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Attitudinal concordance toward uptake and disclosure of genetic testing for cancer susceptibility in patient–family member dyads

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Decisions for cancer susceptibility genetic testing (CSGT) uptake and dissemination of results occur within the family context. A national survey was performed with 990 patient–family member dyads (participation rate:76.2%), with paired questionnaires examining attitudes toward CSGT uptake and disclosure of results in response to a hypothetical scenario in which a reliable CSGT was available for the specific cancer a patient was being treated. While most patients and family members responded they would uptake or recommend CSGT if available, concordance between the dyads was poor for both patient's testing (agreement rate 77.5%, weighted $\kappa = 0.09$) and first-degree relatives' testing(agreement rate 78.0%, weighted $\kappa = 0.09$). Most patients (93.2%) and family members (92.9%) indicated that patients should disclose positive CSGT results to family members, with dyadic agreement of 89.1% ($\kappa = 0.15$). However, there were substantial disagreement regarding when disclosure should take place, who should make the disclosure (the patient or the health care professionals), and to whom the results should be disclosed. Patients and family members may hold different attitudes toward CSGT uptake of and disclosure of results within the family. Our findings reinforce the need for a family system approach to incorporate perspectives of patients as well as their family members.

Conflict of interest

None.

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Genetic predisposition has a major role in the development of many types of cancer, and recent advances in genetic technology have made cancer susceptibility genetic testing (CSGT) available. Efficacy of screening and prevention in mutation carrier has been demonstrated in hereditary breast and ovarian (1, 2), colon (3, 4), thyroid (5), and other cancers (6), and therefore, CSGT has a potential to benefit the family member by identifying those at high risk and motivating them to adopt preventive measures (7, 8).

Genetic information is personal – yet simultaneously familial (9); decisions for CSGT uptake and dissemination of results occur within family context (10, 11). Family history suggestive of a genetic cancer susceptibility is a prerequisite for clinical testing (12). Family members often request genetic testing (13), and family duty and responsibility was among the most frequently stated reasons that patients reported for having CSGT (10, 13–15). Family members who witness a patient's illness report is motivated to participate in CSGT (10, 16), and the identification of a mutation in one member of a family often motivates others to also have testing (12). Positive and negative family impact is the most important consideration noted by patients in the decision to test or not (14) and to disclose the test results to others (17, 18). Health care professionals (HCPs) also face challenges in regard to disclosure in the form of truth-telling *vs* confidentiality when a patient requests non-disclosure of positive results to family members (6, 19, 20).

Patients and family members may hold different attitudes toward CSGT uptake and disclosure of results, and these differences may lead to tensions and communicational conflict (21, 22). According to the family communication patterns theory, agreement, i.e. similarity between two or more persons' perceptions of an object, is one of the factors which determines co-orientation of the family, which in turn underlie the communication behaviors and practices of families that are consequently associated with various family outcomes (23). It may also lead to ethical and legal dilemmas for HCPs (9).

In light of the familial nature of genetic information, a number of questions regarding genetic communication within family context are likely to arise and relatively little is known about this aspect of family dynamics (24, 25). For instance, the extent to which patients and family members agree that CSGT should take place at all, who should be responsible for disclosure of test results to family members is not clear. In addition, little is known about patient's preferences regarding the role that HCPs should play in disclosing test results to family members; when the disclosure should occur, and to whom in a family the information should be disclosed.

Despite the importance of these questions, there have been few studies specifically addressing family communication regarding CSGT (11, 26) and many of these have been limited by small samples, collected in single practices, and characterized by qualitative study designs (10, 14, 18, 21, 24, 27). The purpose of this study was to contribute to this literature by conducting a nationwide study of cancer patients and their family members to better understand their varying perspectives on CSGT, using hypothetical vignettes.

Method

This study was conducted as part of The National Survey of Cancer Patient Experience (CaPE) Study, a large nationwide survey that explored medical care and treatment views of cancer patients and their family members. The National Cancer Center and the nine government-designated Regional Cancer Centers in Korea participated in the survey. The study was approved by the institutional review board of the National Cancer Center, Korea.

Patients accompanied by family members in outpatient waiting areas or in inpatient wards were recruited by study interviewers who explained the survey purpose and procedures. Inclusion criteria for patients were: (1) being over 18 years of age, (2) having a cancer diagnosis, (3) currently receiving cancer treatment or follow-up care, and (4) being in sufficient physical and mental

health to complete the study questionnaire. Inclusion criteria for family members were: (1) being an accompanying family member of a cancer patient (2) over 18 years of age.

Patient–family member dyads were enrolled when both the patients and family members agreed to participate. We approached 1299 dyads and enrolled 990 (participation rate = 76.2%). Consenting patients and their family members were instructed to independently complete study questionnaires in a separate area to avoid consultation or sharing of information. Medical information including primary cancer diagnosis, the Surveillance, Epidemiology, and End Results (SEER) stage, and time since cancer diagnosis were retrieved from hospital information systems of the participating centers.

Measures

Linked patient and family member questionnaires were developed with the specific intent to examine respondent concordance in regard to CSGT uptake and disclosure of results in response to a hypothetical scenario in which a reliable CSGT was available for the specific cancer the patient was being treated (Appendix S1). Patients were asked whether they would undergo the test (15) and family members were asked whether they would recommend the patient to undergo the test (28). Response options were on a 4-point ordinal scale (1: no, 2: not likely, 3: likely, and 4: definitely). Family members were classified as first degree relatives (siblings and children) and others (spouse, son/daughter in laws, etc.). First degree relatives were asked if they would undergo the test themselves and patients were asked if they would recommend the test to the family members. In addition, a nine-item questionnaire was administered measuring perceived benefits of CSGT based on previous literature using 5-point ordinal scale (1: strongly disagree and 5: strongly agree) and demonstrated adequate reliability (Cronbach's alpha = 0.82 for patients and 0.84 for family members; Table A1) (15, 29–31). Respondents were also asked a question regarding attitudes toward patient autonomy in the decision of CSGT uptake ('whether to take a cancer genetic test should be decided solely by the patient'.) in 4-point ordinal scale (1: strongly disagree and 4: strongly agree).

Regarding disclosure, both patients and family members were asked to report their preferences for whether patients should disclose positive test results (i.e. carrier of a specific mutation) to family members (32), and if they should, when disclosure should take place (25–27, 33), who should make the disclosure (the patient or the HCP) (21, 27, 33), and to whom the results should be disclosed (8, 17, 26, 34). In addition, participants were asked about their feelings in regard to the HCP's duty to warn patients' relatives about possible genetic risk (6, 19, 32, 35, 36). The questionnaire was reviewed by a group of experts in survey research methodology and communication, and was piloted among 30 cancer patients and their family members.

The 18-item Cancer Communication Assessment Tool for Patients and Families (CCAT-PF) scale (37) was administered to examine the association of dysfunctional family communication with CSGT uptake and disclosure. Standard translation and back translation practices were used and the scale was validated in a Korean population (Cronbach's alphas = 0.88 for patients and 0.92 for family members;.manuscript in preparation).

Statistical analyses

Responses to the hypothetical scenario in terms of CSGT uptake were cross-tabulated and patient–family member concordance was examined by percentage agreement and weighted kappa statistics. Percentage agreement was calculated as dichotomized responses (definitely, likely *vs* not likely, never). Responses of patients and family members to the disclosure of positive CSGT results were arrayed and examined by McNemar's tests and kappa statistics, respectively.

A series of multivariate logistic regression analyses were performed to identify the factors associated with patient and family member agreement in regard to CSGT uptake and disclosure (yes *vs* no). All related predictor variables (i.e. age, gender, education level and patient disease stage), family member's relationship to the patient (first-degree relatives *vs* others), and the CCAT-PF score were included in the models. Statistical analyses were conducted using STATA version 12.0 (STATA corp., College Station, TX), and p-value <0.05 was considered statistically significant.

Results

Baseline characteristics

Table 1 shows the sociodemographic and health status characteristics of the study participants. More than half (54.9%) of family members were spouses, 18.7% were adult children, and 4.2% were a sibling of the patient.

Patient and family member responses regarding CSGT uptake

Most patients (87.2%) reported that they would want CSGT if available, and most family members (85.8%) reported they would recommend it to the patients. Complete agreement and agreement as dichotomized between patients and family members were 43.7% and 77.5%, respectively, and the dyadic concordance was poor (weighted $\kappa = 0.09$; Table 2).

Similarly, most patients (91.6%) reported they would recommend it to their first degree relatives, and most family members (83.3%) reported their willingness to take the test (Table 3). Complete agreement and agreement as dichotomized between patients and first degree relatives were 45.4% and 78.0%, and the dyadic concordance overall was poor (weighted $\kappa = 0.06$).

Table 1. Characteristics of patient–family member dyads

Patient characteristics	*N*	%	Family member characteristics	*N*	%
Age, mean (SD)	59.5 (12.9)		Age, mean (SD)	50.0 (14.5)	
Sex			Sex		
Male	459	46.4	Male	375	37.9
Female	531	53.6	Female	615	62.1
Marital status			Marital status		
Married	820	82.8	Married	793	80.1
Unmarried	169	17.1	Unmarried	197	19.9
Missing	1	0.1	Missing	0	0.0
Educational status			Educational status		
Less than high school (<9 years)	454	45.9	Less than high school (<9 years)	246	24.8
High school (9–12 years)	299	30.2	High school (9–12 years)	349	35.3
College and above (>12 years)	233	23.5	College and above (>12 years)	391	39.5
Missing	4	0.4	Missing	4	0.4
Income status			Income status		
<2 million KRW	574	58.0	<2 million KRW	465	47.0
≥2 million KRW	406	41.0	≥2 million KRW	520	52.5
Missing	10	1.0	Missing	5	0.5
Cancer type			Relationship to patient		
Stomach	111	11.2	Spouse	544	54.9
Lung and bronchus	108	10.9	Son/daughter	185	18.7
Liver	47	4.7	Son/daughter-in-law	47	4.7
Colorectal	163	16.5	Parents	146	14.7
Breast	226	22.8	Siblings	42	4.2
Cervix and uterus	58	5.9	Others	14	1.4
Others	277	28.0	Missing	12	1.2
SEER cancer stage (current)			Living with patients		
In situ and local	279	28.2	Yes	737	74.4
Regional	377	29.8	No	253	25.6
Distant	383	38.7			
Unknown	33	3.3			
Time since diagnosis, year, mean (SD)	1.6 (2.3)				
<1 year	594	60.0			
1–5 year	327	33.0			
>5 year	69	7.0			
Current treatment status					
Under initial treatment	562	56.8			
On regular follow-up after treatment	196	19.8			
On regular follow-up after cure	26	2.6			
Under treatment for metastasis or recurrence	198	20.0			
Do not know	4	0.4			
Others (e.g. treatment for second primary cancer, etc.)	4	0.4			

SEER, surveillance, epidemiology, and end results; KRW, Korean Won.

Both patients and family members had similarly positive attitudes toward CSGT (mean scores 4.17 and 3.97, respectively), however, the correlations between the dyads were weak (0.23 for scale). Patients (82.5%) were more likely agree with the autonomous decision of CSGT uptake than family members (70.0%). The dyadic concordance was poor (weighted $\kappa = 0.09$).

Patient and family member responses regarding CSGT disclosure

Most patients (93.2%) and family members (92.9%) responded that patients should disclose positive CSGT results to family members, with dyadic agreement of 89.1% ($\kappa = 0.15$). While the majority of patients (74.0%) and family members (68.9%) preferred that disclosure occur immediately after the patient received results, dyadic concordance was low ($\kappa = 0.20$). While the majority of patients (66.8%) and family members (56.9%) answered that they should disclose test results themselves, dyadic agreement on this question was only 58.5% ($\kappa = 0.13$). Most patients (90.0%) and family members (86.6%) responded that children should be informed, but there was less endorsement that siblings, nephews/nieces, and parents should receive test results. Dyadic agreement ranged from 61.2% to 83.4% ($\kappa = 0.18–0.23$). Two thirds of patients and

Table 2. Concordance in attitudes toward patient's uptake of genetic test in hypothetical situation between patients and their family members[a]

Patient's willingness to uptake genetic test	Family member's willingness to recommend patient to uptake genetic test						Concordance between dyads	
	Never	Not likely	Likely	Definitely	Missing	Total	Weighted κ	p-Value
Never	5	5	15	22	0	47 (4.7)		
Not likely	2	10	39	24	0	75 (7.6)		
Likely	14	35	155	132	0	336 (33.9)		
Definitely	25	44	195	263	0	527 (53.2)		
Missing	1	0	3	1	0	5 (0.5)		
Total	47 (4.7)	94 (9.5)	404 (41.1)	442 (44.6)	0 (0.0)	990 (100)	0.09	<0.001

[a]Complete agreement (on diagonal) = 433 (43.7%). Agreement as dichotomized (shaded area) = 767 (77.5%).

Table 3. Concordance in attitudes toward first degree relatives' uptake of genetic test in hypothetical situation between patients and their family members[a]

Patient's willingness to recommend first degree relatives to uptake genetic test	First degree relative's willingness to uptake genetic test						Concordance between dyads	
	Never	Not likely	Likely	Definitely	Missing	Total	Weighted κ	p-Value
Never	1	1	3	5	0	10 (4.4)		
Not likely	0	1	4	2	0	7 (3.1)		
Likely	3	5	35	28	1	72 (31.7)		
Definitely	10	14	45	66	1	136 (59.9)		
Missing	0	1	0	1	0	2 (0.9)		
Total	14 (6.2)	22 (9.7)	87 (38.3)	102 (44.9)	2 (0.9)	227 (100)	0.06	0.099

[a]First degree relatives were defined as siblings and children (parents were excluded). Complete agreement (on diagonal) = 103 (45.4%). Agreement as dichotomized (shaded area) = 177 (78.0%).

family members agreed that HCP should inform at-risk relatives of positive test results without patient consent, but response concordance within dyads was poor (agreement rate = 57.7%; κ = 0.06; Table 4). Responses by relationship to the patients are provided in Table A2.

Predictors of concordance regarding CSGT uptake and disclosure

Among various patient and family member characteristics examined, dysfunctional communication between patients and family member was negatively associated with concordances regarding uptake of CSGT for patients [adjusted odds ratio (aOR) = 0.98; 95% confidence interval (CI), 0.96–1.00], and first-degree relatives (aOR = 0.96; 95% CI, 0.92–1.01) (Table 5).

Discussion

A prominent distinguishing feature of genetic testing is that it not only reveals information about individuals being tested, but their family, as well (38). Such unique characteristic of genetic testing has the potential to raise family tensions and challenging communication issues. To our knowledge, this is the first study to examine CSGT attitudes of patients and family members in matched dyadic analysis.

Consistent with previous studies (15, 39, 40), cancer patients and their family members generally showed high levels of interest in CSGT, expressed positive attitudes toward CSGT and indicated willingness to undergo testing and recommend testing to at-risk relatives. However, at the same time, a minority of patients and family members preferred not to know their own genetic predispositions, or the genetic risk within the family, because of concerns about social stigmatization or discrimination (12, 32). Our study shows that ratings of willingness to undergo or recommend testing were different in more than half of the patient–family dyads. The most important instances of dyadic mismatch was evident in 22.5% of the dyads in which the patient indicated that they were likely or definitely willing to take the test while the family members indicated they were not willing or not likely to recommend that the patient take the test, as well as the inverse. A similar, although slightly weaker pattern of dyadic mismatch (in 22.0% of dyads) was also evident in family member willingness to take the test and patient willingness to recommend the test to them. These were the cases that would represent the most serious indications of potential conflicts in genetic communication.

In this same vein, there has been some ethical debate whether the consent of family members is required before an individual could be tested, as the test results have implication for the whole family (41). Indeed,

Table 4. Concordance of attitudes toward issues related to disclosure of positive genetic testing results between patients and their family members

	Patient response		Family member response		Difference (McNemar)	Concordance between dyads		
Items	No	%	No	%	p-Value	Agreement (%)	κ	p-Value
Patient should disclose the positive test results to family member(s)								
Yes	923	93.2	920	92.9				
No	66	6.7	70	7.1	0.65	89.1	0.15	<0.001
If disclosing, when do you think is the proper timing for the disclosure?								
As soon as patients know the result	733	74.0	682	68.9				
At proper timing such as family meeting (e.g. thanksgiving day)	195	19.7	255	25.8				
Wait until critical timing when the family should know it (e.g. when planning marriage or pregnancy)	57	5.8	53	5.4	<0.001[a]	65.2	0.20	<0.001
If disclosing, who do you think is the best people to disclose the positive results?								
Patient him/herself is better to disclose it	661	66.8	563	56.9				
Patient is better to ask the health care professional to disclose it for him/herself	325	32.8	427	43.1	<0.001	58.4	0.13	<0.001
Who do you think is the family who should be informed?								
Children	891	90.0	857	86.6	0.008	83.4	0.20	<0.001
Brothers/sisters	692	69.9	763	77.1	<0.001	68.4	0.19	<0.001
Nephews/nieces	208	21.0	155	15.7	<0.001	75.5	0.18	<0.001
Parents	362	46.6	514	51.9	<0.001	61.2	0.23	<0.001
Do you think the health care professional can inform the patients' positive results to his/her family members without patients' consent?								
Yes, as it can affect his/her family member(s) as well	654	66.1	648	65.5				
No. Only with patients' consent, as it is his/her privacy	335	33.8	341	34.4	0.73	57.7	0.06	0.026

[a]By Friedman statistics.

minority of patients and family members did not agree with autonomous decision of CSGT uptake. Acknowledging the family responsibility aspect of CSGT, some have proposed formal family agreement before the test (i.e. 'family covenant') to address proactively boundaries of privacy and information sharing within the family (42). However, the practicality of such model needs to be evaluated in a real clinical setting because some patients even might not want to share the fact that they are considering the test.

Dysfunctional cancer communication within the family was associated with poor concordance regarding the uptake of genetic testing in our study, consistent with previous findings that open communication was observed in families that request testing (43). Provision of emotional support to both patients and family through genetic counseling could improve family communication, and consequently increase family alignment in regard to CSGT uptake (26, 44).

Our results indicated that most patients and family members thought that the patient should disclose positive test results to family members. Like previous studies (32, 39), it seems to reflect the notion that effective preventive measures may be taken if at-risk individuals knew about a positive test result (22, 32). Patient might feel a sense of moral obligations to inform family members of a positive result (8, 27), and people usually discuss their genetic test results with their family (8). Nevertheless, a significant minority of patients and family members disagreed about patients' responsibility to disclose the positive CSGT results to the family. It has been well-documented that index patients do not always convey their genetic risk information to their at-risk family members (26), mainly because of the burden of delivering bad news and concern about the quality of their relationship (26, 27, 39).

Beyond the decision to disclose test results, dilemmas can arise in regard to when the disclosure should be done, by whom and to whom (8, 21). While many people prefer immediate disclosure, others prefer deferring disclosure until the timing is right and the family is emotionally ready (26) or when it is convenient, for instance during a family gathering (21, 27), or at the point when disclosure is necessary for preventive action or reproductive planning (21, 26). Respondents varied in their opinion regarding the role of HCPs in disclosure process. While direct disclosures by index person were favored by majority

Table 5. Predictors of concordances for cancer genetic susceptibility testing uptake and disclosure of the results[a]

	Concordance between patient–family member responses		
	Patient's uptake ($N = 934$)	First-degree relative's uptake[b] ($N = 217$)	Disclosure ($N = 938$)
	aOR (95% CI)	aOR (95% CI)	aOR (95% CI)
Patient characteristics			
Age (per 10 year)	0.96 (0.81–1.13)	1.03 (0.73–1.46)	1.12 (0.90–1.38)
Female sex (*vs* male)	1.26 (0.82–1.92)	1.61 (0.70–3.72)	0.75 (0.42–1.32)
Cancer type (Ref: stomach cancer)			
Lung and bronchus	0.85 (0.45–1.63)	0.35 (0.09–1.4)	1.01 (0.35–2.89)
Liver	1.29 (0.53–3.16)	0.45 (0.06–3.35)	0.58 (0.17–1.89)
Colorectal	1.06 (0.58–1.94)	1.19 (0.31–4.65)	**0.36 (0.16–0.82)**
Breast	1.03 (0.54–1.95)	1.21 (0.29–5.1)	0.99 (0.41–2.39)
Cervix and uterus	1.27 (0.53–3.06)	0.90 (0.16–4.91)	0.59 (0.21–1.68)
Others	1.09 (0.63–1.90)	0.31 (0.09–1.12)	0.95 (0.41–2.16)
Cancer stage, current (*vs* local)			
Regional	0.83 (0.54–1.29)	1.24 (0.43–3.59)	1.20 (0.69–2.07)
Distant	0.66 (0.43–1.00)	1.36 (0.47–3.92)	1.28 (0.75–2.17)
Education (*vs* <9 years)			
9–12 years	0.92 (0.62–1.39)	1.06 (0.40–2.82)	0.91 (0.52–1.58)
>12 years	1.37 (0.81–2.31)	0.64 (0.19–2.16)	0.68 (0.35–1.32)
Family member characteristics			
Age (per 10 year)	0.96 (0.82–1.13)	0.88 (0.61–1.27)	1.11 (0.91–1.37)
Female sex (*vs* male)	1.19 (0.83–1.72)	1.27 (0.58–2.81)	1.51 (0.92–2.46)
Education (*vs* <9 years)			
9–12 years	0.99 (0.61–1.60)	1.26 (0.31–5.14)	1.39 (0.75–2.57)
>12 years	0.66 (0.38–1.16)	0.94 (0.23–3.89)	1.78 (0.85–3.71)
First-degree relative (*vs* non)	0.73 (0.49–1.09)	N.A.	0.82 (0.49–1.39)
Communication characteristics			
CCAT-PF (per point)	**0.98 (0.96–1.00)**	0.96 (0.92–1.01)	0.99 (0.97–1.01)

aOR, adjusted odds ratio; CI, confidence interval; N.A., not applicable.

Cancer communication assessment tool-patient and family (CCAT-PF, possible range: 18–108; higher score indicates dysfunctional communication).

[a]Subject numbers included in the analyses do not match to all participants because of some missing responses in predictor variables.

[b]First-degree-relative only: $N = 217$. Bold values denote statistically significant associations.

(21), family members were slightly more likely to prefer disclosure by HCPs than patients, and their opinions tend to be not concordant within the family. Conflict may also arise regarding the boundary for discussion of genetic information in regard to the nuclear family or first-degree relatives (24, 45). Most respondents agreed to disclose risk information to their children. This might be because it is generally seen as a parent's responsibility (21, 22, 33). However, there was significant disagreement in attitudes regarding disclosure to siblings, parents, and nephews/nieces. In the case of parents and siblings, concern for old age has been noted (45), but in the case of nephews/nieces patients noted emotional distance or a sense that they did not have the authority to do so (21, 22, 34).

The duty to maintain confidentiality and the duty to warn is an area of potential conflict between patients and HCPs. HCPs may be faced with such a dilemma when patients refuse to notify at-risk relatives and request non-disclosure of their genetic information to the family (6, 19, 38). Professional guidelines generally respect the legal and ethical norm of patient confidentiality (9, 12). US women value confidentiality over the duty to warn at-risk individuals (32, 46), and few genetic counselor indicate willingness to breach confidentiality, although some noted that they seriously considered notifying family members without consent (38). However, within the context of malpractice, the situation may be changing with momentum toward acknowledging the HCP's discretion to disclose and duty to warn (6, 9, 19). Family members at risk tend to approve direct contact from HCPs (36). In our study, about two third of patients and family members indicated that positive test results should be disclosed to at-risk relatives without patient consent, despite the possibility of family discord. While resolution of such conflicts has been reported in clinical situations (38), insight from these exchanges could be useful to patients and the HCPs who guide them.

Several limitations of the study should be noted. First, a hypothetical situation cannot capture family communication as a 'process' (13, 21, 22), and may not reflect how patients and their family members act when they are faced with such situations in real situations (38). A second limitation of this study is

that patients with various cancers characterized by variable inheritability and preventability were included. However, the attitude toward uptake and disclosure did not differ substantially across cancer types in our study (data not shown). Finally, generalizability outside of the Korea needs to be examined as family communication of genetic information is likely to be influenced by cultural, legal, and health system context (26, 28). Currently, cancer genetic counseling is usually conveyed by oncologists, and genetic counselors or general practitioners have little role in Korea.

Despite these limitations, this study provides a unique look at family communication regarding CSGT uptake and disclosure. As more CSGTs become available in clinical practice, HCPs should be aware of the multitude of facets of genetic communication and how these may affect family function. Our study results showing areas of discordance among dyads may help HCPs to better understand the communication issues in family context, and to develop the appropriate communication skills to facilitate harmonious decision and to resolve potential conflicts regarding genetic information (42). Our findings reinforce the need for a family system approach to incorporate perspectives of patients as well as their family members (22). Future research is warranted on the identification of communication patterns regarding genetic testing decisions and disclosure within the family system, and how families adapt to and cope with such challenges (24).

Supporting Information

The following Supporting information is available for this article:

Appendix S1. Hypothetical scenario.

Additional Supporting information may be found in the online version of this article.

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