# The invisible child: sibling experiences of growing up with a brother with severe haemophilia – an interpretative phenomenological analysis.

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**Abstract**

*Introduction*: Haemophilia is an inherited chronic condition that causes bleeding in the joints and soft tissue. Healthy siblings growing up in the family of a person with haemophilia can be affected socially and psychologically.

*Aim*: To explore qualitatively the experiences of healthy siblings who grew up with a brother with severe haemophilia.

*Methods*: 11 healthy siblings (10 female, 1 male) who grew up with a brother with severe haemophilia A were recruited via the Haemophilia Society UK. The verbatim transcripts of individual semi-structured interviews were analysed using interpretative phenomenological analysis (IPA).

*Results*: Three themes were identified: *lack of parental attention, negative social emotions,* and *carrier status anxiety.* Participants described having engaged in attention seeking behaviours because they felt they lacked parental attention. They also described the resentment, anger and frustration they felt about the effect their brothers' haemophilia had on their lives. Female participants described the impact their carrier status or lack of it had on their lives.

*Conclusion*: These findings could be translated into better advocacy and support for siblings through haemophilia centres. More research is also needed on how healthy siblings are affected by haemophilia, including studies guided by family systems theory.

## Introduction

Haemophilia is an inherited bleeding disorder caused by the absence or deficiency of coagulation factor VIII (haemophilia A) or factor IX (haemophilia B). It is an X-chromosome-linked genetic condition that is usually carried by females and suffered as an illness by males. Like many other chronic conditions, haemophilia can impact on family life, adjustment and coping [1, 2]. Sibling relationships are important family bonds, for siblings share a common genetic heritage, cultural environment and early experiences, and childhood is when siblings are emotionally and physically closest, spending more time with each other than with other family members [3]. However, healthy siblings of children with serious chronic illnesses have been described as 'forgotten' family members despite the fact that they can experience changes to everyday life just as much as the clinically affected child [4].

In one study, rates of social dysfunction in leisure, school and family settings were as high among healthy siblings as they were among boys with haemophilia [1]. Parents of children with severe haemophilia described in interviews how siblings might not understand why they needed to be careful with a brother with haemophilia; how they had to be taught how to behave appropriately without being overprotective; and how siblings could be supportive early in life but become frustrated later as they became more aware of how family life was being disrupted [5]. One very brief summary report suggested that female siblings of people with bleeding disorders were more affected than male siblings; that female carrier siblings had greater anxiety than female non-carrier siblings; and that 40% of siblings felt the child with a bleeding disorder was treated better than they were [6].

However there is no published evidence to our knowledge about the social and psychological implications for healthy siblings of children with haemophilia from the perspective of the siblings themselves. The present study therefore explored the lived experiences of healthy siblings who grew up with brothers diagnosed with severe haemophilia A. We used semi-structured interviews and a qualitative, phenomenological approach to gain insights into participants' experiences of growing up with a brother with severe haemophilia, and how they experienced family interactions and social and emotional functioning and adjustment in that context.

## Methods

### Design

Phenomenological research enables researchers to understand and explore specific experiences of groups of individuals [7]. Interpretative phenomenological analysis (IPA) aims to understand participants' day-to-day lived experiences by making sense of their beliefs, perceptions, behaviours and motivations through a process of interpretation [8-10]. One goal of IPA is to produce an account that is as close to the participants' own experiences as possible [11]. IPA has its roots in health psychology [12], and has been described as a 'qualitative methodology of choice in healthcare research' [13], especially for research in previously unexplored areas [14].

### Recruitment and participants

Participants were recruited in a collaboration with the Haemophilia Society UK, using a purposive sampling strategy [15] to achieve a small, homogenous sample of 5 to 10 participants, as recommended for IPA studies to achieve a detailed analysis with all the participants represented [10, 12]. The inclusion criteria included being over 18 years old and having grown up with a brother with severe haemophilia A.

**Table 1: Participant details**

| Pseudonym | Age | Place of residence | Haemophilia/ carrier status | Brothers with haemophilia | Type of treatment the brother received | Children |
|---|---|---|---|---|---|---|
| Alice | 60s | South East England | Negative | One older, one younger (both now deceased) | Hospital-based | Three boys (none with haemophilia), one girl |
| Sophie | 30s | South East England | Positive | One younger | Portacaths and prophylaxis | One daughter |
| Ben | 50s | England | Negative | One younger | Portacaths and prophylaxis | None |
| Rose | Late teens | Northern England | Did not say | One younger | Portacaths and prophylaxis | None |
| Sally | 50s | California, USA | Positive | One older (now deceased) | Hospital-based | Two daughters |
| Mary | 30s | North West England | Did not say | One younger | Portacaths and prophylaxis | None |
| Jane | 20s | Central England | Negative | One younger | Portacaths and prophylaxis | None |
| Katie | 20s | Scotland | Positive | One younger | Portacaths and prophylaxis | One son (not with haemophilia) |
| Rachel | 20s | England | Not tested | One older, one younger | Prophylaxis | None |
| Hilary | Not known | England | Positive | One older | Hospital-based | None |
| Jessica | 20s | South East England | Negative | One older | Prophylaxis | None |

Note to table 1: Some personal details have been changed to protect participants' identities

An invitation to participate was posted on the Society's Facebook page and shared with the Haemophilia Youth Society and 'The Clot Thickens' Facebook pages, to target those most likely to meet the inclusion criteria. The sample comprised 11 adult siblings (10 female and 1 male). The participants were all white British and were all living in the UK except for Sally who had moved to the USA to study. See Table 1 above for participant information (pseudonyms were used to protect participants' identities).

**Procedure**

Individuals who responded to the invitation were directed to a Qualtrics weblink giving an information sheet and consent form. Eligible, consenting respondents were asked to create a unique identifying code, enabling their anonymised data to be identified and deleted if they changed their mind after the data collection and wanted to withdraw from the study. The data were collected using semi-structured interviews, which were conducted over Skype or Facebook Messenger and, in one case, face-to-face, at a time convenient for participants. The interview schedule, which was provided for participants prior to the interview, is given in Table 2 below. For IPA, interview schedules should be as brief as possible, starting with broad questions [16]. They should allow interviewees to lead the conversation with the researcher, who should use the schedule only as a guide, and use additional prompts to encourage participants to describe and explore further where necessary [11, 13, 17].

The interviews lasted 22–31 minutes and were recorded using an Acer laptop for the Skype and Facebook Messenger interviews and an Android mobile phone for the face-to-face interview. When the interview was completed, participants were debriefed verbally and sent a written debriefing consisting of further information about the aims and purpose of the study; a very brief summary of previous findings; a reminder of participants' right to withdraw from the study and have their data deleted after the interview; signposting to participants' GPs, haemophilia centres and the Haemophilia Society if participants had any concerns about haemophilia; and contact details of the researchers. The study protocol was approved by the University of Derby Human Sciences Research Ethics Committee. British Psychological Society ethical guidelines for internet-mediated research were followed throughout [18, 19]. The data were anonymised and pseudonyms were used to protect participants' identities. All audio recordings and transcripts were stored on a secure password-protected laptop, and the archived data will be kept for seven years following the study.

**Analytic approach**

The interviews were transcribed verbatim by CT. In keeping with the IPA commitment to an idiographic approach, each transcript was analysed individually and in depth [10]. Exploratory comments about initial thoughts on the content, language and concepts were noted in one margin. After further reading of the text the other margin was used to note emergent themes, drawing from both the transcript and the exploratory comments. The analysis of each transcript followed this pattern until all the transcripts had been analysed, and the emergent themes from each transcript were then organised in clusters of related super-ordinate themes. The final stage was looking for patterns across cases, which was achieved by clustering the super-ordinate themes into master themes.

**Table 2: Interview schedule**

| |
|---|
| Thank you for agreeing to be interviewed about your experiences growing up with a sibling with haemophilia. Please answer the following questions as openly as you can. If you decide you would rather not answer any questions or require a break if you find the questions emotive please indicate this to be the case. |
| How would you describe your experiences of growing up with a brother with haemophilia? |
| Can you describe to me how you felt when your brother had to go to hospital? |
| Can you describe for me the relationship you had with your brother as a child? |
| Can you describe to me how your brother's disorder affected your family life? |
| Can you describe to me if you felt like you were treated any differently to your brother? How did this make you feel? |
| Can you describe to me any feelings of jealousy you had towards your brother? |
| Can you describe to me any feelings of guilt you may have had as you did not have haemophilia? |
| Can you describe to me how having a brother with haemophilia affected your school life? |
| Can you describe to me the relationship you have with your brother now? |
| As an adult, can you describe to me how your experiences growing up with a haemophiliac sibling has affected your adult life? |

## Results

Three themes emerged from the analysis: *lack of parental attention, negative social emotions,* and *carrier status anxiety*. These are described below along with representative quotations, which are presented with participants' pseudonyms and transcript line numbers as part of the audit trail for the data analysis.

### Theme 1: Lack of parental attention

This theme captured the different ways participants experienced reduced parental attention and feelings of being left out, which led to experiences of greater independence, closer relationships with other siblings and development of attention-seeking behaviours. Some feelings of being left out and not getting attention resulted from participants seeing their parents caring for their brother whereas they were not allowed to do so themselves. For example, Jessica recalled that when her brother was having his injections it involved both her parents but because of what she perceived as the seriousness of the situation, she was not allowed to be present:

*'I want to be involved, why am I not? I wanna help, you know?'* (Jessica: 130-131)

Mary often felt left out by her parents because of her brother's hospitalisations, which led to her becoming more independent from a young age:

'*And I would be just left to my own devices quite a lot'* (Mary: 148-149)

Jane, on the other hand, recalled how she had to stay with different relatives while her parents were with her brother in hospital, and how she pulled away from her mother and formed an almost maternal attachment with her older sister:

'*So, I think we became quite, like, independent and close'* (Jane: 95-96)

Jane was also aware that her brother received more attention and understood it was not his fault, so she tried to use positive behaviours to get her mother's attention:

*'I'll just be really nice and really good. And be quiet'* (Jane: 224-225)

However, other participants' attention-seeing behaviours included 'acting out' in response to what Rachel described as a need to be validated by others because her brother received so much attention, and more extreme attention-seeking later in life, which Hilary attributed to feeling excluded by her parents:

*'Erm, I think I acted out quite a lot as well, just with not getting my mum's attention'* (Rachel: 113-114)

'*But also, I was desperate for attention from people I ended up, erm, having sexual relationships with people who weren't interested in me, just because I wanted attention'* (Hilary: 381-384)

**Theme 2: Negative social emotions**

Participants described internalising negative feelings like frustration, resentment and anger about their brothers with haemophilia, which began during childhood and continued during adult life. Frustration often occurred during childhood and was sometimes associated with not being able to help their brothers with their illness. In one example, Jessica described how she felt when her brother was in pain in hospital with a bad bleed:

'*It's the frustration of watching him, you know, when you watch your sibling'* (Jessica: 229-300*)*

Other participants described their frustration during childhood over ways that haemophilia affected their own lives by limiting or disrupting their own activities or family activities. In one example, Sophie described her frustration over an experience where her chance to achieve a personal goal related to a family day out had been blocked:

*'Yeah, it did happen a few times and it can, it could be frustrating'* (Sophie: 90-91)

Participants also described resentment that continued into adult life. For example, Jane described how she and her sister both felt they had needs that were never satisfied during childhood, so they still felt resentment as adults, having created a self-fulfilling prophecy by pushing aside the one person they wanted a relationship with by their continued display of negative emotions:

'*There are parts of us that resent him, resent him and resent all the attention'* (Jane: 314-315)

Another participant described how her parents praised her brother excessively while disregarding her own achievements. She regarded her parents as living their lives though her brother, having stripped him of his true identity and put him on a pedestal:

'*My brother is seen as the Golden Child'* (Hilary: 299)

Several participants described feeling angry about the ways their brother's haemophilia had affected them. For example, asked if she ever felt angry towards her brother, Hilary's answer was very definite and without hesitation, and her emphasis and repetition showed the strength of her feelings: '*Yes, yes, very'* (Hilary: 220). Hilary seemed to have used anger as a form of psychological self-soothing for both her childhood and adult experiences, which had made her feel invalidated, and she yearned for the secure attachment with her parents that was lacking in childhood.

One participant began feeling angry when he felt that even as an adult, his brother was using his haemophilia as an excuse not to make the most of his life. He felt self-righteous and critical of his brother, which gave him a powerful but temporary self-esteem boost, and found it more satisfying to feel angry than acknowledge his pain and vulnerability over his feelings towards his brother:

*'Mostly, I started feeling some anger towards him when we were, sort of, young adults'* (Ben: 120-121)

Negative emotions seemed to develop and progress over time, with frustration over practical issues during childhood being translated into more complex feelings of resentment and anger that remained with participants well into adult life, as they reflected on their childhood experiences and made interpretations and attributions about the actions and motivations of their brothers and their parents. However, not all the emotional responses described by participants were negative. Some participants described normal aspects of their childhood experiences:

'*I never felt anything other than that was normal life, and I didn't feel put out by it or anything*' (Alice: 89-90)

'*We forget actually that he has haemophilia because its…he handles it so well*' Sophie: 297-299)

Other participants described ways their childhood experiences had affected them in positive ways:

'*You grow up always thinking of someone else*' (Sally: 391-392)

'*I am definitely appreciative, like, of other people and other disabilities as well*' (Rose: 400-401)

**Theme 3: Carrier status anxiety.**

Four of the participants described having been tested and finding they were carriers of haemophilia; Sophie and Katie did not give the age at which they were tested, but Hilary described how she was tested at age 16, and Sally described how she was tested when she was pregnant. These four all described the impact of the knowledge of being a carrier. For example, Sally, whose brother died because of human immunodeficiency virus (HIV), could not bear the thought of her own children suffering in the same way:

'*The biggest effect it had is that I am a carrier'* (Sally: 357-358)

Sophie, who had a daughter, described how her knowledge of haemophilia made her anxious when considering having another child, and how if she had a son she would be worried for him because of her own experience of seeing her brother suffer:

*We do think how our lives will probably change, you know, if we were to have a little boy with haemophilia'* (Sophie: 426-428)

None of the participants had children with haemophilia, but one participant who wanted to have children described how negative experiences of growing up with a brother with haemophilia, as well as having seen her mother being extremely anxious when her brother was a child, led her to try to avoid this experience by using in-vitro fertilisation (IVF) with pre-implantation genetic diagnosis (PGD):

'*We were actually going through PGD…'* (Hilary: 475-476).

Rachel, who said about being tested, 'I really should but I have not' (lines 278), described how she had observed her own mother's anxiety about being a carrier and having sons with haemophilia, and now felt anxious herself about the risk of having a child with haemophilia, which had so far deterred her from having children.

*'I feel like, if haemophilia hadn't been there I would have done it already'* (Rachel: 272-273)

Other participants also described mixed emotions about their negative carrier status. In one case, Jane and her older sister had formed a strong sibling bond in childhood (see earlier) so when it became known that her sister was a carrier but Jane was not, Jane felt this brought her sister closer to her brother:

'*So, she's…I'm the odd one out in the middle' [...]* '*I wasn't a carrier and [Sister's name] was, I felt a little bit, like, left out*' (Jane: 11, 166-167)

This led to Jane feeling more bitterness and resentment about feeling left out, which may have caused her attention-seeking behaviours to continue into adulthood as she believed that if she were also a carrier, she might have received more attention from her mother.

## Discussion

All the participants reported feeling left out because their parents devoted more attention to their brother, and the analysis gave insights into the ways both positive and negative adaptations and behaviour changes can result from reduced parental attention.

There are a number of parallels between the themes above and evidence about the effects of childhood chronic illness more generally. For example, siblings of children with chronic illnesses often struggle with feelings of loneliness, loss and separation because of a lack of parental attention [20], and acting out to gain attention was also reported in a study where competition for parental affection and attention led to maladaptive behaviours among the healthy siblings of chronically ill children [21].

The main emphasis in the experiences of participants in the present study as captured in the three themes identified here was negative experiences, but participants did also describe positive experiences, for example '*I am a lot more positive about life, I think*' (Rachel: 321-322).

Healthy siblings of children with chronic disorders also often report positive effects, including increased independence and autonomy [22]. One study found the siblings of children with chronic health conditions modified their behaviour to reduce the burden on their parents [23], and another found they developed greater compassion, empathy, sensitivity and patience [24]. A study of the siblings of disabled children reported that they felt a sense of personal fulfilment when the affected sibling accomplished new goals [25]. A study of communication in families affected by genetic illness found that some siblings reported intense relationships with their affected siblings [26], and there is evidence that children with a chronically ill sibling understand the fragility of life in a way that siblings of healthy children may not be able to comprehend [21].

However, being the sibling of a child with a chronic illness often has negative effects on psychological adjustment and development, and a meta-analysis showed that the psychological impact was greater for illnesses that involved daily treatment regimes than for those that did not affect daily functioning [27]. Another study of healthy siblings of children with chronic physical disorders found that better sibling adjustment was associated with greater maternal awareness of their attitudes and perceptions [28]. Based on those findings, more frequent disruption of daily life cause by a brother's haemophilia, and consequently reduced parental attention to the healthy sibling, could act as risk factors for reduced adjustment and wellbeing, which could help to explain the negative experiences of participants in the present study.

The participants' experiences of carrier status anxiety are also consistent with previous research, for knowledge and experiences of the condition and its severity may be important factors for carriers of haemophilia when considering their own reproductive choices [29]. For example, an interview study of 40 mothers of sons with haemophilia found their child bearing decisions were based on knowledge of carrier status. All the women stated that knowing their carrier status enabled them to make informed reproductive choices, and 30 of the 40 women said they would not have more children [30].

In-vitro fertilisation followed by post implantation genetic diagnosis, which Hilary described (see earlier) is an effective way for a woman who is a haemophilia carrier to avoid having an affected child, and all couples at risk of having a child with haemophilia, including all women at risk of being carriers,

are advised to be tested and have knowledge of their genetic and carrier status before making decisions about reproduction [31].

There are some potential limitations to the study that should be considered alongside the findings. First, the sample was restricted to siblings of people with severe haemophilia A, and participants were recruited to the study via the Haemophilia Society UK. The restriction to severe haemophilia A was intended to maximise sample homogeneity and ensure that participants shared the experience of growing up with a sibling with the same form of severe haemophilia. However, it also means the findings may not generalise to siblings of people with haemophilia B or mild haemophilia A.

Recruitment was undertaken via the Haemophilia Society in order to extend the invitation to participate to a large number of people likely to meet the inclusion criteria and be willing to take part. However, it might also mean that participants were more affected by haemophilia, or more actively engaged in haemophilia-related issues, than non-Society members, for example if Society members were more likely to join support groups and get involved in haemophilia-related debate and activity.

Second, although the sample was homogenous in relation to the type and severity of haemophilia involved, participants were quite variable in terms of age, which meant that the treatments their brothers received also varied. The older participants' brothers mainly had hospital-delivered care, and three of the brothers (both of Alice's and Sally's) died as a result of contaminated blood. The brothers of the younger siblings mainly had portacaths and prophylaxis. Some younger participants spoke of their relief that their sibling's treatment was safer than that received by the previous generation, which meant they were less affected themselves by their siblings' haemophilia.

Third, reliability and validity cannot be definitively demonstrated in qualitative research, which must instead depend on 'trustworthiness': credibility, transferability, dependability and confirmability [32,33]. To maximise those elements of trustworthiness, the procedures for confidentiality and anonymity were designed to encourage and enable all participants to be as honest as possible; a second person (JE) reviewed the transcriptions and analysis; the data analysis was undertaken very systematically, with an audit trail showing the specific data on which themes were based and the process by which themes were arrived at; and both authors undertook a reflexive exercise to reduce the likelihood of biases resulting from their own experiences or interests.

Ultimately, however, the validity and transferability of the findings will depend on further research, or evaluations of interventions informed by the findings. For example, the findings could guide the development of interventions to support healthy siblings of children with haemophilia by helping them develop better coping and adjustment strategies. Resources like that presently consist mainly of written information and advice leaflets [34, 35]. Those materials could be extended with first-person accounts of sibling experiences like those collected in the present study, and the present findings and further research could be translated into improved advocacy and counselling for healthy siblings in families affected by haemophilia, which could potentially be offered through Haemophilia Centres, especially if specific issues were identified and targeted for intervention.

Theoretical models try to explain how sibling and family relationships function, and ecological systems theory (EST) focuses on the whole family which is seen as organised into hierarchal subsystems; the sibling, the parents, the sibling relationship, the parent/child relationship and the whole family system [36, 37]. This approach could help practitioners to focus on family systems that influence sibling wellbeing, in order to provide more effective supportive services to siblings and their families. In doing this, practitioners should understand that each sibling is different, with potentially different support needs.

More research is also needed on how healthy siblings are affected by haemophilia, and these could include studies guided by family systems theory. Future research could also include comparative studies where ethnicity can be considered, for the present study included only siblings of white European heritage. Comparative and ethnological methods could produce more inclusive findings that would help practitioners to be more culturally sensitive to healthy siblings and their brothers with haemophilia from different cultures.

To conclude, the study provided insights into ways that healthy siblings were significantly impacted by being in a family affected by haemophilia. The findings can inform the design and content of better interventions, advocacy and support for siblings, which could potentially be provided through haemophilia centres.

**Reflexivity**

The realist epistemology of IPA recognizes the impact the researcher has on their interaction with their participants and the subsequent interpretation of the data [38]. CT reflected: "I am a haemophilia carrier with two sons with moderate haemophilia A. My father has haemophilia, but he is the only one out of four brothers and only one of his three sisters is a carrier. This made me consider how my father's siblings were affected while they were growing up with him." JE reflected: "My family is not affected by haemophilia and my main experience of haemophilia comes from meeting and working with people with haemophilia as part of teaching and research."

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**References**

[1] Clemente, C., Tsiantis, J., Kolvin, I., Ba, G., Christogiorgos, S., Lees, C.,…& Miller, R. (2003). Social adjustment in three cultures: data from families affected by chronic blood disorders. A sibling study. *Haemophilia, 9*(3), 317-324.

[2] Cassis, F. Y., Querol, F., Forsyth, A., & Lorio, A. (2012). Psychosocial aspects of haemophilia: a systematic review of methodologies and findings. *Haemophilia*, *18*(3), e101-e114.

[3] Dunn, J., & McGuire, S. (1992). Sibling and peer relationships in childhood. *Journal of Child Psychology, 31*(1), 67-105.

[4] Sidhu, R., Passmore, A., & Baker, D. (2006). The effectiveness of a peer support camp for siblings of children with cancer. *Paediatric Blood & Cancer*, *47*(5), 580-588.

[5] Beeton, K., Neal, D., Watson, T., & Lee, C. A. (2007). Parents of children with haemophilia–a transforming experience. *Haemophilia*, *13*(5), 570-579.

[6] Fung, E. (2010). What does the research tell us? *In Special Sibs*, produced by the Hemophilia Federation of America (2014). Retrieved from http://www.hemophiliafed.org/uploads/Special-Sibs_Resource.pdf
[7] Langdridge, D. (2007). *Phenomenological psychology: Theory, research and method*. Harlow, UK: Pearson Education Ltd.
[8] Larkin, M., Watts, S., & Clifton, E. (2006). Giving voice and making sense in interpretive phenomenology analysis. *Qualitative Research in Psychology, 3*(2), 102-120.
[9] Smith, J.A. and Osborn, M. (2008) Interpretative phenomenological analysis. In: J.A. Smith (ed.) *Qualitative Psychology: A Practical Guide to Methods*, 2nd edition. London: Sage.
[10] Smith, J.A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory and research*. London: Sage.
[11] Smith, J. A. (2011). Evaluating the contribution of interpretative phenomenological analysis. *Health Psychology Review, 5*(1), 9-27.
[12] Smith, J.A. (2004). Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative psychology. *Qualitative Research in Psychology, 1*(1), 39-54.
[13] Biggerstaff, D., & Thompson, A.R. (2008) Interpretative Phenomenological Analysis (IPA): A qualitative methodology of choice in healthcare research. *Qualitative research in Psychology, 5*(3), 214-224.
[14] Reid, K., Flowers, P., & Larkin, M. (2005). Interpretative phenomenological analysis: An overview and methodological review. *The Psychologist, 18*(1), 20-23.
[15] Rubin, A., & Babbie, E. (2005). Sampling and surveys. In Gebo, L., & Michelena, A.D. (Eds.), *Research methods for social work* (239-280). Belmont: CA Thomson Brooks/Cole.
[16] Hefferon, K., & Gil-Rodriguez, E. (2011). Reflecting on the rise in popularity of interpretive phenomenological analysis. *The Psychologist, 24*(10), 756-759.
[17] Creswell, J. (2012*). Qualitative inquiry and research design: Choosing among five approaches* (3rd ed). Thousand Oaks, CA: Sage Publications, Inc.
[18] British Psychological Society (2013). *Ethics guidelines for internet-mediated research*. Leicester: British Psychological Society.
[19] British Psychological Society (2018). *Code of Ethics and Conduct*. Leicester: British Psychological Society.
[20] Knecht, C., Hellmers, C., & Metzing, S. (2015). The perspective of siblings of children with chronic illness: A literature review. *Journal of Paediatric Nursing: Nursing Care of Children and Families*, *30*(1), 102-116.
[21] Fleary, S. A., & Heffer, R. W. (2013). Impact of growing up with a chronically ill sibling on well siblings' late adolescent functioning. *ISRN Family Medicine*, 737356.
[22] Havermans, T., & Eiser, C. (1994). Siblings of a child with cancer. *Child: care, health and development*, *20*(5), 309-322.
[23] Vermaes, I. P., van Susante, A. M., & van Bakel, H. J. (2012). Psychological functioning of siblings in families of children with chronic health conditions: A meta-analysis. *Journal of Paediatric Psychology*, *37*(2), 166-184.
[24] Bellin, M. H., & Kovacs, P. J. (2006). Fostering resilience in siblings of youths with a chronic health condition: A review of the literature. *Health & Social Work*, *31*(3), 209-216.
[25] De Caroli, M. E., & Sagone, E. (2013). Siblings and disability: A study on social attitudes toward disabled brothers and sisters. *Procedia-Social and Behavioural Sciences*, *93*, 1217-1223.

[26] Metcalfe, A., Coad, J., Plumridge, G. M., Gill, P., & Farndon, P. (2008). Family communication between children and their parents about inherited genetic conditions: a meta-synthesis of the research. *European Journal of Human Genetics*, *16*(10), 1193.

[27] Sharpe, D., & Rossiter, L. (2002). Siblings of children with a chronic illness: a meta-analysis. *Journal of Paediatric Psychology, 27*(8), 699-710.

[28] Taylor, V., Charman, T., & Fuggle, P. (2001). Well sibling psychological adjustment to chronic physical disorder in a sibling: How important is maternal awareness of their illness attitudes and perceptions? *The Journal of Child Psychology and Psychiatry and Allied Disciplines*, *42*(7), 953-962.

[29] Tedgård, U., Ljung, R., & McNeil, T. F. (1999). Reproductive choices of haemophilia carriers. *British Journal of Haematology*, *106*(2), 421-426.

[30] Naicker, T., Aldous, C., & Thejpal, R. (2016). Haemophilia: A disease of women as well. *South African Journal of Child Health*, *10*(1), 29-32.

[31] Street, A. M., Ljung, R., & Lavery, S. A. (2008). Management of carriers and babies with haemophilia. *Haemophilia*, *14*(s3), 181-187.

[32] Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information*, *22*(2), 63-75.

[33] Morrow, S. L. (2005). Quality and trustworthiness in qualitative research in counseling psychology. *Journal of Counseling Psychology*, *52*(2), 250.

[34] McKay, C. (2015). Siblings – best of friends and rivals. *Bloodline* (Newsletter of the Haemophilia Foundation of New Zealand), 43 (1), 4-5. Retrieved from http://www.haemophilia.org.nz/community/bloodline/bloodline-march-2015/

[35] Hemophilia Federation of America (2014). *Special Sibs.* Retrieved from http://www.hemophiliafed.org/uploads/Special-Sibs_Resource.pdf

[36] Cridland, K., Jones, S., Magee, C., & Caputi, P. (2013). Family-focused Autism Spectrum Disorder research: A review of the utility of family systems approaches. *Autism,18*(3), 213-222 .

[37] Whiteman, S., McHale, S., & Soli, A. (2011). Theoretical perspectives on sibling relationships. *Journal of Family Theory & Review, 3*(1), 124-139.

[38] Willig, C. (2013). *Introducing qualitative research in psychology*. Maidenhead: Open University Press.