sciendo

COMMUNITY FOCUS

The strategies of parents who tell their daughters about the possibility of being a haemophilia carrier

Keiko Nozaki, Akemi Yamazaki

KEIKO NOZAKI
Department of Clinical Education, Ashiya University, Hyogo, Japan

AKEMI YAMAZAKI
Division of Health Sciences, Graduate School of Medicine at Osaka University, Osaka, Japan. Email: akemiyamazaki@sahs.med.osaka-u.ac.jp


© Unsplash/Lau keith

This qualitative study from Japan suggests that enabling and encouraging parents in families affected by haemophilia to speak with their daughters about being a 'carrier' could help increase identification of women who carry the haemophilia gene and improve their access to care.

Introduction: Women who carry the haemophilia gene have a genetic risk of having a son with haemophilia, as well as the risk of abnormal bleeding; thus, there is an increasing interest in 'carriers' as subjects that potentially require medical support. However, in Japan, only about half of individuals with a family history of haemophilia inform their daughters that they may be carriers. **Aims:** The purpose of this study was to identify strategies used by parents to inform their daughters about their possibility of being haemophilia carriers. **Method:** Parents of daughters with confirmed or suspected carrier status, based on family history, were included in the study. A semi-structured interview was conducted, and data were analysed qualitatively using an inductive approach. **Results:** Eight parents (two men, six women) were included. The mean age of participants was 58 (range: 44-70) years; interviews lasted 76 minutes on average (range: 49-100 minutes). Data showed that parents align their values with each other and share information about their daughters between them (information sharing between partners). They also adopt roles according to sex. Mothers often played the primary role in the process of sharing information with their daughters as they are of the same sex. Since all daughters of fathers with haemophilia would be confirmed carriers, fathers were more concerned about how their daughters might react and had more guilt about their daughters. Parents also attempted to prepare for informing their daughters about haemophilia by observing their stage of mental development to determine the optimal timing to have these conversations. When sharing information about haemophilia, parents were careful to inform their daughters while considering their feelings to ensure that daughters received the information in a positive light. After sharing information about haemophilia, parents played

the role of 'daughter's supporter' by confirming their level of understanding and their feelings and considering possible ways to support them in the future. Conclusion: Assessment of carrier status can only begin if parents tell their daughters about the possibility of being a haemophilia carrier. Based on the five strategies identified, medical professionals should provide parents with information about haemophilia carriers and sharing information on genetic risk.

Keywords: *Haemophilia, Carriers, Parents, Communication*

Haemophilia is an X-linked recessive hereditary disorder. It is the most common congenital coagulation disorder in Japan, affecting approximately 6,900 individuals [1]. Clinical manifestations of haemophilia include deep internal bleeding in joints and muscles. With the emergence of regular replacement therapy, which has been widely used since the 2000s, the prognosis and quality of life of people with haemophilia (PwH) have improved dramatically [2]. However, approximately 2-4% of newborns with haemophilia are still at risk for intracranial haemorrhage [3]. Furthermore, instrumental delivery using forceps, which increases the risk of intracranial haemorrhage in newborns, is performed more commonly during the delivery of boys in mothers who are not aware that they carry the haemophilia gene compared with those who are aware that they are carriers [4].

The World Federation of Hemophilia (WFH) estimates that the number of women who carry the haemophilia gene (hereafter referred to as 'carriers') is approximately 1.6-fold the number of PwH [5]. Historically, carriers were only considered at genetic risk of having children with haemophilia; however, one third of carriers experience abnormal bleeding to an extent similar to that of people with mild haemophilia [6]. As such, haemostatic management is critical for carriers in cases of decreased quality of life, labour and delivery, and unforeseen accidents.

Carriers face the genetic risk of having a son with haemophilia as well as the risk of abnormal bleeding; thus, there is an increasing interest in carriers as persons potentially requiring medical support [2]. In Japan, the number of hospitals that specialise in haemophilia care is limited, and there is little support available for carriers. Carriers typically enter the medical system to undergo the initial examination when accompanying PwH (probands) to hospital visits [2]. However, a study has demonstrated that only about half of parents informed their daughters that they were confirmed or suspected carriers [7]. Although parents recognise the need to inform their daughters of the possibility that they may carry the haemophilia gene, many are unable to actually tell their daughters due to lack of knowledge and anxiety about how their daughters might react [8]. Their daughters are therefore not able to obtain information about their carrier status and are not provided with the necessary medical support for haemophilia. Even when they actively share information about carrier status with their daughters, parents often feel that it is challenging to provide information about heredity [9] and they worry about the psychological impact they may cause to their daughters [10]. Studies also have shown that having knowledge of the genetic risks puts the daughters at risk of feeling guilt at having the gene that causes haemophilia [11], resulting in psychological burden [12,13].

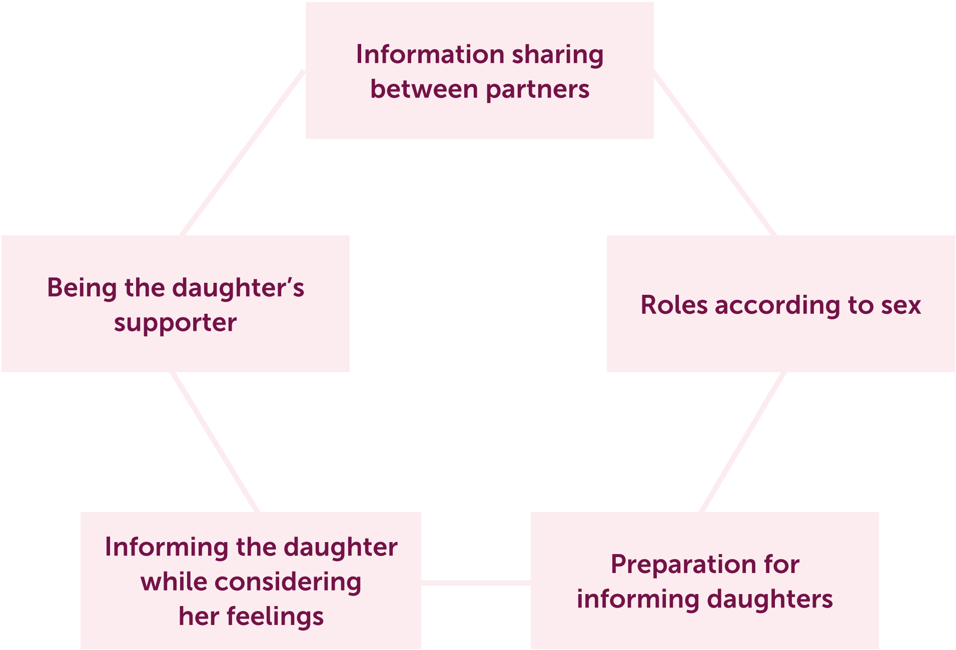
Collectively, these studies show that there are underlying issues between parents and their daughters in the experience of sharing information about haemophilia and being a carrier. A limited number of studies have focused on the process of how information about carrier status is shared between parents and their daughters. Identifying strategies used by parents who are willing to tell their daughters about the possibility of being a carrier may help those who have difficulty in doing so. Thus, the purpose of the present study was to identify strategies that can be used by parents to inform their daughters about haemophilia and being a haemophilia carrier.

METHOD

Parents who had a daughter with confirmed or suspected carrier status and who had shared information about their carrier status with their daughters were included in the study. Eligible participants were recruited through patient support group meetings, where the purpose of the study was explained; through referrals from patient support groups; through the newsletters and mailing lists of the patient support groups; and by snowball sampling from existing participants. Those who expressed interest in participating were provided with details of the study in writing; parents whose consent was obtained were included in the study. All participants provided written, informed consent to participate in the study before taking part in an interview.

Approval for this study was obtained from the Committee on Human Research at Osaka University Hospital (Approval number 19223). The study was conducted from October 2019 to August 2020.

Figure 1. Five strategies used by parents to inform their daughters about haemophilia, including being a haemophilia carrier



Semi-structured interviews were conducted, and data were analysed qualitatively using an inductive approach. Interviews were recorded on a digital voice recorder and transcribed verbatim for analysis. Before beginning the interview, a family tree was constructed to confirm the family background and genetic information of the participants. In the interview, participants were asked about the motivation for sharing information about haemophilia and carrier status with their daughters, as well as what was discussed and their thoughts on the reaction of their daughters after the information was shared.

The interview transcripts were coded to analyse the contents. Data from each interview were analysed, and the properties (categories) and dimensions (subcategories) that were extracted were reviewed repeatedly in our qualitative research group [14]. The constant comparative method of the grounded theory approach (GTA) was used. For each code, properties and dimensions were extracted and labelled as concepts that represented the codes. Similar labels were grouped together in a single category. The analysis was repeated as each case was added, and missing properties and dimensions were identified. Data collection and subsequent integration were repeated to increase the number of properties and dimensions.

RESULTS

Descriptive data

Eight participants were interviewed; three had daughters with confirmed carrier status, and the remaining five had daughters with suspected carrier status. The mean age of the participants was 58 (range: 44-70) years, and their daughters ranged in age from the 10s to 40s. The participants included two fathers with haemophilia, three mothers who were confirmed carriers, two mothers who were suspected of being carriers, and one mother whose husband was diagnosed with haemophilia. Interviews lasted an average of 1 hour and 19 minutes (range: 40 minutes to 1 hour and 40 minutes).

Parents' strategies to inform their daughters about haemophilia

Analysis of the interview data showed that study participants adopted five strategies to facilitate information sharing on haemophilia carriers with their daughters (Figure 1, Table 1):

- Information sharing between partners
- Roles according to sex
- Preparation for informing daughters
- Informing the daughter while considering her feelings
- Being the daughter's supporter.

Table 1. Five strategies used by parents to inform their daughters about haemophilia, including being a haemophilia carrier

CATEGORY	SUBCATEGORY	CONCEPT
Information sharing between partners	Creating opportunities to talk about the daughter	Parents reconciled different viewpoints on their daughters before and after sharing information on haemophilia and carrying the haemophilia gene with them.
	Considering an information-sharing approach	
	Differences of opinion between couples	
Roles according to sex	Relationship between mothers and daughters because they are of the same sex	Mothers played a direct role in sharing information with their daughters as they were of the same sex. In contrast, fathers felt anxious and guilty when providing their daughters with information due to be being of a different sex and because daughters of fathers with haemophilia will carry the haemophilia gene.
	Mothers of haemophilia carriers are concerned about their daughters	
	Relationship between fathers and daughters as they are of the opposite sex	
	Fathers with haemophilia feel guilty for their daughters	
Preparation for informing daughters	Collecting information about haemophilia	Parents determined the timing of telling their daughters about haemophilia according to their stage of physical and psychosocial development.
	Intentionally taking the daughter to patient association meetings	
	Consulting with a specialist	
	Observing the daughter's mental development	
Informing the daughter while considering her feelings	Gradual information sharing according to the daughter's developmental stage	While considering the daughter's stage of development mentally, parents used a positive approach to tell them about haemophilia so that they could feel comfortable in dealing with the fact that they carry the haemophilia gene.
	Natural information sharing	
	Telling the daughter about haemophilia using a positive approach	
	Intentionally talking with an open mind	
Being the daughter's supporter	Answering questions from the daughter	After informing their daughters about haemophilia, parents acted as their supporters. They also considered how they would support their daughters if they were to have children with haemophilia.
	Encouraging daughters to visit the hospital	
	Encouraging daughters and their partners to obtain information	
	Thinking about their daughters as parents	

In the results that follow, representative quotes from parents are presented in italics.

1. Information sharing between partners

This is a concept whereby parental couples are open to each other by sharing values and information on their daughters. This category is divided into the following three subcategories:

1.1 Creating opportunities to talk about the daughter: Parents ensured that there were opportunities to talk about their daughters before and after telling them about haemophilia and potentially being a carrier, when they began puberty, when they began exploring romantic relationships, and when they got married.

> *"When my daughter began menstruating, I was slightly concerned about it and asked my wife whether my daughter was experiencing continuous menstrual bleeding." (Male, 60s)*

1.2. Considering an information sharing approach: Before parents with haemophilia disclosed haemophilia to their daughters, they discussed an approach to sharing information with them. In so doing, the mothers could overcome the disadvantages of fathers who had difficulty communicating with their daughters.

> *"I discussed the timing of disclosing haemophilia with my husband. 'What should we do? Should we talk about it today because she said she heard about the disease today?' 'OK, we will.' Our discussion went something like this." (Female, 50s)*

1.3. Differences of opinion between couples: Parental couples realised that there were sex differences in terms of values and understanding of haemophilia, as well as concerns about daughters who are haemophilia carriers.

> *"My husband is slightly pessimistic. I believe that if my daughter says, 'I broke up with my boyfriend because of the disease,' it is just not meant to be. But I believe that someone will get married to my daughter regardless of the disease." (Female, 40s)*

2. Parents' roles according to sex

This strategy shows that sex differences affect parents' roles when genetic risk information is shared with their daughters. The mothers played a direct role in sharing such information with their daughters because they are of the same sex. In contrast, the fathers felt anxious and guilty when they provided their daughters with such information because they are of a different sex, and because if fathers have haemophilia all daughters will carry the haemophilia gene. This category is classified into the following four subcategories:

2.1. Relationship between mothers and daughters because they are of the same sex: Participants reported that mothers and daughters have a close relationship. The mothers played a supporting role, due to being of the same sex, in the daughters' life milestones, specifically during puberty when menarche occurred, pregnancy when the daughter may deliver a baby with haemophilia, and after delivery. Thus, the mothers played a direct role in informing their daughters that they may be haemophilia carriers.

> *"Yes, it was easier to talk with a person of the same sex." (Female, 40s)*

2.2. Mothers of haemophilia carriers are concerned about their daughters: The mothers sympathised with their daughters because the daughters' childhood was plagued with worries about their siblings who had haemophilia. In addition, the mothers were worried that their daughters would experience similar difficulties as they had through being the mother of a boy with haemophilia.

> *"I thought that if I cry, my daughter would cry too. I really wanted my daughter to cry [when a boy with haemophilia was born]. Because my daughter did not cry, I tried hard not to cry." (Female, 70s)*

2.3. Relationship between fathers and daughters as they are of the opposite sex: After daughters began puberty, their fathers preferred communicating with them via their wives rather than communicating directly with them on subjects such as menstruation, romantic relationships, and marriage.

> *"I did not remember when my daughter's menstrual bleeding increased. Daughters never ask fathers about menstruation. I think my daughter also never asked me about such a thing." (Male, 50s)*

2.4. Fathers with haemophilia feel guilty for their daughters: Since all daughters of fathers with haemophilia will be haemophilia carriers, these fathers worried about their daughters' response to the situation. Furthermore, they felt anxious about how their daughters might feel towards them.

> *"I was worried that my daughter would dislike me or hold a grudge against me. I felt anxious that my daughter would tell me, 'Why was I born?' and lash out at me." (Male, 50s)*

3. Preparation for informing daughters

This is an approach in which the parents proactively collect information on haemophilia, determine the timing of telling their daughters about haemophilia according to their stage of physical and psychosocial development, and adopt appropriate measures against the disease in line with this. This category is divided into the following four subcategories:

3.1. Collecting information about haemophilia: Parents proactively collected information about haemophilia. Information regarding haemophilia carriers was obtained through books, educational programmes provided by patient associations, and mothers of other haemophilia carriers.

> *"First of all, knowledge was required. But at that time, internet was not available. I asked my friend who was a medical student, 'Where can I buy medical journals?' Also, I went to a large library." (Female, 40s)*

3.2. Intentionally taking the daughter to patient association meetings: When parents participated in haemophilia patient association meetings, they took their daughters with them so that they could also obtain information about the disease. By attending the association, their daughters developed awareness of the progression of haemophilia treatment and had an opportunity to meet children with haemophilia and haemophilia carriers around the same age.

> *"In the first few years after participating in the patients' association, my daughter was small, thus we had to take her to the association. At that time, we often went on family vacations, and attending the patient association was something like a family trip." (Male, 50s)*

3.3. Consulting with a specialist: Parents asked haemophilia specialists if their daughters were haemophilia carriers, and asked about haemophilia carrier testing.

> *"I was worried that my children may carry the haemophilia gene. And I was told that you should consult Dr U." (Female, 60s)*

3.4. Observing the daughter's mental development: To determine the timing of information sharing, parents carefully observed the stage of their daughters' mental development.

> *"I thought that now is the time to tell my daughter what is a carrier." (Female, 40s)*

4. Informing the daughter while considering her feelings

Whenever parents explained haemophilia to their daughters, they used simple expressions depending on the daughters' age so that they could easily understand the explanation. While considering their daughters' stage of mental development, parents told them about haemophilia using a positive approach to enable them to feel comfortable dealing with the fact that they are carriers. This category is classified into the following four subcategories:

4.1. Gradual information sharing according to the daughter's developmental stage: Parents provided information about haemophilia, the likelihood of being a carrier, and the chances of having a child with haemophilia, according to their daughters' developmental stage.

> *"My wife started to tell the daughter, maybe she was around ten years old, that your father has haemophilia." (Male, 60s)*

4.2. Natural information sharing: Since haemophilia is a genetic disorder, the parents tried to inform their daughters about the disease through everyday life conversations.

> *"My haemophilia gene would be passed on the daughter, so I decided that I teach her about haemophilia through everyday life conversations." (Female, 40s)*

4.3. Telling the daughter about haemophilia using a positive approach: The parents discussed haemophilia with their daughters using approaches that would enable them to develop a sense of empowerment to manage the implications of their genetic condition, e.g. through involving siblings with haemophilia or considering future partners.

> *"When I told my daughter about haemophilia, I said that this is used like a litmus paper. I told her that you are a carrier and may face difficulty after having a child. I think the person who will marry my daughter after knowing such a fact would be a nice guy." (Male, 50s)*

4.4. Intentionally talking with an open mind: Mothers talked to their daughters about sex with an open mind so that they could correctly inform them about abnormal menstrual bleeding and the likelihood of having children with haemophilia.

> *"We often have an opportunity to talk about medicine with our daughter; thus, it is natural to talk about sex matters in the context of such a conversation." (Female, 40s)*

5. Being the daughter's supporter

This approach involves the parents providing continuous support after information sharing and acting as their supporters. Parents supported their daughters according to their stage of physical and psychosocial development, while considering the future effects of haemophilia on them. They confirmed whether their daughters understood haemophilia, and encouraged their daughters and their partners to seek consultation and participate in patient associations to obtain detailed information. Furthermore, the parents considered how they would support their daughters if their own children were to have haemophilia. This category is classified into the following four subcategories:

5.1. Answering questions from the daughter: Parents confirmed whether their daughters could understand

and accept information about the genetic risk of being a carrier, and answered questions from them. In doing so, they tried to encourage their daughters to deepen their knowledge of the condition.

> *"Every time I was asked, I and my son [with haemophilia] responded thoroughly until she said, 'I got it.' This had been continued for a long time." (Female, 40s)*

5.2. Encouraging daughters to visit the hospital: Parents acted as a bridge between their daughters and the haemophilia specialist so that their children could obtain detailed information and advice on being a carrier.

> *"By talking to the physician, she can get medical knowledge. She goes to the hospital to receive support of medical professionals and paramedics… I wanted her to utilise such a situation as much as possible to choose her life… I wish I can help her." (Female, 40s)*

5.3. Encouraging daughters and their partners to obtain information: Since daughters and their partners would encounter issues such as marriage and pregnancy, parents encouraged them to collect information about haemophilia.

> *"If [my daughter] becomes pregnant, she and her husband… go to the hospital and receive brief advice on haemophilia… I recommended [them] prenatal screening." (Male, 60s)*

5.4. Thinking about their daughters as parents: Since haemophilia is a genetic disorder, parents were worried that it would be passed on to their daughters' children. Thus, they intended to provide support around parenting if their daughters had children with haemophilia or children who carried the haemophilia gene.

> *"About a grandchild, I and my wife will definitely support [our daughter and her child]." (Male, 50s)*

DISCUSSION

In this study, we demonstrated that parents of daughters with confirmed or suspected carrier status used five strategies when sharing information about this with their daughters. No previous study has evaluated the role of parental couples in sharing information about being a haemophilia carrier. The present study demonstrated that the couples were open to each other by sharing values (i.e., information sharing between partners). Generally, a family with open communication handles stresses effectively during the family life cycle [15].

A previous study by Sorensen et al. showed that mothers who are haemophilia carriers frequently talk about haemophilia carrier testing [16]. Another study involving university students examined communication in the family, with results indicating that indirect communication with mothers improves family satisfaction among students who have less opportunity to directly talk to their fathers. [17]. The present study showed that mothers played a direct role in informing their daughters about haemophilia as they were of the same sex. Fathers tended to obtain information regarding their daughters, such as abnormal bleeding and concerns about romantic relationships and marriage, via the mothers (i.e., parents' roles according to sex). A Japanese survey of fathers with haemophilia found that 89% of fathers were concerned about haemophilia when they had children [7]. Since all daughters of fathers with haemophilia will carry the haemophilia gene, it is important for medical professionals to provide psychological support for these fathers and complementary support for couples.

Insufficient knowledge of a genetic disorder increases anxiety when parents inform their children about the disease [18]. Genetic risk information is shared according to the daughter's age and her relative stage of development [19]. The present study showed that parents strived to collect information on inheritance and carefully observed their daughters' mental development (i.e., preparation for informing daughters). Open communication about genetic risk throughout childhood helps children obtain deep insights into a genetic disorder, thereby helping to manage the implications of the condition. In contrast, insufficient communication about genetic risk and lack of knowledge regarding a genetic disorder can cause major stress and negative feelings within families [9]. The present study showed that the parents informed their daughters about genetic risk through everyday life conversations while considering their mental developmental stage (i.e., informing the daughter while considering her feelings).

Women who carry the haemophilia gene have a 50% chance of delivering a boy with the disorder. After delivering such a child, they can initially feel guilty, sad, and anxious about the infant. To accept the child's condition and their situation themselves, they have to feel that they receive sufficient information and support [20]. It is important to continue supporting the daughter after the genetic risk is shared with her. Open communication about genetic risk within families facilitates family members to help each other, resulting in strong family bonding [21]. As in previous studies, the present study demonstrated that parents acted as supporters to their daughters. Specifically, they advised their daughters and their partners to obtain further information about carrying haemophilia, and had intentions to try and reduce the parental and psychological burden on their daughters if their they had children with haemophilia in the future.

LIMITATIONS

The findings of the present study are not representative of all parents who have daughters with confirmed or suspected carrier status; participants were those who were willing to share information with their daughters about their carrier status. Furthermore, the findings may not apply to daughters and their mothers who are carriers of sporadic cases without a family history of haemophilia.

CONCLUSION

In the present study, we found that parents used five key strategies to communicate information about haemophilia carrier status with their daughters; specifically, parents shared information about their daughters between themselves while obtaining appropriate information about carriers. We demonstrated that it was mostly mothers who communicated this information to their daughters, based on the daughters' level of understanding and their physical and psychosocial developmental stages. After the information was shared and the daughters were aware of the possible carrier status, the parents made efforts to provide continuous support for them.

In Japan, the number of hospitals specialising in haemophilia is limited. The only way for health care providers to have contact with carriers is through parents with a family history of haemophilia; specifically, they can only start the initial assessment if the parents tell their daughters about the possibility of carrier status and encourage a hospital visit. Based on strategies such as those outlined above, medical professionals should provide parents with information about haemophilia carrier status and sharing information on genetic risk. This will enable fathers with haemophilia who visit the hospital and mothers accompanying siblings with haemophilia on hospital visits to obtain such information at an appropriate time. This could help to increase identification of haemophilia carriers and thereby improve their access to care.

ACKNOWLEDGEMENTS

The authors have advised no interests that might be perceived as posing a conflict or bias.

Informed consent has been obtained from the participants in the study reported in this paper.

Author Contribution Statement

KN interviewed all of the study participants. Both authors contributed to the study design and were involved in drafting, review, and final approval of the manuscript.

ORCID

Keiko Nozaki *https://orcid.org/0009-0007-0078-0915*
Akemi Yamazaki *https://orcid.org/0000-0002-8564-1039*

REFERENCES

1. Japan Foundation for AIDS Prevention by the Ministry of Health, Labour and Welfare: Nationwide Survey on Blood Coagulation Disorders 2021. (In Japanese). Available from *https://api-net.jfap.or.jp/image/data/blood/r03_research/r03_gaiyou.pdf* (accessed 2 February 2023)
2. Nishida Y. Care for carriers. In: Shirahata S and Fukutake K, eds. *Basic and Clinical Aspects of Hemophilia Useful for Everyone*, Revised Edn. 2016; 305-312, Osaka: Iyaku Journal Company. (In Japanese)
3. Chalmers E, Williams M, Brennand J, et al. Guideline on the management of haemophilia in the fetus and neonate. *Br J Haematol* 2011; 154(2): 208-215. doi: 10.1111/j.1365-2141.2010.08545.x
4. MacLean PE, Fijnvandraat K, Beijlevelt M, Peters M. The impact of unaware carriership on the clinical presentation of haemophilia. *Haemophilia* 2004; 10(5): 560-564. doi: 10.1111/j.1365-2516.2004.00955.x.
5. World Federation of Hemophilia (WFH). Women and Girls with Bleeding Disorders (WGBD) Initiative. Available from *https://wfh.org/treatment-and-care/#wgbd* (accessed 2 February 2023).
6. World Federation of Hemophilia (WFH). Hemophilia Carriers and Female Hemophilia 2012. (In Japanese). Available from *http://www.wfh-japanese.org/wp-content/uploads/2016/03/B01_Carriers-and-Women-with-Hemophilia-1.pdf* (accessed 2 February 2023).
7. Nakatsuka T. *Life Skills Survey Report of Hemophilia Patients*. Patient and Family Research Committee ed., NPO Network Medicine and Human Rights, 2016; 83-88. Osaka. (In Japanese)
8. Fujii T, Koga A, Ishikawa M, et al. A questionnaire survey about the needs in mothers of children with hemophilia for the purpose of supporting them. *Journal of Japan Society of Genetics and Nursing* 2015; 13(2): 83-90. (In Japanese)

9. Metcalfe A, Plumridge G, Coad J, Shanks A, Gill P. Parents' and children's communication about genetic risk: a qualitative study, learning from families' experiences. *Eur J Hum Genet* 2011; 19(6): 640-646. doi: 10.1038/ejhg.2010.258.
10. Nozaki K, Kawahara T, Kikuchi R, Yamazaki A. Experience of parents sharing information with daughters about the possibility of daughters being hemophilia carriers. *Japanese Journal of Family Nursing* 2022; 27(2):105-115. (In Japanese)
11. Thomas S, Herbert D, Street A, et al. Attitudes towards and beliefs about genetic testing in the haemophilia community: a qualitative study. *Haemophilia* 2007; 13(5): 633-641. doi: 10.1111/j.1365-2516.2007.01454.x.
12. Kadir RA, Sabin CA, Goldman E, et al. Reproductive choices of women in families with haemophilia. *Haemophilia* 2000; 6(1): 33-40. doi: 10.1046/j.1365-2516.2000.00353.x.
13. von der Lippe C, Frich JC, Harris A, Solbrække KN. "It was a lot tougher than I thought it would be". A qualitative study on the changing nature of being a hemophilia carrier. *J Genet Couns* 2017; 26(6): 1324-1332. doi: 10.1007/s10897-017-0112-9.
14. Flick U, Oda H, Yamamoto N, Kasuga T, Miyaji N. *Qualitative Sozialforschung*. 2018. Tokyo: Shunjusha. (In Japanese)
15. Tachiki S. *Annular Model Hypothesis and Empirical Research, Analytical Perspectives of Family Sociology. Applications and Problems of Sociological Approaches* 1996, 166, Tokyo: Minerva Shobo. (In Japanese)
16. Sorenson JR, Jennings-Grant T, Newman J. Communication about carrier testing within hemophilia A families. *Am J Med Genet C Semin Med Genet* 2003; 119C(1): 3-10. doi: 10.1002/ajmg.c.10001.
17. Itakura N. Examining the association of direct and indirect communication in family with adolescents: focused on relations with family satisfaction. *The Annual Reports of the Graduate School of Education*, Tohoku University 2013; 62(1):273-282. (In Japanese)
18. Fujii T, Fujii T, Miyakoshi Y. Mothers' intentions and behaviours regarding providing risk communication to their daughters about their possibility of being haemophilia carriers: A qualitative study. *Haemophilia* 2019; 25(6): 1059-1065. doi:10.1111/hae.13864.
19. Gregory M, Boddington P, Dimond R, et al. Communicating about haemophilia within the family: the importance of context and of experience. *Haemophilia* 2007; 13(2): 189-198. doi: 10.1111/j.1365-2516.2006.01417.x.
20. Myrin-Westesson L, Baghaei F, Friberg F. The experience of being a female carrier of haemophilia and the mother of a haemophilic child. *Haemophilia* 2013; 19(2): 219-224. doi: 10.1111/hae.12026.
21. McConkie-Rosell A, Heise EM, Spiridigliozzi GA. Genetic risk communication: experiences of adolescent girls and young women from families with fragile X syndrome. *J Genet Couns* 2009;18(4):313-25. doi: 10.1007/s10897-009-9215-2.

HOW TO CITE THIS ARTICLE:
Nozaki K, Yamazaki A. The strategies of parents who tell their daughters about the possibility of being a haemophilia carrier. *J Haem Pract* 2023; 10(1): 39-47. *https://doi.org/10.2478/jhp-2023-0008*