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ARTICLE

Patients' and professionals' perspective of non-in-person visits in hereditary cancer: predictors and impact of the COVID-19 pandemic

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PURPOSE: To identify predictors of patient acceptance of non-in-person cancer genetic visits before and after the COVID-19 pandemic and assess the preferences of health-care professionals.

METHODS: Prospective multicenter cohort study ($N = 578$, 1 February 2018–20 April 2019) and recontacted during the COVID-19 lockdown in April 2020. Health-care professionals participated in May 2020. Association of personality traits and clinical factors with acceptance was assessed with multivariate analysis.

RESULTS: Before COVID-19, videoconference was more accepted than telephone-based visits (28% vs. 16% pretest, 30% vs. 19% post-test). Predictors for telephone visits were age (pretest, odds ratio [OR] 10-year increment = 0.79; post-test OR 10Y = 0.78); disclosure of panel testing (OR = 0.60), positive results (OR = 0.52), low conscientiousness group (OR = 2.87), and post-test level of uncertainty (OR = 0.93). Predictors for videoconference were age (pretest, OR 10Y = 0.73; post-test, OR 10Y = 0.75), educational level (pretest: OR = 1.61), low neuroticism (pretest, OR = 1.72), and post-test level of uncertainty (OR = 0.96). Patients' reported acceptance for non-in-person visits after COVID-19 increased to 92% for the pretest and 85% for the post-test. Health-care professionals only preferred non-in-person visits for disclosure of negative results (83%).

CONCLUSION: These new delivery models need to recognize challenges associated with age and the psychological characteristics of the population and embrace health-care professionals' preferences.

Genetics in Medicine (2021) 23:1450–1457; <https://doi.org/10.1038/s41436-021-01157-2>

INTRODUCTION

The worldwide pandemic caused by coronavirus SARS-CoV-2 led to the implementation of lockdown in many Western countries. Health-care models have needed to adjust to allowing for social distancing, travel restrictions, and limits imposed on health-care resources.

Hereditary cancer units have a multidisciplinary composition mainly comprised of physicians, nurses, and genetic counselors. In their daily clinical practice, they offer visits to provide cancer risk assessment and genetic testing, disclose testing results, and evaluate the suitability of early detection strategies or prophylactic options. Traditionally, in-person visits were performed by health-care providers. However, due to the increasing demand for genetic testing, and the need for a rapid turnaround, a gradual implementation of innovative delivery models has emerged. On one hand, *mainstreaming* genetic testing has been evaluated as part of the medical oncology visits,^{1–3} while the feasibility of non-in-person visits has been tested to ease and expand access to cancer genetic counseling services.^{4–8} Since the COVID-19 outbreak, telephone contact with patients has been universally used by health-care professionals to maintain a partial continuity with them. Scientific oncology societies have recommended avoiding in-person visits during the lockdown and encourage the use of

telemedicine especially for stable patients and those with oral therapies.⁹

Telephone and videoconference-based genetic counseling alternatives (also called telegenetics) provide remote genetic counseling by telephone or videoconference, instead of the traditional in-person face-to-face approach.¹⁰ These methods are helpful to overcome time or distance constraints, and while both share the characteristic of being a non-onsite contact, they differ in other features, such as the face-to-face communication or the skills needed for use of technology.

A new scenario of e-health medicine is being proposed worldwide. Non-in-person medicine is progressively being implemented, which could also be an opportunity to expand genetic services and approach more people according to their needs. Therefore, we aimed to investigate whether non-in-person genetic visits in hereditary cancer were perceived as an acceptable option by patients, as well as considered a useful delivery model for health-care professionals. We hypothesized that the lockdown caused by the SARS-CoV-2 pandemic would change the acceptance of non-in-person cancer genetic testing consultations among patients. This study aimed to (1) compare patients' reported acceptance of non-in-person cancer genetic counseling visits before and after the lockdown, (2) identify predictors of acceptance of telephone and videoconference-based visits, and

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(3) assess hereditary cancer professionals' experiences and preferences regarding non-in-person visits.

MATERIALS AND METHODS

Participants

Participants were recruited from the ARPA cohort, a prospective multi-center longitudinal study enrolling individuals undergoing cancer susceptibility genetic testing in five hereditary cancer units from the Hereditary Cancer Catalan Network. The ARPA study collects demographic, clinical, genetic, and psychological data at baseline; after results disclosure; and 3 and 12 months after results disclosure. All participants underwent in-person pretest (T0) and results disclosure visits (T1) within two years before the COVID-19 pandemic started (1 February 2018, and 30 April 2019). This cohort was recontacted during the COVID-19 lockdown (T2) in April 2020 for a cross-sectional subanalysis. The study was approved by each center's institutional review board (IRB) and all participants signed the informed consent before enrollment. Data were de-identified except to the study investigators. The study followed the Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) statement.¹¹

Health-care professionals working in hereditary cancer from the Spanish Society of Medical Oncology (SEOM), the Spanish Society of Genetic Counselors (SEAGen), and the Spanish Society of Gastroenterology (AEG) were invited to participate in May 2020.

Measures

Patients' data were taken from database registries in each recruiting center. Patients were visited in their referral center, which is usually less than 80 km from their home address. Variables and outcomes were collected or measured after the pretest in-person genetic counseling testing visit (T0), after the in-person results disclosure visit (T1), and during the lockdown caused by the COVID-19 pandemic (T2) (Supplementary Fig. 1).

Patients' reported acceptance and psychological scales. Validated scales and customized questionnaires were used to assess participants' psychological characteristics and reported acceptance of non-in-person visits. Questionnaires were delivered via the REDCap platform the day after the pretest (T0) and the results disclosure (T1) visits and during the lockdown (T2).

Acceptance of telephone- and videoconference-based genetic counseling visits were assessed by a customized questionnaire with four items collected at T0, T1, and T2. Overall acceptance of non-in-person visits were defined as the acceptance of at least one of the two proposed delivery models.

Personality traits were assessed baseline (T0) by the Spanish validated version of the NEO Five-Factor Inventory (NEO-FFI).¹² Cancer worry (6 items) was measured baseline (T0) and in the post-test genetic counseling session (T1) by the Spanish validated version of the Cancer Worry Scale (CWS).¹³ Uncertainty derived from genetic testing was assessed by the uncertainty subscale from the Spanish version of the MICRA scale (T1).¹⁴

Professionals' experiences and preferences for non-in-person visits. Previous experiences and preferences for non-in-person visits were assessed by a 13-item customized questionnaire at T2 via the REDCap platform.

Genetic counseling and testing

All participants received genetic counseling with a genetic counselor, or a genetics nurse accredited with the European Board of Medical Genetics. Genetic counseling sessions were based on models that intended to maximize patient understanding of issues addressed in the consultation.¹⁵ Genetic testing for inherited cancer risk was offered to all participants fulfilling the clinical criteria according to local guidelines¹⁶ or as predictive testing in families with a known pathogenic variant. Positive results were considered when a pathogenic or likely pathogenic variant was identified. If no pathogenic variant or variant of unknown significance was identified the result was considered as negative. Single predictive testing was offered to individuals belonging to a family with a known pathogenic variant.

Statistical analysis

The sample size was based on the availability of at least recruiting 350 patients in a 14-month period rather than in a formal hypothesis testing.

A descriptive analysis was carried out to summarize participants' characteristics. Categorical variables were expressed as absolute values and percentages, and continuous variables as median with interquartile range (IQR). Categorical variables were compared using the Fisher's exact test. Univariate logistic regression models were carried out to study predictors of the acceptance of non-in-person visits and to estimate odds ratio (OR) with 95% confidence interval (CI). To select variables with the highest impact, we performed a least absolute shrinkage and selection operator (LASSO) regression using package *glmnet* in R software to build the multivariate model. We investigated significant interactions between the acceptance of telephone or videoconference visits and the study variables ($P < 0.05$ according to analysis of variance [ANOVA] test). All analyses were performed using R statistical software version 4.3.6.2.

RESULTS

A total of 760 patients were enrolled in the main study cohort. Of these, 182 were excluded (24%) for two reasons: (1) genetic testing results had not been disclosed at the data cutoff for this analysis ($n = 106$, 14%), (2) patient withdrawn the consent form ($n = 76$, 10%). Overall, 578 patients (76%) completed the baseline (T0) and the post-test (T1) procedures. Of these, 439 (77%) participated in the analysis during the COVID-19 lockdown (T2) (Supplementary Fig. 2). Participants' median age at inclusion was 48.2 (IQR = 39–58), 75% of them were female. Half of the participants (54%) had a cancer diagnosis, mainly breast (64%), ovarian (15%), or colorectal cancer (6%). Overall, 55% of individuals underwent panel testing and 45% a single-gene predictive test. No significant differences in clinical characteristics were observed between the T0/T1 and T2 study populations (Table 1).

Patients' acceptance of non-in-person visits before and after the COVID-19 lockdown

Before the COVID-19 pandemic, 31% and 34% of patients reported that they would have accepted non-in-person visits for the pretest and the results disclosure, respectively. During the lockdown, the proportion of patients who reported that they would accept non-in-person visits after the COVID-19 lockdown increased to 92% for the pretest and to 85% for the results disclosure visit (p value < 0.001) (Fig. 1).

Predictors of patients' reported acceptance of telephone and videoconference-based visits

Before the COVID-19 pandemic, the patients' reported acceptance was higher for the videoconference-based visits compared with the telephone-based visits, both in the pretest (28% for videoconference and 16% for telephone visits) and the results disclosure visits (30% for videoconference and 19% for telephone visits). After the COVID-19 lockdown, the reported acceptance rate for pretest videoconference and telephone visits was 80% and 81%, respectively. For results disclosure visits, the rate was 74% for videoconference and 70% for telephone (Supplementary Fig. 3).

Figure 2 shows that age was the only predictor for pretest telephone-based visits at multivariate analysis (OR per 10-year increment = 0.79 [0.65–0.96], $p = 0.02$), while for results disclosure visits, age (OR = 0.78 [0.65–0.92], $p = 0.004$), panel testing (OR = 0.60 [0.37–0.96], $p = 0.04$), positive results (OR = 0.52 [0.29–0.91], $p = 0.03$), conscientiousness group (low vs. high OR = 2.87 [1.55–5.64], $p = 0.001$), and levels of uncertainty related to the genetic results (OR = 0.93 [0.88–0.97], $p = 0.002$) were the main predictors of telephone visit acceptance. In the multivariate analysis for videoconference-based visits, age (OR = 0.73 [0.62–0.85], level of education (OR = 1.61 [1–2.62], $p = 0.05$), and the neuroticism group (low vs. high OR = 1.72 [1.06–2.79], $p = 0.03$) predicted acceptance of a non-in-person pretest visit, while age (OR = 0.75 [0.65–0.87], $p < 0.001$), extraversion group (medium vs. high OR = 0.59 [0.36–0.99], $p = 0.04$), and levels of

Table 1. Demographic, clinical, and psychological characteristics of the patients participating in the study.

	Before the COVID-19 pandemic (T0 and T1) N = 578	During the COVID-19 pandemic (T2) N = 439
Demographics	n (%)	n (%)
Gender		
Female	433 (74.9)	333 (75.9)
Male	145 (25.1)	106 (24.1)
Age at inclusion (years)	48.2 [39–58] ^a	46.7 [39–55] ^a
Age at inclusion (group)		
<30	57 (9.9)	43 (9.8)
31–40	115 (19.9)	96 (21.9)
41–50	171 (29.6)	148 (33.7)
51–60	123 (21.2)	90 (20.5)
61–70	79 (13.7)	45 (10.2)
>70	33 (5.7)	17 (3.9)
Level of education		
High school or more	495 (85.6)	319 (72.7)
Up to secondary school	83 (14.4)	120 (27.3)
Partner		
Yes	443 (76.6)	328 (74.7)
No	135 (23.4)	111 (25.3)
Clinical characteristics	n (%)	n (%)
Cancer diagnosis		
Yes	312 (54)	236 (53.8)
No	266 (46)	203 (46.2)
Number of cancers		
cancer	249 (43.1)	190 (43.2)
Multiple cancers	63 (10.9)	46 (10.5)
Type of first cancer		
Breast cancer	201 (64.5)	160 (67.8)
Ovarian cancer	46 (14.7)	27 (11.4)
Colorectal cancer	20 (6.4)	16 (6.8)
Other cancer	45 (14.4)	33 (14)
Type of genetic test		
Single PV testing	259 (44.8)	197 (44.9)
Panel testing	319 (55.2)	242 (55.1)
Genetic test results		
No PV detected	432 (74.7)	328 (74.7)
PV detected	146 (25.3)	111 (25.3)
Psychological characteristics	n (%)	n (%)
Cancer worry		
Baseline	11.2 [9–13] ^a	11.1 [9–13] ^a
Post-test	10.9 [8–12.75] ^a	10.8 [9–12] ^a
Post-test uncertainty	6.3 [2–9] ^a	6.2 [2–9] ^a
Personality traits		
Neuroticism		
High	326 (56.4)	244 (55.6)
Medium	145 (25.1)	107 (24.3)
Low	107 (18.5)	88 (20.1)

Table 1 continued

	Before the COVID-19 pandemic (T0 and T1) N = 578	During the COVID-19 pandemic (T2) N = 439
Extraversion		
High	114 (19.7)	84 (19.1)
Medium	193 (33.4)	153 (34.9)
Low	271 (46.9)	202 (46)
Openness		
High	143 (24.7)	123 (28)
Medium	192 (33.2)	141 (32)
Low	243 (42.1)	175 (40)
Agreeableness		
High	141 (24.4)	112 (25.5)
Medium	196 (33.9)	153 (34.9)
Low	241 (41.7)	174 (39.6)
Conscientiousness		
High	125 (21.6)	96 (21.9)
Medium	135 (23.4)	106 (24.1)
Low	318 (55)	237 (54)

PV pathogenic variant.
^aMedian [IQR].

uncertainty caused by the test result (OR = 0.96 [0.92–0.99], $p = 0.04$) predicted non-in-person visits for results disclosure (Fig. 3 and Supplementary Table 1).

Hereditary cancer professionals' experiences and opinions regarding non-in-person visits

A total of 106 professionals responded to questions about previous experiences and preferences of non-in-person visits. Most of them were physicians (72%), followed by genetic counselors (20%) and nurses (8%). Over half of the participants admitted not having videoconference technologies in their offices at the time of the survey (67%) (Supplementary Table 2). Before the COVID-19 pandemic, telephone and videoconference approaches were used by a minority of professionals in pretest visits (21% for telephone and 2% for videoconference) and in result disclosure visits (40% for telephone and 3% for videoconference) (Supplementary Table 3).

Regarding professionals' preferences after the COVID-19 lockdown, in-person visits were reported as the preferred option for pretest counseling and disclosure of a positive or variant of unknown significance result by 77%, 95%, and 57% of professionals, respectively (Supplementary Fig. 4). In-person visits were indicated as more preferred than telephone-based visits in all scenarios, except in disclosure of a negative genetic test result. For negative results, videoconference-based visits were preferred by 43% of professionals, followed by 40% who preferred them by telephone. For visits related to results of early detection surveillance, percentages of preferences were 32% for in-person visits, 30% for telephone, and 37% for videoconference.

DISCUSSION

These data resulting from a multicenter cohort study demonstrate that the COVID-19 pandemic sharply increased patients' reported acceptance of non-in-person visits in the hereditary cancer setting.

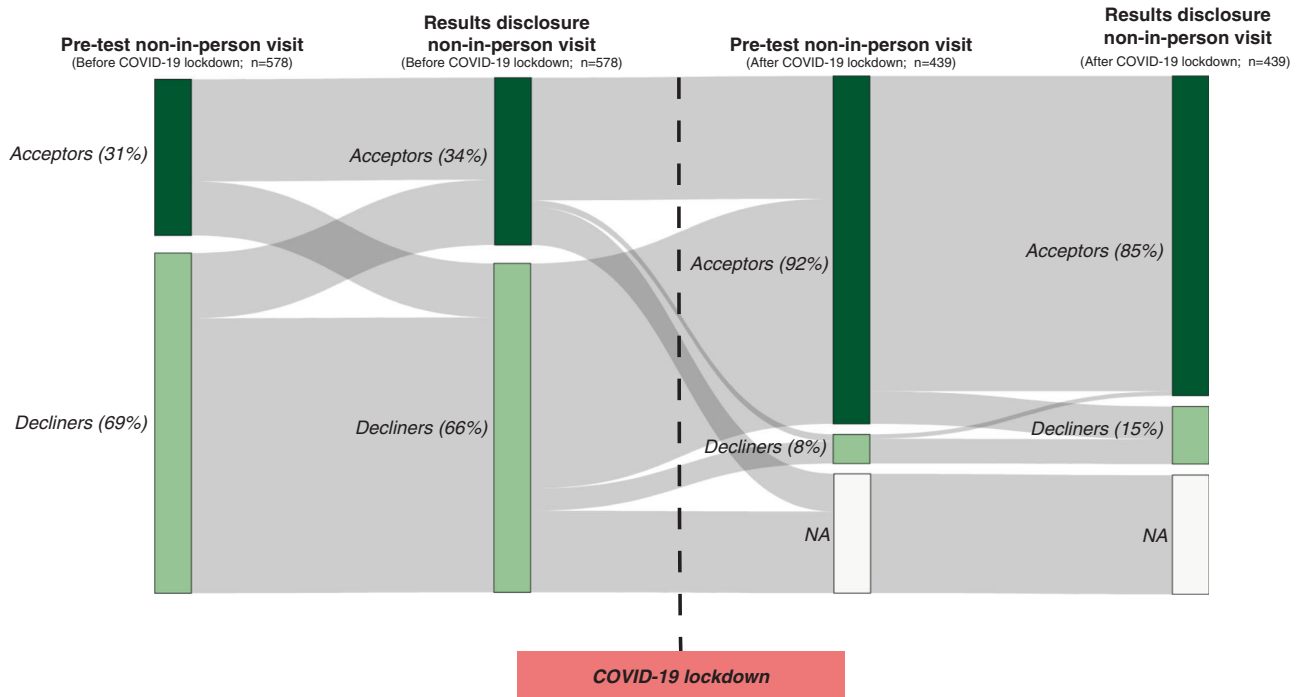


Fig. 1 Evolution of patients' reported acceptance of non-in-person visits before and after the lockdown caused by COVID-19. Acceptors (dark), decliners (light) of non-in-person visits.

Our study also provides a supplementary view of these delivery models according to the professionals' preferences, who are more likely to perform in-person visits, especially for potentially complex results and the pretest counseling visit. This study compares patients' reported acceptance of non-in-person visits before and after the COVID-19 pandemic lockdown and identifies professionals' preferences of these models after the lockdown.

The results show that in our setting, patients were reluctant to accept non-in-person visits before the COVID-19 pandemic. The reported disavowal of hereditary cancer non-in-person visits before the pandemic was high, since 2 of 3 individuals reported to decline these types of visits. This reluctance is not consistent with other studies, such as the one carried out in a US population, where the majority of patients (82%) agreed to be randomized to in-person versus telephone-based results visits.¹⁷ Cultural background and physical proximity to the public health-care system may explain these differences.

Not surprisingly, the acceptance rate drastically increased after the pandemic. Data of T2 was collected during the lockdown (April 2020) and investigated the intended acceptance once the lockdown had ended. Subsequently, overall health concern during the COVID-19 lockdown rose as a new factor that modified decision-making related to approaching medical centers for issues not directly related to emergencies or COVID-19. It seems reasonable to presume that social perception of being infected by SARS-COV2 will decrease, and these rates of acceptance will reach a plateau in the future.

We aimed to identify the predictors for non-in-person visits, differentiating telephone from videoconference-based visits. Analyses were performed with the data obtained before COVID-19 lockdown (T0 and T1) to avoid that pandemic risk perception would have biased the results. In addition to substantial physical distance, traditional predictors of non-in-person visits were age and disclosure of multiplex panel testing results.¹⁷ In our work, we hypothesized that other individual features, such as the personality traits of the person undergoing germline genetic testing, could be relevant in predicting the acceptance of non-in-person visits.

For pretest visits, young age was the only predictor associated to acceptance of telephone-based visits, while a high level of education and belonging to a low neuroticism group foresaw videoconference visits. Regarding results disclosure visits, some interesting differences were observed between telephone and videoconference visits. Young age and a low score in uncertainty derived from the genetic test were associated with accepting these two types of visits, while individuals undergoing single pathogenic variant testing (versus multiplex panel testing) and receiving a negative test result reported a higher acceptance of telephone-based visits. Interestingly, individuals belonging to a low conscientiousness group were also more prone to telephone-based visits. Nevertheless, this last predictor disappeared for videoconference-based visits. To sum up, individuals belonging to a low conscientiousness group, as well as individuals belonging to a low neuroticism group, were more interested in non-in-person visits. People with low levels of neuroticism have a tendency toward greater emotional stability when facing significant challenges.¹⁸ In contrast, high scores in neuroticism impair the ability to address difficulties,¹⁹ and these individuals may need more emotional and communication skill resources to address counseling issues related to hereditary cancer. On the other hand, conscientious individuals are good at self-regulation, they prefer scheduling and planning, and they are considered diligent and careful.²⁰ Thus, either individuals with a tendency toward emotional stability and a high tolerance of stress, or individuals with high flexibility who are easygoing (i.e., scoring low in neuroticism or conscientiousness, respectively) may be more prone to accept non-in-person contact with a health-care provider. Identifying those individuals may help health-care professionals to foresee the response when offering non-in-person results disclosure visits to their patients. Videoconference allows patients and health-care professionals to use and interpret the body language and simulates an in-person consultation. Therefore, it is reasonable that low conscientiousness only predicted acceptance to telephone-based results disclosure visits.

Among the health-care professionals in our study, the majority preferred in-person visits (despite the COVID-19 pandemic),

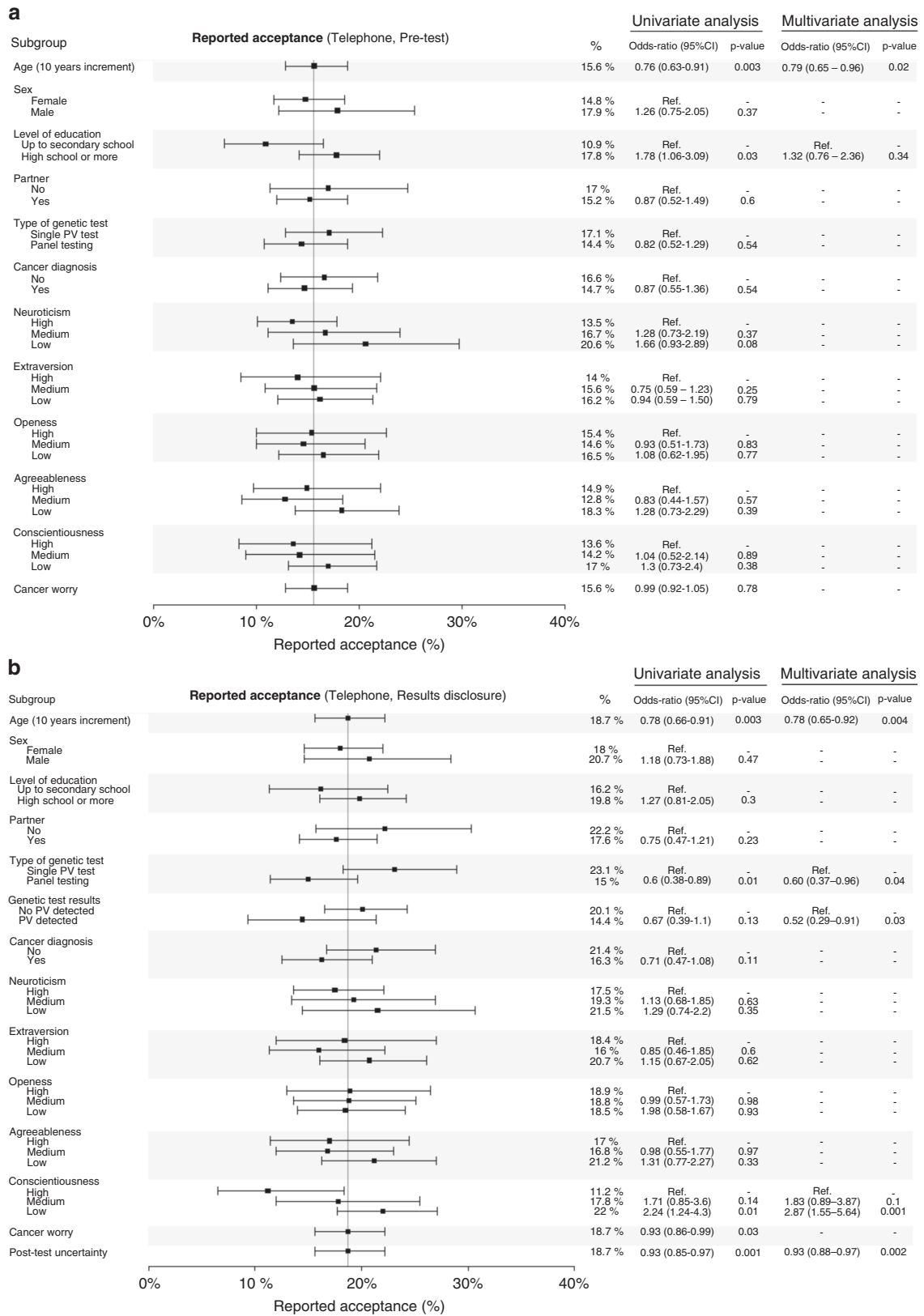


Fig. 2 Univariate and multivariate analyses of predictors of reported acceptance to pretest and result disclosure telephone-based visits, before the COVID-19 pandemic (N = 578). a pretest and **b** result disclosure telephone-based visits. The percentage of acceptance with 95% CI is plotted for each variable. Odds ratio with 95% CI and p-values were calculated using the logistic model. PV pathogenic variant.

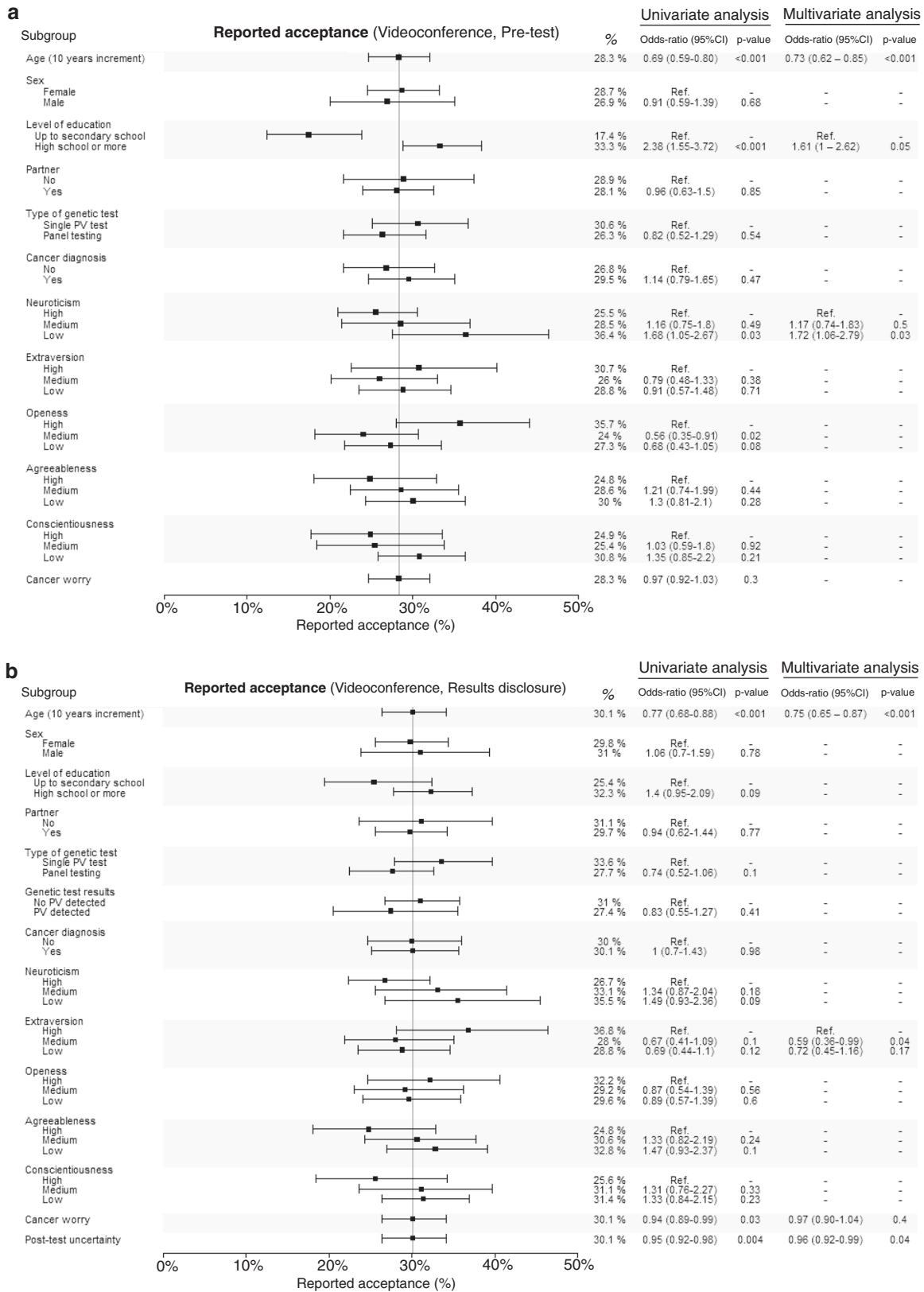


Fig. 3 Univariate and multivariate analyses of predictors of reported acceptance to pretest and result disclosure videoconference-based visits, before the COVID-19 pandemic (N = 578). **a** pretest and **b** result disclosure videoconference-based visits. The percentage of acceptance with 95% CI is plotted for each variable. Odds ratio with 95% CI and p-values were calculated using the logistic model. PV pathogenic variant.

especially for pretest visits and disclosure of positive results. Telephone contact was considered a good approach for negative results. It is worth highlighting the magnitude of the difference in acceptance of non-in-person visits between patients and health-care providers post-COVID-19 lockdown. Therefore, health-care providers may need to adjust their preferences to better align with patients' needs. Considering patients' acceptance rates and professionals' viewpoints, videoconference seems to be an adequate approach to satisfy the current needs while preserving face-to-face interaction. Videoconference approaches have been implemented recently to facilitate access to genetic services^{21–25} and during the lockdown to maintain routine clinical assistance in hereditary cancer services.²⁶

We acknowledge some limitations. First, this study shows the reported patients' acceptance of non-in-person visits, but it is not designed to analyze the outcomes of non-in-person genetic visits since all patients were attended to in-person. Secondly, the study was performed in a setting where non-in-person medicine was not common before the pandemic; therefore, acceptance rates and predictors identified in our population may be different in other populations and in the near future. Finally, the study was conducted within a national health system in which patients are not charged with direct costs according to the type of visit. Therefore, this may limit the extrapolation to other health systems.

Applicability

This study assessed the opinion of telephone and videoconference visits at different times of the genetic counseling process in hereditary cancer units. The results reveal the importance of face-to-face contact between health-care professionals and patients, which can be supported by videoconference visits. Based on patients' acceptance and professionals' preferences reported in this study, a customized approach to new genetic delivery models would embrace videoconference visits for young populations, and consign telephone visits only to disclosure of negative results or those associated with a low level of uncertainty.

Future research

It will be essential to assess patients' opinions on non-in-person visits once the overall effects of the pandemic are over. Further studies validating the role of personality traits of individuals undergoing genetic testing to assess the psychological impact of genetic results are warranted. With results of this further research, we will be able to personalize the indication of resources to patients' characteristics.

Conclusion

Age, personality traits, type of genetic testing, and results predicted acceptance to non-in-person visits. After the COVID-19 pandemic lockdown, patients' acceptance of non-in-person visits increased overall almost threefold, with videoconference visits being more accepted than telephone visits. On the other hand, health-care professionals continue to favor in-person visits, except for negative results. Adjustments in e-health models need to incorporate patients' requirements and recognize potential challenges faced by health-care professionals.

DATA AVAILABILITY

All data and methods used in the analysis are described or included in this article and the electronic supplementary information. Raw data is available upon request.

Received: 30 November 2020; Revised: 10 March 2021; Accepted: 12 March 2021;
Published online: 6 April 2021

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ACKNOWLEDGEMENTS

This study was supported by the Carlos III National Health Institute and Ministerio de Educación y Ciencia grant (P116/01363); and CERCA Programa/Generalitat de Catalunya for institutional support (J. Balmaña).

AUTHOR CONTRIBUTIONS

Conceptualization: A.L.-F., J. Balmaña Data curation: A.L.-F., S.T.-E., M.T. Formal analysis: G.V., A.L.-F. Funding acquisition: J. Balmaña. Investigation: A.L.-F., J. Balmaña, G.V. Methodology: A.L.-F., J. Balmaña, G.V. Project administration: A.L.-F. Resources: E.G., M.S., E.D., E.C., S.I., A.S., N.G., A.V., G.U., N.T. Software: S.T.-E. G.V. Supervision: J. Balmaña, J. Brunet. Validation: A.L.-F., J. Balmaña. Visualization: A.L.-F., G.V. Writing: A.L., G.V. Writing—review & editing: J. Balmaña, J. Brunet, S.C.

ETHICS DECLARATION

This study was reviewed by the Institutional Review Board of Hospital Universitari Vall d'Hebron, Hospital Universitari de Bellvitge, Hospital Universitari Germans Trias i Pujol, and Hospital Universitari Josep Trueta. All individuals participating in the study properly signed the informed consent according to the Institutional Review Board. All clinical data were de-identified before the analysis.

COMPETING INTERESTS

The authors declare no competing interests.

ADDITIONAL INFORMATION

Supplementary information The online version contains supplementary material available at <https://doi.org/10.1038/s41436-021-01157-2>.

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