

Japanese women's reasons for accompaniment status to hereditary breast and ovarian cancer-focused genetic counseling

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Abstract

Genetic counselors routinely assess and understand clients' needs at the beginning of a session. Attending a genetic counseling session with or without companions is an objective sign that genetic counselors can easily notice. This study focused on clients' reasons for their accompaniment status for genetic counseling, which we categorized into attending with or without a companion(s). A questionnaire survey and interviews were conducted using snowball sampling, starting with the chief executive officer (CEO) of the Japanese hereditary breast and ovarian cancer (HBOC) support group. Of 32 participants, 19 continued with an in-depth interview after answering the questionnaire. Five themes were identified from the interview: (1) personal confidence, (2) decision-making style, (3) family members' habits and time availability, (4) considerations and conflicts with family members, and (5) healthcare provider's suggestion. Our data suggested that the clients expected their companion(s) to play certain roles. This indicates that the reasons of accompaniment status will be helpful for genetic counselors to understand both clients' and their families' motivations, personalities, habits, and psychosocial backgrounds. In a high-context culture such as that of Japan, accompaniment status may be a helpful sign to understand clients' true worries. In addition, some companions may be future clients in genetic counseling, due to the genetic nature of the disease. In conclusion, our study indicated that it is important for genetic counselors to record accompaniment status before the initial genetic counseling and to pay attention to its reasons at the beginning of the session, which may lead them to understand the client's psychosocial background to facilitate better client-centered genetic counseling.

KEYWORDS

accompaniment status, communication, genetic counseling, hereditary breast and ovarian cancer, Japan, psychosocial

1 | INTRODUCTION

Psychosocial assessment is one of the key skills of genetic counselors. Individuals including affected patients, recovered clients, and unaffected clients, who are referred to genetic counseling may have varied forms of psychosocial distress, such as worries about their own or a relatives' cancer diagnosis and treatment, effects of genetic testing on their children, or dealing with a rare hereditary disease experienced by no one around them (Campacci et al., 2020; Dean et al., 2017; Mellon et al., 2008; Palmero et al., 2020; Postolica et al., 2017). Eijzenga and colleagues utilized a literature review to create the Psychosocial Aspects of Hereditary Cancer (PAHC) questionnaire as a first-line screener for psychosocial problems related to cancer genetic counseling. Six problem domains were identified: genetics, practical issues, family, living with cancer, emotions, and children (Eijzenga, Bleiker, et al., 2014). A randomized control trial was conducted with the PAHC questionnaire, concluding that routine assessments of psychological problems before the initial genetic counseling reduced clients' distress level ($p = .02$) (Eijzenga, Aaronson, et al., 2014; Eijzenga et al., 2015). These studies suggested that psychosocial assessment ahead of genetic counseling is a significant factor for client-centered genetic counseling.

Japan's national health insurance is increasingly covering genetic counselling for hereditary cancers. By 2020, five genes were covered: *RB1* and *RET* were first covered in 2016 *MEN1* and *BRCA1/2* in 2020. Before April 2020, out-of-pocket costs for patients included genetic testing at 2,000 USD, genetic counseling at 50–100 USD, and Bilateral Salpingo-Oophorectomy (BSO) at 6,700 USD. Nowadays, *BRCA1/2* genetic testing, genetic counseling fees, and BSO procedures are covered for breast and ovarian cancer patients who meet national criteria (Central Social Insurance Medical Council, 2020; Guidebook for Diagnosis and Treatment of Hereditary Breast and Ovarian Cancer Syndrome, 2017). This was an enormous advancement in the national health system for preventive medicine in Japan.

Japan has a high-context and collectivist culture (Hall & Hall, 1990; Uhlmann et al., 2009). The Japanese have long emphasized the need to evaluate the trustworthiness of a stranger to discuss their private topics with (Davies & Osamu, 2002; Donahue, 1998; Duronto et al., 2005). Communication with strangers is a difficult process in Japanese culture. Therefore, at the beginning of the session, Japanese genetic counselors must establish a trusting atmosphere with clients so that clients recognize them as safe people with whom they can share information.

The presence of medical visit companions can be helpful or unhelpful, and may reveal social relationships such as a dominant spouse or parents. Companions perform specific communication functions during a visit, including sharing information about the patient, recording the doctor's comments or instructions, asking questions, and explaining the doctors' instructions (Cené et al., 2015; Reid et al., 2002; Schilling et al., 2002; Sharp & Hobson, 2016; Wolff & Roter, 2008). Physical assistance is also helpful for patients (Schilling et al., 2002). However, it has also been reported that some companions limit the exchange of information between medical doctors and

What is known about the topic?

Psychosocial background assessment is an important part of genetic counseling. Some clients attend genetic counseling with a companion(s), and the companion(s) may be either helpful or unhelpful to them.

What this paper adds to the topic

The reasons for attending genetic counseling with or without a companion will help genetic counselors understand both clients' and their families' backgrounds, including their families' motivations, personalities, habits, and psychosocial backgrounds.

patients, particularly relating to sensitive topics (Ellingson, 2002). It is also reported that patients without a companion demonstrated poorer physical and mental health as well as lower incomes, self-care maintenance, and management than patients with companions (Cené et al., 2015; Glasser et al., 2001; Wolff & Roter, 2008).

In the genetic counseling field, not all clients need medical support; however, even such clients are sometimes accompanied by relatives (Ellington et al., 2005; Green et al., 1997; Hodgson et al., 2010). Notably, male clients who sought predictive genetic testing for Huntington's disease were more often accompanied by partners (Arning et al., 2015). Companions of high-risk patients of Alzheimer's disease were verbally active overall, disclosed more medical information, made more supportive statements, and made more orientation statements indicative of agenda-setting (Guan et al., 2017). Pregnant women seemed to be less stressed and less uncomfortable if the companion was more involved in the genetic counseling (Aalfs et al., 2006). Some clients came alone to the test disclosure session, even though all counselees had been advised to bring a companion (Aktan-Collan et al., 2001). However, to the authors' knowledge, there is no qualitative study evaluating the effects of accompaniment status for genetic counseling from the clients' perspective.

We assumed that some genetic counseling clients would have reasons for their accompaniment status and expectations of their companions and genetic counseling, especially at their first session. We also hypothesized that psychosocial background may affect the process of selecting their accompaniment status. To confirm this assumption, we conducted a study on clients who were suspected to carry genes for hereditary breast and ovarian cancer (HBOC), one of the biggest genetic counseling client populations in Japan, to elucidate the reasons clients brought a companion(s) or came alone to the initial genetic counseling session. To ensure authentic responses, clients were reassured of the confidentiality of the interview and that it would not interfere with their medical care process. This study aims to contribute to psychosocial assessment in genetic counseling by exploring clients' reasons for their accompaniment status.

2 | METHODS

2.1 | Participants and procedures

The eligibility criteria for participation were being 20 years old and above (legal adult age in Japan) and having experienced genetic counseling due to concerns of HBOC. These criteria were applied in order to sample clients who have gone through genetic counseling regarding HBOC. A brochure of this study was attached to the questionnaire.

Once a client had answered the questionnaire, a 'snowballing' technique was incorporated from the CEO of HBOC support group, the *Clavis Arcus*, to invite further participants. Participants had the choice of responding to the questionnaire online or on paper. The CEO also posted the questionnaire link to the *Clavis Arcus* website so that website visitors could participate in the study. Those who agreed to the interview provided their e-mail addresses or phone numbers, and interviews were scheduled by an author. Semi-structured interviews were conducted over the phone or in person and involved asking details about the answers each participant had provided in the questionnaire. All data were collected from September 2016 to April 2017. Each interview was recorded and transcribed verbatim with the use of a digital audio recorder.

This study was approved by the Kyoto University Graduate School and Faculty of Medicine Kyoto University Hospital Ethics Committee (approval number E841 and R0731). Informed consent was obtained from all participants for being included in both the questionnaire and interview.

2.2 | Instrumentation

A pilot study was performed to create the questionnaire. We collected data regarding the reasons of accompaniment status, from 1,395 cases represented by clinical genetic counseling notes in Kyoto University Hospital between October 1996 and March 2015. From the note review, it was assumed that the actual accompaniment status was not always the accompaniment status the client expected. In addition, client accompaniment status may have been influenced by client demographics at the initial genetic counseling appointment, including cancer status, marital status, number of children, and living status, and family communication before and after genetic counseling. Accordingly, we included questions about actual accompaniment status as well as ideal accompaniment status.

The accompaniment status reasons from the genetic counseling notes were reflected as choices in the questionnaire. As for the current demographic, we asked questions to obtain the minimum information necessary to gather the features of the subject population. Finally, the questionnaire comprised four sections: the initial genetic counseling demographic (age, cancer status, marital status, number of children, and living status), reasons of accompaniment status including feedback for the genetic session attended either with or without the companion(s), family communication before and

after the initial genetic counseling, and the current demographic (age, sex, member status of the *Clavis Arcus* and genetic testing status [see Appendix S1]). The interview was conducted following the returned questionnaire. The detailed interview guide is provided in Appendix S2. During the interviews, we asked participants (a) how and why they came to genetic counseling and (b) what they and their families were thinking and expecting from genetic counseling at that time (to remind them why they selected their accompaniment status). In addition, we carefully explained the needed to record the interview and our analytical process (triangulation). Moreover, we allowed the participants to ask the interviewer questions about the study at the beginning of the interview to reduce their stress about disclosing private information to a stranger.

All questionnaires and interviews were carried out with individuals who lived in Japan and spoke Japanese. After all the analyses were completed in Japanese, the themes, categories, and quotes were translated into English. During the translation process, back translation was also carried out by a native English speaker fluent in Japanese, Mr. James R. Valera, to properly adjust the English expressions to Japanese.

2.3 | Data analysis

Participant characteristics were summarized using frequencies, medians, and ranges. Statistical analysis was carried out using R Statistical Software (Foundation for Statistical Computing, Vienna, Austria) to compare the frequency of the with-companion-visit participants group (WCG) and solo-visit participants group (SG) by Fisher's Exact test or the Exact Wilcoxon rank sum test.

Inductive thematic analysis was utilized as a method of qualitative data analysis (Braun & Clarke, 2006). First, the data were carefully read several times by the researcher (MM). Second, meaningful units of text relevant to the topic 'Why did you choose to attend initial genetic counseling with a companion(s) or without a companion(s)' were extracted from the data. Third, units of text dealing with similar topics were grouped into analytical categories and were given codes that featured the group. Next, codes were collapsed into higher-level categories organized around related codes. As a result, reasons emerged in the 'with a companion(s)' category and 'without a companion(s)' category; both included the participants' reason for attending with specific family members as companions. These two groups were named as with-companion-visiting factors (WCF) and without-companion-visiting factors (WOCF). Furthermore, similar themes were formulated from the WCF and WOCF and grouped into a theme based on similarity. Therefore, a cross table by themes and WCF/WOCF was created. All processes were first performed by one researcher (MM) who then discussed the validity of the exhaustive set of data, the category names, and the themes with other researchers (MT, CS, and SH). Each process went back and forth until all researchers agreed on the categories and themes. All four researchers are certified genetic counselors who have previously been involved in qualitative research.

3 | RESULTS

3.1 | Participants demographics

Of the 32 participants who completed the questionnaire, 15 (46.9%) answered it online, and 17 (53.1%) returned hand-written questionnaires. All 32 participants were Japanese, aged between 37 and 81 years (median: 46 years; Table 1). Most of the participants were women ($n = 31$, 96.9%) and members of the *Clavis Arcus* ($n = 23$, 71.9%; Table 1). Thirty-one participants had completed *BRCA1/2* genetic testing ($n = 31$, 96.9%; Table 1), including one participant who underwent genetic counseling as a part of a research project. Most participants had initial genetic counseling in their 30s to 50s ($n = 29$, 90.6%; Table 1), and 24 of them were diagnosed with cancer at the same time (75.0%; Table 1). Thirteen participants were accompanied: 11 were accompanied by one companion, one was accompanied by two companions, and one was accompanied by three companions. The client's companion was either their spouse ($n = 3$),

mother ($n = 3$), father ($n = 2$), sister ($n = 3$), brother ($n = 1$), daughter ($n = 2$), first cousin ($n = 1$), or niece ($n = 1$); all participants brought blood relatives as companions. In total, there were 10 female companions and 6 male companions. In a comparison between WCG and SG, no statistically significant differences were found in age, number of children, and number of housemates (Table 1). There were slightly less married participants in WCG (Table 1).

Nineteen participants agreed to participate in the in-depth interview. Interviews were conducted over the phone for 15 participants and in person for 4 participants. The interviewees' demographics were similar to those of the questionnaire groups (Table 1). Eighteen of the individuals (94.7%) interviewed were positive for a *BRCA1/2* mutation (Table 1). Participants were aged between 37 and 65 years (median: 46 years; Table 1). At the initial genetic counseling appointment, 16 participants had already been affected by breast cancer, including one participant with ovarian cancer; however, there were three participants who were not affected (Table 1). Eleven participants (57.9%) had scheduled or already undergone BSO. The initial

TABLE 1 Participant demographics in the questionnaire ($n = 32$) and interview ($n = 19$)

Demographic variable	Questionnaire			Interview		
	w companion (<i>n</i> = 13)	solo (<i>n</i> = 19)	<i>p</i> -Value	w companion (<i>n</i> = 8)	solo (<i>n</i> = 11)	<i>p</i> -Value
	<i>n</i> (%) / Median (Range)	<i>n</i> (%) / Median (Range)		<i>n</i> (%) / Median (Range)	<i>n</i> (%) / Median (Range)	
At the time of survey						
Age	46 (37–81)	46 (38–65)	.867	46 (37–59)	47 (39–65)	.478
Sex						
Female	12 (92.3)	19 (100. 0)	.406	8 (100.0)	11 (100.0)	1.000
Member of the HBOC support group	9 (69.2)	14 (73.7)	1.000	6 (75.0)	9 (81.8)	1.000
Have done <i>BRCA1/2</i> testing	12 (92.3)	19 (100. 0)	.406	7 (87.5)	11 (100.0)	.421
At the initial genetic counseling						
Age						
<29 years	0 (0.0)	0 (0.0)	–	0 (0.0)	0 (0.0)	–
30–39 years	2 (15.4)	6 (31.6)	–	2 (25.0)	2 (18.2)	–
40–49 years	8 (61.5)	7 (36.8)	–	5 (62.5)	5 (45.5)	–
50–59 years	1 (7.7)	5 (26.3)	–	1 (12.5)	3 (27.2)	–
60–69 years	0 (0.0)	1 (5.3)	–	0 (0.0)	1 (9.1)	–
70–79 years	1 (7.7)	0 (0.0)	–	0 (0.0)	0 (0.0)	–
>80 years	1 (7.7)	0 (0.0)	–	0 (0.0)	0 (0.0)	–
Affected by cancer	9 (69.2)	15 (78.9)	.684	7 (87.5)	9 (81.8)	1.000
Marital status						
Married	10 (76.9)	18 (94.7)	.279	7 (87.5)	11 (100.0)	.421
Children						
Have children	10 (76.9)	15 (78.9)	1.000	6 (75.0)	10 (90.9)	1.000
Daughter	7 (53.8)	10 (52.6)	.440	4 (50.0)	6 (54.5)	1.000
Son	5 (38.5)	7 (36.8)	1.000	3 (37.5)	5 (45.5)	1.000
Living status						
Number of housemates	2 (0–3)	2 (1–4)	.323	2 (1–2)	2 (1–3)	.686

genetic counseling was conducted in WCG between 2 months and 9 years ago before the study (median: 2.5 years) and in SG between 1 month and 6 years before the study (median: 2.5 years). There were four participants from WCG and three participants from SG who received instructions from their healthcare providers that they should bring a companion to genetic counseling. Companions for WCG were either their mother ($n = 2$), spouse ($n = 2$), daughter ($n = 1$), or sibling ($n = 3$). The number of relatives who experienced cancer was between zero and five (median: three relatives) and zero and four (median: two relatives) in WCG and SG, respectively ($p = .120$). Solo-visit participants were less likely to have been told in advance by their healthcare providers that they could bring a companion to the genetic counseling appointment, though the difference was not significant (5/8, 62.5% in WCG; 3/11, 27.3% SG, $p = .180$).

3.2 | Questionnaire results

Frequent reasons for attending either with or without a companion(s) were 'Wanted to explain the disease to her/him' ($n = 4$, 25.0%), 'He/She was worried about me' ($n = 3$, 18.8%), and 'He/She has been to genetic counseling' ($n = 2$, 12.5%; Table 2). Surprisingly, no participants answered 'No specific reason' (Table 2). However, in the group that went to the initial genetic counseling appointment without a companion, most participants chose the reason 'It is about my own disease' ($n = 18$, 94.7%; Table 2).

Participants who went to genetic counseling with a companion(s) gave the following feedback: 11 participants felt satisfied ($n = 11$, 84.6%), one participant felt dissatisfied ($n = 1$, 7.7%), and one participant felt neither satisfied nor dissatisfied ($n = 1$, 7.7%; Table 3). The reasons for the satisfaction were (in order of frequency): 'He/She explained the things which were difficult for me to express', 'He/She understood the conversation better than me', 'I felt relaxed', and 'He/She is good at connecting with our family and it helped' (Table 3). The participant who answered 'dissatisfied' commented that 'Looking at my brother, I thought he might have taken the discussion about heredity hard'. The participant who answered 'neither' commented that 'Because my daughter (who accompanied me to the consultation) had a 50% probability of inheriting the disease, I'm not sure if telling her about it was a good thing as it came to her as a shock'.

3.3 | Interview results

Interviews lasted between 42 min and 227 min (median: 62 min). Eight categories for WCF, nine categories for WOCF, and five themes emerged.

3.3.1 | Theme 1: Personal confidence

Nine participants explained their confidence in accepting, understanding, or explaining things during the consultation. Five

participants thought they could understand and accept things on their own.

I know a little about genetics, so I thought, 'I could probably understand this on my own'. Yeah, so that's part of it.

(solo, 6-17)

Four participants did not have confidence in understanding and explaining things. They were anxious about whether they could accept things on their own, experienced difficulties in explain things to their families, or expected the companion to help them understand the geneticists' comments.

I couldn't answer if I was asked anything by her because all I could say to her was, 'How should I know?' So, I suggested going together and so we went together. There were probably things that, if I had been asked directly, I wouldn't have been able to answer.

(w companion, 7-22)

3.3.2 | Theme 2: Decision-making style

Two participants explained that they were the type of person who made decisions on their own.

It was the same as the first time I got breast cancer. Since it was something concerning myself, I made all my own decisions. Of course, I spoke with my husband, but I made the decisions as I always have.

(solo, 2-20)

A participant wanted to bring her husband because she wanted to consider her family's opinion while making an important decision.

When I was informed about how the surgery would be done or that I could have a partial mastectomy or a total mastectomy, I'd think, 'Maybe a total mastectomy would be better', and then I'd be in two minds. So, I thought it might be a good idea for my husband to understand the surgical choices as well because it might make it easier for me to make decisions.

(w companion, 11-23)

3.3.3 | Theme 3: Family members' habits and time availability

Two participants reported that when they went to the hospital their family always accompanied them. One was with her spouse (companion) when genetic counseling was recommended. Meanwhile, the other participant was accompanied by family to the initial examination and important visits.

TABLE 2 Reasons for attending genetic counseling with or without a companion

	<i>n</i>	%
Reasons for bringing a companion(s) to genetic counseling (total companions <i>n</i> = 16)		
Wanted to explain the disease to her/him	4	25.0
He/She was worried about me	3	18.8
He/She has been to genetic counseling	2	12.5
I just wanted him/her to accompany me	1	6.3
I was unsure if I would understand the session	1	6.3
I was worried that it might be passed down to him/her	1	6.3
He/She was concerned about our relatives considering the hereditary nature of the disease	1	6.3
He/She was affected	1	6.3
He/She was concerned about themselves considering the hereditary nature of the disease	0	0.0
He/She had a sense of responsibility	0	0.0
He/She is involved in the medical sector	0	0.0
It may affect our child	0	0.0
I may marry him/her in the future	0	0.0
Could not find any babysitter	0	0.0
I was told to come with him/her	0	0.0
No specific reason	0	0.0
Other	2	12.5
Reasons for going solo for genetic counseling (<i>n</i> = 19)		
It is about my own disease	18	94.7
I had a complicated feeling, and don't want to inform any of my relatives about genetic counseling	0	0.0
He/she was not available	0	0.0
He/She was available but didn't want to come because of other reasons	0	0.0
I had no idea that I should attend genetic counseling with someone	0	0.0
Other	1	5.3

Yes, at the moment, basically, I suppose it was the same as when I got the news about my cancer and heard about the treatment strategy. But my husband was with me the whole time. That's why I just went on to the counseling with him. He was also with me when I was asked if I wanted to undergo genetic testing. When it was suggested to me that I might get

counseling before the genetic testing, he was there and heard the same conversation, which is what I mean when I said that he was by my side through the whole process.

(w companion, 5-17)

Eight participants mentioned they always went to medical examinations on their own. It was their habit to be the first ones to hear about the disease's explanation and treatment.

It wasn't so serious that I needed someone to go with me. I thought, 'Well, so what?' I would be alone anyway while I was having the cancer treatment, so I went to the examination alone. When I had surgery, except for the times [the hospital] said 'Please have a family member come with you', I did everything alone. So, I guess you could say I'm used to being alone. I just think that is the way it is.

(solo, 13-61)

Seven participants mentioned their family member's time availability and circumstances. Two participants explained that their companion happened to be available or that their companion agreed to accompany them.

Five participants described that their family (companion) was not available. The family member did not have the time to go either because of work or school, had already passed away, or could not understand the situation.

My daughter came with me at the time. 'Cause she just happened to say she'd go with me.

(w companion, 10-33)

Let's see...my husband was busy with work (laughing), and since I had to go during the day on a weekday, I thought, 'Well, so be it.'

(solo, 8-19)

If my mother were in a condition at that time, in which she could have understood, we would have gone together. My mother is still alive, but she has dementia.

(solo, 9-34)

3.3.4 | Theme 4: Considerations and conflicts with family members

Two participants mentioned that their companion wanted to go with them.

Well, my husband had things that he wanted to ask, and so we went together and listened together.

(w companion, 11-17)

TABLE 3 Feedback for bringing companion(s)

Feedback and reason	n
Satisfied (n = 11, 84.6%)	
He/She explained the things which were difficult for me to express	3
He/She understood the conversation better than me	2
I felt relaxed	2
He/She is good at connecting with our family and it helped	1
Other	3
Dissatisfied (n = 1, 7.7%)	
He/She was talking all the time	0
I couldn't talk freely because he/she was there	0
Other	1
Neither (n = 1, 7.7%)	
Didn't experience anything specific	0
Didn't show interest and wasn't listening carefully	0
Other	1

Conversely, four participants explained that their family members (e.g., daughter, spouse, and parents) did not show interest in genetic counseling, as they did not think it had anything to do with them, already understood problems related to genetic inheritance, or did not want to accompany the participant since the subject was difficult.

Even before any talk about genetic testing, my daughter was thinking she might have a high probability of having the pathogenic variant, so she said, 'Mom, I might as well get tested' (laughing). It was like, 'Yeah, you probably have the mutation anyway!' (laughing).

(solo, 9-28)

My daughter, in particular, seemed to be unconcerned. I spoke to her about it for a long time, but still, her attitude was one of unconcern. She didn't say anything like 'Don't talk about it' or 'Let me find out exactly what is going on' or any particular response like that. It seemed like she felt that it had nothing to do with her.

(solo, 14-76)

Well, umm, my husband didn't seem to be very interested (laughing). It was, you know, something I had to deal with on my own. But it's a really difficult issue to deal with.

(solo, 9-22)

My parents said that they wouldn't understand what was being said because it was too difficult for them.

(solo, 3-33)

Eight participants understood that their relatives (companion) were at risk, and therefore considered the timing at which to inform the at-risk person. Two participants expressed worry that their family members (companion) might also get the disease.

(After my older sister died) I got cancer, which made my younger sister worry that she might have it as well. That's why I offered to go with her.

(w companion, 15-14)

Six participants did not want to cause any more trouble for their family members. They thought their relatives were not old enough to know about the risk and the syndrome before receiving a definitive diagnosis, and they did not want to worry their family members. One participant had relatives who did not want to know about HBOC. Another did not wish to make the family relive the loss of her sister who had passed away. Yet another shared that she did not want to worry her family unnecessarily because she did not think they were at risk.

Both my mother and I got cancer after getting married and having children. But my daughter wasn't even 20 years old, so I didn't want to worry her too much by mentioning the subject.

(solo, 14-63)

It never occurred to me to go with my mother. My mother is not at risk, I guess, and [I didn't want her to] remember what happened to my older sister [and that's why I went with my younger sister and not my mother]. (Woman whose older sister passed away from ovarian cancer; w companion, 15-97)

Two participants brought their family members, because they wanted their family members to understand their disease. They

expected that their companion would better understand HBOC if the geneticist and the genetic counselor explained it to them directly. One participant wanted to discuss their genetic background with the non-affected sibling.

But with regard to my daughter, if something were to happen to me, then her older brother would be the one to look after her, so in the event that something was to happen, I thought it would be better for him to have more information so that he could better understand what happened to his younger sister. Also, I thought that this knowledge might be useful to him to take care of my daughter after I'm gone.

(Divorced woman, w companion, 18-52)

Four participants experienced conflict with their families. One participants' family did not understand her, even though she was assumed to be the carrier and the discussion would be regarding their blood relations. Three participants lamented that the family members were not supportive of HBOC predictive testing and therefore would not understand their worries.

Well, it's difficult for anyone other than the patient to understand this issue (having genetic testing done and undergoing BSO), and it's even difficult for family members to understand.

(solo, 1-40)

It was difficult to talk about it even with my family, and because it was inherited...it just wasn't the same as 'the usual type' of breast cancer. There was no one around that I could talk to.

(solo, 4-42)

Five participants wanted to prioritize themselves. They revealed that they wanted to concentrate on their own on things concerning themselves and that it would be distracting if someone else was in the clinic.

At the stage at which I was going to counseling, I understood [the implications this disease had for other members of my family], but even more than that, I was concerned about myself.

(solo, 8-41)

Well, basically speed, I guess? When I had ovarian cancer, if it hadn't been discovered, I would have died. That's what I was thinking.' (Woman who had genetic testing done when breast cancer occurred after onset of ovarian cancer; solo, 12-20)

3.3.5 | Theme 5: Healthcare provider's suggestion

There were eight participants who were informed about bringing a companion to the genetic counseling session by healthcare providers, including genetic counselors and clinicians.

Well, first, my older sister was diagnosed with cancer at the Department of Breast Surgery at Hospital A, and since they suspected that the condition was hereditary and they told her to bring her younger sister (me) with her on her visit. My older sister told me to go with her so that I could get genetic counseling. That's why I went to Hospital A for genetic counseling.

(w companion, 16-5)

Well, I hadn't thought about going to genetic counseling with someone else"

(solo, 3-27)

4 | DISCUSSION

4.1 | Participants characteristics

Twenty-three of the 32 participants who answered the questionnaire (71.9%), and 15 of the 19 participants who gave the interview (78.9%), were members of the *Clavis Arcus* (Table 1). In addition, 11 interview participants (57.9%) had scheduled or completed BSO. Even though about 2,300 patients had undergone *BRCA1/2* genetic testing in Japan (Okano et al., 2020), a limited number of institutions offer HBOC patients the opportunity to pursue BSO, and the surgery fee was not covered by the national health insurance at that time. Most of the participants were members of the *Clavis Arcus* which was not widely known to Japanese HBOC patients and medical staffs. Compared to previous studies (Arning et al., 2015; Di Pietro et al., 2020; Ellington et al., 2005; Griswold et al., 2011; Guan et al., 2017, 2018; Hodgson et al., 2010; Ibisler et al., 2017), our study had a larger sample of HBOC patients who attended genetic counseling alone. We identified that many participants who attended the initial genetic counseling alone confidently understood and accepted things and were able to make decisions on their own (Table 4); that is, they were easily able to act without the support of a companion. From these results, and our understanding of Japan's collectivist culture (Hall & Hall, 1990; Uhlmann et al., 2009), we can speculate that our participants were more proactive about their treatments than the general population, especially in terms of, gathering information, treatment planning, and contacting healthcare professionals. It might also be said that the participants were patients, who were aware of and had the opportunity to reach out to the support group.

TABLE 4 Schematic diagram of each category

Theme	Category	
	With-companion-visiting factors (WCF)	Without-companion-visiting factors (WOCF)
A. Personal Confidence	(1) Because I didn't have the confidence to understand and/or explain things	[1] Because I can understand and accept things on my own
B. Decision-making style	(2) Because I base my decision on my family's opinions	[2] Because I am the sort of person who makes decisions on my own
C. Family members' habits and time availability	(3) Because my family always accompanies me while going to the hospital	[3] Because I always go to medical examinations by myself
	(4) Because my companion (family) was available	[4] Because my companion (family) was not available
D. Considerations and conflicts with family members	(5) Because my companion (family) was hoping to go with me	[5] Because my companion (family) didn't express interest in genetic counseling
	(6) Because I was worried that he/she might get the disease	[6] Because I didn't want to cause my family any more trouble
	(7) Because I wanted my family to understand my disease	[7] Because even my family doesn't understand me
		[8] Because I prioritized myself
E. Healthcare provider's suggestion	(8) Because the healthcare provider recommended that someone accompany me	[9] Because none of the healthcare providers mentioned anything about bringing a companion

4.2 | Psychosocial background and accompaniment status

Five themes emerged both from WCF and WOCF: (1) Personal confidence, (2) Decision-making style, (3) Family members' habits and time availability, (4) Considerations and conflicts with family members, and (5) Healthcare provider's suggestion. These five themes may act as important factors in considering accompaniment status during the initial period of genetic counseling. Moreover, accompaniment status should enable genetic counselors to understand clients' psychosocial situations better from the beginning of the consultation.

More fully understanding the reasons behind client accompaniment status may require accessing different information from PAHC (Phelps et al., 2010) and The Genetic Risk Assessment Coping Evaluation (GRACE; Eijzenga, Bleiker, et al., 2014). Clients' personal traits are important for genetic counselors to assess their needs (Geirdal & Dahl, 2008). Notably, our interviews offered information useful for categorizing clients' psychosocial characteristics, personalities, and habits. The WCF category 'Because my companion (family) was hoping to go with me' and the WOCF category 'Because my companion (family) didn't express interest in genetic counseling' (Table 4) indicate family members' motivations toward genetic counseling and the support they offer to the client. 'Because my companion (family) was not available' (Table 4) indicates family members' priorities or availabilities. While the accompaniment status cannot assess the clients' psychosocial background or coping styles thoroughly, WCF and WOCF may indicate crucial traits of the client and their family members.

4.3 | Companion roles in genetic counseling

This is the first study to focus on exploring the reasons of accompaniment status using qualitative analysis. It can be assumed that many clients went for genetic counseling as a part of their medical treatment plan, as recommended by their physicians. However, interestingly, all participants had reasons for their accompaniment status. This suggests that genetic counseling clients make the choice, of visiting alone or with company with certain expectations about the consultation. Previous studies have found that geriatric patients, patients with Alzheimer's, and emergency care patients generally took companions, as a medium of support for physical and psychosocial problems (Cené et al., 2015; Schilling et al., 2002; Sharp & Hobson, 2016; Wolff & Roter, 2008). Di Pietro reported that for some patients the reasons for being accompanied were to not be alone, to feel supported, or because the accompanying person was also getting *BRCA1/2* testing (Di Pietro et al., 2020). However, some participants brought family members, 'Because I wanted my family to understand my disease' and 'Because I was worried that he/she might get the disease' (Table 4). It is reported that companions are often the key persons who discuss cascade testing with other family members (Di Pietro et al., 2020) and are typically the next to be tested (Gilbar & Barnoy, 2018; Kosugi, 2019; Petersen et al., 2016; Veyseh et al., 2018). Therefore, it is very important to point out that genetic counseling companions are more likely to promote family communication and become future clients than companions attending consultations in other clinical departments.

Information about the choices of accompaniment status need to be informed before the consultation. Not all solo-visit participants

were willing to go to the initial genetic counseling appointment alone; the relatives of some participants were simply not available (Table 4). The instructions of accompaniment were less frequent in SG than WCG and could be explained by the following statements: 'Because none of the healthcare providers mentioned anything about bringing a companion' for WOCF, and 'Because the healthcare provider recommended that someone accompany me' for WCF. These results suggest that if the solo-visit participants were instructed to bring companions before the consultation, they might have complied. Of late, telegenetics have become more widespread (Cohen et al., 2013; Greenberg et al., 2020), which makes it easier for relatives to join consultations remotely and thus without the hassles of transportation or time (Lea et al., 2005; Mahon, 2020). We should note that accompaniment status should be mentioned beforehand for both in-person and online genetic counseling to make the session much more effective for clients and their families.

4.4 | Companions in HBOC genetic counseling

In our study, visit companions were predominantly female blood relative. This might be because HBOC can be misinterpreted easily, as a female-related disease, due to its name. This is another reason to pay attention to the accompaniment status, so that if the clients have any misperceptions, they can be clarified.

The features of HBOC clients were unclear from this study. Many participants brought up topics related to BSO and a bilateral mastectomy in their interviews. However, the concern of a second primary cancer did not emerge as WOCF nor WCF in our study. If we collect WOCF and WCF for the session in which results were returned, categories related to risk management or body image problem might have emerged. Focusing on the companion selection aspect, one participant mentioned that her daughter was too young to develop cancer, and therefore she had not brought her for genetic counseling. Conversely, some participants had brought their children, 'Because I was worried that he/she might get the disease' (Table 4). This result indicates that children's accompaniment with the client could possibly be affected by the children's age. Thus, it is difficult to predict the companions of HBOC clients, and we must keep in mind that HBOC clients belong to a wide range of age groups, ranging from early adulthood to later maturity, which are the stages of psychosocial and emotional development experience for a wide range of people (Erikson, 1998; Havighurst, 1953).

4.5 | Japanese culture and genetic counseling

The WCF category 'Because I base my decision on my family's opinions' speaks to a normative cultural approach to decision making in Japan. Japanese patients prefer making decisions along with family members, within 'Uchi' community (Bito et al., 2007; Ruhnke et al., 2000; Uhlmann et al., 2009). 'Uchi' is a term meaning 'inside', used for people who are akin to the family or are trustworthy. In

Japan's collectivistic culture, decision-making and problem-solving are performed within the private community, 'Uchi' (Uhlmann et al., 2009). Adding to this result, all the companions in our study were family members. In contrast, reports from Western Europe indicate that a small proportion (approximately under 15%) of participants (clients) brought friends as companions to genetic counseling (Arning et al., 2015; Guan et al., 2017, 2018). These results suggested that hereditary conditions are a private topic for the Japanese and are hardly shared with non-family members. However, when it comes to the 'Uchi' community, Japanese people take into consideration much of their family members' opinions. Genetic counselors should keep in mind that there are some Japanese clients who are willing to decide with their companions.

Accompaniment status is indicative of a person's psychosocial background as WCF and WOCF (Table 4) and attending with or without companion(s) are objective signs that genetic counselors can easily explore at the beginning of consultations. Japanese patients rarely mention their personal issues—'Uchi'—topics, at the beginning of the session (Ishikawa & Yamazaki, 2005; Uhlmann et al., 2009). The evaluation process, whether the stranger is a trustworthy person or not, may be one of the reasons for this phenomenon (Davies & Osamu, 2002; Donahue, 1998; Duroto et al., 2005). 'It was a thorny path to establish the Japanese Hereditary Breast and Ovarian Cancer support group. However, after I gave my real name to everyone in 2015, my peers shifted to share their true issues' reported Makiko Dazai, the CEO of the *Clavis Arcus*. Her peers could not trust her without knowing who she was. Forming harmonious relationships with strangers is a hard process in Japanese culture. When addressing sensitive topics, such as 'Uchi' topics, indirect questions and engaging in empathic guesswork—'Sasshi'—is appreciated in Japan (Ishii, 1984; Miike, 2002). If the genetic counselor utilizes 'Sasshi' skills, clients feel they are understood without words, that is, the genetic counselor is a 'safe' person to share their 'Uchi' topics with (Miike, 2002). A client's accompaniment status may give us a hint about their psychosocial background and help us build rapport by 'Sasshi' with Japanese clients in accordance with Japanese culture.

4.6 | Study limitations

The data were collected when all the patients in Japan had to pay for BRCA1/2 genetic testing and BSO surgery out-of-pockets. Starting the snowball sampling from the CEO of the Japanese HBOC support group was another limitation. This was the first study that recruited participants through a support group at a time when HBOC patients were not familiar with participation in psychosocial research. As a result, only dedicated HBOC patients in Japan participated in this study. We can also assume that only clients who had reasons for their accompaniment status participated in this study as we lacked participants who did not have any reasons for theirs. In addition, we limited WCF and WOCF to the initial genetic counseling appointment. Different WCF and WOCF might be formulated if we expand our study to all genetic counseling sessions, this is, include

the sessions concerning the return of the genetic testing results. Currently, companion diagnostic *BRCA1/2* genetic testing under the Japanese national insurance has started. Ovarian and breast cancer patients who visited genetic counseling services after genetic testing may have different WCF and WOCF as well. As welfare systems are different in each country, it is difficult to compare genetic counseling clients' psychosocial backgrounds across nations in this regard. For these reasons, our findings are not intended to be generalized to the population of interest.

4.7 | Practice implications

This study offers two key insights for genetic counseling practices: (1) informing the client when they reserve their initial appointment about their choice to bring a companion so that client can effectively utilize the session. This may also motivate the companion (at-risk relative) to undergo their own genetic testing, help explain genetic testing and the disease directly to the companion, or allow the patient to avoid attending with a companion with whom they do not want to share information. (2) A client's accompaniment status may suggest the client's and their family's background and their expectations of the session, which may help genetic counselors understand clients and their families at the beginning of the sessions.

4.8 | Research recommendations

Focusing on other hereditary diseases should be the next step to expand this study. Reasons of accompaniment status for the initial genetic counseling session for other diseases may vary or may be comparable to those found by our study. Such results will give us suggestions for better client-centered care in genetic counseling. Expanding the study to include second and third genetic counseling sessions is another way to consider the effectiveness of accompaniment status in psychosocial assessment. Comparing cultural differences among clients would be another aspect to broaden this study.

Genetic testing is expanding to comprehensive analysis. In this new genomic era, accompaniment status reasons might be useful to understand both the influence of genetic testing and the impact on the client's family, which will guide us to more client-centered genetic counseling.

5 | CONCLUSIONS

This is the first study to qualitatively explore reasons for accompaniment status in the genetic counseling field. We found that the reasons behind a client's accompaniment status were influenced by client and family motivation, personality, habits, healthcare providers' suggestion, and psychosocial background. As a companion can be a future client and a key person to be informed about cascade testing, it is important to inform clients that

"companions are welcome" before the initial consultation to give both the client and their family opportunities to receive as much information as possible. Furthermore, from a cultural perspective, in Japan, understanding accompaniment status may promote rapport improvement with clients at the beginning of the session. This study indicated that paying attention to the clients' accompaniment status may help genetic counselors in understanding client context and background, which will help facilitate client-centered genetic counseling.

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COMPLIANCE WITH ETHICAL STANDARDS

CONFLICT OF INTEREST

All authors, MM, MT, CS, SH, and SK, declare that they have no conflicts of interest.

AUTHOR CONTRIBUTIONS

M. Matsukawa provided substantial contributions to the conception, design, data collection, and drafting of this work; aided in revising the work critically for important intellectual content; and provided final approval of the version to be published. M. Torishima, C. Satoh, and S. Honda made substantial contributions to the data analysis, and interpretation and manuscript review and approval of this work. S. Kosugi contributed to conceptualization, methodology, manuscript review, and supervision. M. Matsukawa confirmed that she had full access to all the data in the study and took responsibility for the integrity of the data and the accuracy of the data analysis. All the authors gave final approval of this version to be published and agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

HUMAN STUDIES AND INFORMED CONSENT

The study was approved by the Kyoto University Graduate School and Faculty of Medicine Kyoto University Hospital Ethics Committee (approval number E841 and R0731). Consent was implied with the completion of the anonymous survey (in accordance with IRB approval). All procedures followed were in accordance with the ethical standards of the responsible committee on human experimentation (institutional and national) and with the Helsinki Declaration of 1975, as revised in 2000 (5). Informed consent was obtained from all participants for being included in both the questionnaire and interview.

ANIMAL STUDIES

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

DATA SHARING AND DATA ACCESSIBILITY

The data are not shared due to privacy or ethical restrictions.

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