine and use of highly effective protective masks designed to lower the transmission of COVID-19 in medical facilities. However, they also value the presence of a significant other during medical consultations and procedures.

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**Contributors** RS and AD conceptualised the study and planned the data analysis, acquired the data, performed data analysis and drafted the manuscript. KS, WB, MS and AH offered substantial intellectual input to analysis and interpretation of data. All authors contributed to the manuscript drafting and approved the final version of the manuscript for publication. RS is the guarantor of the study.

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**Competing interests** RS: honoraria: Roche Pharma, AstraZeneca, streamdup!.
MS: received personal fees from AstraZeneca, BioNTech, Eisai, Lilly, MSD, Novartis, Pantarhei Bioscience, Pfizer, Roche and Seagen; institutional research funding from AstraZeneca, BioNTech, Eisai, Genentech, German Breast Group, Novartis, Palloes, Pantarhei Bioscience, Pierre Fabre and Roche; and travel reimbursement from Pfizer and Roche. In addition, MS is named an inventor on patent EP 2390370 B1 and granted patent EP 2951317 B1. AH: honoraria: AstraZeneca, Cellegene, MedConcept, med update, medicitus, Pfizer, ProMedics, Softconsult, Roche Pharma, streamdup!, Tesaro Bio Germany and LEO Pharma; Ad Board: PharmaMar, ProMedics, Roche Pharma, Tesaro Bio Germany, AstraZeneca, LEO Pharma, MSD and Sharp & Dohme.

**Patient and public involvement** Patients and/or the public were involved in the design, conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

**Patient consent for publication** Not required.

**Ethics approval** This study involves human participants and was conducted in accordance with the Declaration of Helsinki and adhered to the principles of best clinical practices. Prior to data collection, all patients gave their informed consent, allowing us to collect the data and publish the results. Participants’ privacy and confidentiality were guaranteed following German and European laws and regulations. This survey was approved by the ethical review board of the medical association of Rhineland-Palatinate (approval number/reference number 15612).

**Provenance and peer review** Not commissioned; externally peer reviewed.

**Data availability statement** Data are available upon reasonable request. Data are available on reasonable request to bona fide researchers.

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**ORCID iD**
Roxyana Schwab http://orcid.org/0000-0002-1489-0011

**REFERENCES**
How old are you?  [___] years

Do you live in a stable partnership? (Yes – No)

How would you describe your home/private environment?
- Living alone (Yes – No)
- Living with children under 18 years (Yes – No)
- Living with older people (over 65 years) (Yes – No)
- Living with my spouse/life partner (Yes – No)
- others

What is your highest educational qualification?

Are/was you infected by the SARS-CoV-2-virus yourself? (Yes – No)

Is/was someone in your environment infected with the SARS-CoV-2-virus? (Yes – No)

How much, on average, did you reduce your social contact network in the last 12 months due to the covid-19-pandemic?
Not at all – a little – moderate – significant – very much

Questions about your risk of developing breast and/or ovarian cancer

To which risk group do you belong:
- I was diagnosed with a mutation in the BRCA1 or BRCA2 gene
- I was diagnosed with a different mutation (except BRCA1 or BRCA2 gene)
- I have an increased risk due to my family history, but I wasn’t diagnosed with a gene mutation (yet)

Are/was you already suffering from breast and/or ovarian cancer (benign tumors excluded) (multiple selection possible)
- no, I am not/was not previously diagnosed with invasive breast and/or ovarian cancer or the respective premalignant lesions (in situ)
- yes, I am/was diagnosed with insitu breast lesions
- yes, I am/was diagnosed with in situ ovarian/tubal lesions
- I am/was diagnosed with invasive breast cancer
- I am/was diagnosed with invasive ovarian cancer

Below we are interested in your opinion on hygiene measures in clinics during the covid-19-pandemic:
1. Would you have liked to be informed about hygiene protocols in advance of your appointment? *(Yes – No – I don’t know/does not apply)*

2. Would more information about the prevailing hygiene protocols have had a positive influence on your behavior (e.g., meeting appointments)? *Yes – No – I don’t know/does not apply*

3. Do you think that patients should be tested for SARS-CoV-2 infection before an ambulatory visit/appointment? *Yes – No – I don’t know/does not apply*

4. Do you think that medical personnel/physicians should be tested for SARS-CoV-2 infection on a regular basis? *Yes – No – I don’t know/does not apply*

5. Do you think that appointments should be scheduled in such a way to ensure that distancing rules can be strictly observed? *Yes – No – I don’t know/does not apply*

6. Should a relative or a close person be allowed to accompany patients in the healthcare setting, despite the COVID-19 pandemic? *Yes – No – I don’t know/does not apply*

7. Do you think/agree that appointments, which do not require one’s physical presence (e.g., counseling appointments) should be conducted as teleconferences or video conferences during the COVID-19 pandemic? *Yes – No – I don’t know/does not apply*

8. Do you think that medical personnel should at least wear an FFP-1 mask (surgical mask) during the COVID-19 pandemic? *Yes – No – I don’t know/does not apply*

9. Do you think that medical personnel should always wear an FFP-2 mask masks during the COVID-19 pandemic to ensure patients’ safety? *Yes – no – I don’t know/does not apply*