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Social support and resilience in persons with severe haemophilia: An interpretative phenomenological analysis

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Abstract

Introduction: Haemophilia is a hereditary haemorrhagic disorder characterized by deficiency or dysfunction of coagulation factors. Recurrent joint and muscle bleeds lead to progressive musculoskeletal damage. Haemophilia affects patients physically but also socially and psychologically. Traumatic experiences, chronic stress and illnesses can lead to mental disorders, but many persons with haemophilia maintain a highly positive outlook.

Aim: To explore qualitatively which coping mechanisms persons with haemophilia use and in what way they help them to live with their diagnosis.

Methods: We recruited five adults with haemophilia and conducted semi-structured face-to-face interviews. Transcripts were analysed using interpretative phenomenological analysis (IPA).

Results: Two core themes emerged from the analysis: social support as an external factor and resilience as an internal factor of coping with the disease. Persons with haemophilia usually need help with health-related complications, and this affects the social support they require. Their wider support network tends to involve family and friends but also healthcare professionals and other specialists. This network provides practical help but also functions as an important psychological protective factor. An unexpected finding was that persons with haemophilia want not only to receive support but are also keen to offer support to others.

Conclusion: These findings can help identify persons who provide most support to people suffering from haemophilia. Haemophilic centres should include in their teams psychologists and social workers and offer individual and group therapy to their clients, group meetings for friends and families of persons with haemophilia, provide learning resources to teachers aiming to incorporate children with haemophilia in their peer group, and organize Balint groups for physicians, psychologists and other healthcare professionals.

KEYWORDS

group therapy, haemophilia, individual therapy, resilience, social support

1 | INTRODUCTION

Haemophilia is a hereditary haemorrhagic disorder characterized by deficiency or dysfunction of certain coagulation protein factors.[1] Recurrent joint and muscle bleeds lead to severe and progressive musculoskeletal damage. It is a genetic condition which mainly affects men, while women are often carriers of the affected gene.[2] To prevent or minimize the impact of the disease, patients are treated with concentrates of the missing factors.[3] Patients with severe haemophilia are often treated preventively with repeated intravenous infusions of factor concentrates to prevent bleeding.[4] Patients with non-severe phenotype are usually treated only on demand.[3] One of the most severe complications of haemophilia is the development of inhibitors,[5] ie allo-antibodies against the therapeutically administered factor. In the Czech Republic, inhibitors are detected in 33% of previously untreated patients with severe haemophilia A.[6] Inhibitors present a serious challenge to persons with haemophilia (PWH): their presence makes treatment less effective than the treatment of haemophilia without inhibitors, and bleeds tend to be significantly more frequent.[7] Although new treatment options for both inhibitor and non-inhibitor patients, including those with subcutaneous application, are emerging on the market,[8] most patients are still treated with repeated intravenous infusions. This places additional burden on patients whose quality of life is already compromised.[9] Haemophilia, and especially haemophilia with inhibitors, thus affects patients physically but also socially and psychologically.[10] Available evidence shows that adults with haemophilia face many challenges linked to their disease, including difficulty to control bleeding episodes,[11] deterioration of joints,[12] arthritic pain,[13] physical disability,[14] emotional turmoil,[15] social issues,[16] financial problems[17] and treatment-related issues,[18] all of which also affects relationships in their families.[19] Traumatic experiences, chronic stress and health complications can lead to the development of mental disorders.[20]

Despite all this, a study measuring quality of life in PWHs found that they perceive their quality of life very positively.[21] Another study indicates the enormous importance of self-esteem in PWHs with respect to whether they develop depressive disorders and/or anxiety states.[22] Health psychology studies show that adequate use of coping strategies can help patients to cope with disease-related stress.[23]

To the best of our knowledge, however, evidence and detailed knowledge of the specific coping mechanisms that help PWH cope with disease-related stress are lacking. Our aim here was to explore how patients diagnosed with severe haemophilia (possibly also with inhibitors) cope with their disease and stress in everyday life. We also investigated which coping mechanisms PWHs apply, in what situations and in what ways this helps them.

2 | METHODS

2.1 | Design

Phenomenological approach works by focusing on specific phenomena, their identification and description of how they are perceived by actors in particular situations. In research that deals with people, this tends to translate into gathering 'deep' information and perceptions by inductive, qualitative methods such as interviews, discussions, and observation, and representing gathered information from the perspective of the research subject.[24] Interpretative phenomenological analysis (IPA) was developed as a particular approach to qualitative research in psychology.[25] Its aim is to explore in detail how participants make sense of their personal and social world.

TABLE 1 Participant information

Pseudonym	Age	Haemophilia
Jan	44	A with inhibitors
Pavel	67	B without inhibitors
Petr	26	A with inhibitors
Milan	44	A with inhibitors
Adam	63	A with inhibitors

2.2 | The sample

Participants were recruited in a collaboration with the Haemophilia Society of the Czech Republic and haemophilic centres in tertiary hospitals using purposive sampling, ie a technique also known as non-probability, purposeful, qualitative sampling. Purposive sampling involves a selection of subjects based on a specific purpose rather than randomly.[26] To achieve a detailed analysis of all participants, it is recommended that IPA be applied to small, homogenous samples of 2-22 participants. Our inclusion criteria were age over 18 years and diagnosis of severe haemophilia A or B with or without inhibitors.

Potential participants were addressed by their attending physician or the head of the Haemophilia Society of Czech Republic to target those most likely to meet our inclusion criteria and willing to participate. Our final sample included five adult men, four of whom have haemophilia A with inhibitors and one haemophilia B without inhibitors. Participants were all of Czech nationality, Caucasian and resident in the Czech Republic. In the following, their identity is protected by pseudonyms. For more on participant information, see Table 1.

2.3 | Procedure

When addressed about participation in our study, subjects were informed about the purpose of the study and an interview schedule was provided to them in advance. They had enough time to voice questions or concerns about the study. Those who agreed to participation were invited either to a hospital or visited at home for a semi-structured interview.

Interpretative phenomenological analysis interviews consist of one or two central questions followed by several sub-questions.

These sub-questions narrow the focus but leave space for questioning. Qualitative researchers often use open-ended questions because it leaves space for interviewees who wish to explore some subject in more depth.[27]

Before completing the interview, participants were reminded about their right to withdraw from the study. All participants signed informed consent and received contact details of the researchers. They were reimbursed for the time they spent in the interviews. Interviews took 55-104 minutes and were recorded on a Sony voice recorder. The study protocol was approved by the Institute of Social Health Ethics Committee of Palacky University. Data were anonymized and pseudonyms used throughout to protect participants' identity. Audio recordings and transcripts were securely stored in accordance with relevant legal requirements. All procedures complied with current Czech and EU legislation on personal data protection.

2.4 | The analytical approach

During the first reading of interview transcripts, we recorded all subjects related to social support and/or resilience. This first stage of analysis took the form of noting participants' particular statements about social support or resilience. After a deeper analysis of transcripts, we grouped these statements according to their relation to the subjects of our interest. Each transcript was analysed independently by two authors who followed the same method. Statements pertaining to resilience are gathered in Table 3 (see Section 3). Statements pertaining to social support were further classified according to who provides it, what form it takes and in what situations it is provided. These results are presented in Table 2 (with a commentary and including examples, see Section 3).

3 | RESULTS

Analysis had shown that PWHs in our sample tend to rely on two main resources which help them cope with their disease, namely social support as an external factor and resiliency as an internal factor.

TABLE 2 Main providers of social support to persons with haemophilia

Main providers of social support to persons with haemophilia
Primary family (parents, siblings)
Wider family (grandparents, grandchildren, in-laws, brother and sister-in-law)
Spouse
Experts (psychologists, healthcare providers, teachers)
Friends

3.1 | Social support networks of persons with haemophilia

In our analysis, we identified who provides social support, in what situations and in what way. The relevant part of the analysis is structured accordingly.

The most important factor in this network is help which PWHs need in relation to health complications due to their disease. This need links all of the above-mentioned forms of social support. The support network involves all persons mentioned in Table 2. For instance, the primary family helps with getting to school and application of the factor. A spouse saved her husband's life when she recognized a life-threatening intracranial haemorrhage. In another subject, wife provided the meaning of life when the patient was in very poor health and considered suicide.

In the case of experts, psychologists play a key role in providing information, support and a 'listening ear' during treatment and especially in connection with operations necessitated by haemophilic complications. Teachers can facilitate the integration of children and young adults with haemophilia into their peer group as well as sport and social activities, from which PWHs are often excluded due to fears for their health. Physicians and nurses provide support by openly communicating about the disease. PWHs need to be able to express their views, voice their concerns and share their emotions. Interest in a patient is important and so is easy access to medical care. PWHs need to have medicines at home to use as they need. This gives them a sense of freedom.

Friends help where PWHs are limited by their disease: a friend teaches haemophiliac's son to ride a bycicle. Another PWH need his friend to help dressing of a bleeding wound.

Family, ie primary and wider family as well as spouses, provide PWHs with emotional stability, help and support during health complications due to their disease, a sense of future thanks to children and grandchildren, meaning of life in crises, feeling of satisfaction in life, as well as help with childcare.

3.1.1 | Social support provided by persons with haemophilia

An unexpected finding made by our study is that PWHs wish to provide social support to others. They not only receive but also provide meaningful help. In comparison with other persons' diseases or problems, their health problems may not seem so great and insurmountable, which may help them cope with their own disease.

3.1.2 | Negative relationship experiences

Due to serious health issues, PWHs also have negative relationship experiences. In our sample, the father of one of the subjects failed to cope with his son's disease and left the family. In another case, it was the mother who left. Two marriages fell apart because healthy partners

TABLE 3 Resilience: Persons with haemophilia and their attitudes to their disease

Resilience: PWHs and their attitudes to their disease	
There are worse diseases than haemophilia.	Responsibility and independence make me feel free.
Even in a difficult situation, one can still live.	I don't succumb to self-pity. I'm not asking for sympathy and benefits from people around me.
I can't win but I will fight.	I'm an optimist.
I hope there will appear a new treatment that would be easier to apply.	The disease is part of me, I can't have everything.
I'm active in contact with people, and I have my interests and hobbies.	Permanent impact on my health is something I have accepted, though it was difficult. It's part of me.
I don't think of the worst that could happen to me.	I'm not afraid of problems. They may not even come.
I'm limited only in some things. If I stick to doctors' advice, I can live a full life.	

Note: The statements attesting to resilience demonstrate some of the inner mechanisms which enable PWHs cope with problems caused by their disease. Table 3 summarizes the content of these attitudes in our sample.

failed to cope with complications due to their partners' disease. One man with haemophilia had a problem finding a romantic relationship because women were too worried about his health status. There were also cases of social exclusion when a teacher did not wish to have a haemophiliac child in her classroom because she feared for his health.

3.2 | Resilience

The statements attesting to resilience quoted below demonstrate some of the inner mechanisms which enable PWHs cope with problems caused by their disease. They attest to inner attitudes to the disease. Table 3 summarizes the content of these attitudes in our sample.

4 | DISCUSSION

4.1 | Social support

Haemophilia is a serious disease whose unpredictability causes complications in daily life. It leads to severe complications, such as bleeding, internal bleeding into joints and intracranial bleeding. It also prevents sufferers from full integration into society due to frequent absences from school, limited ability to engage in sports, need to have medications always at hand, intravenous application of medicines, etc. This is why PWHs need a wide range of social support both from their families, which help them deal with the daily complications due to their disease, and from experts, who help them manage their health.

In addition to practical help, social support also constitutes an important psychological protective factor in coping with haemophilia (emotional base, future prospects, having someone to live for, having someone to turn to when needing help). Studies dealing with other chronic diseases, diabetes, or cancer, arrived at the same conclusion with respect to the impact of social support on psychological health.[28-30] Reliable, high-quality social support can enhance resilience to stress, help protect against trauma-related psychopathology, decrease the functional consequences of trauma-induced disorders (such as posttraumatic stress disorder) and reduce medical morbidity and mortality.[31] The above-mentioned indicates that psychologists and/or social workers would be the ideal provider of requisite support for PWHs. So far, however, not all haemophilic centres provide this kind of service. We believe that comprehensive care of PWHs should include psychosocial support and each haemophilic centre should offer the services of a trained psychologist and/or social worker.

4.2 | Social support provided by patients themselves

An unexpected result of our study was the finding that it is important for PWHs not only to receive but also to provide social support. When faced with other people's diseases, they find their own health issues less insurmountable. Being in the position of help providers

makes them feel valuable and useful. Three of five participants of our study describe that it is important for them to not only accept support but also provide it. Caring for others makes them feel good and reduces their stress.[32]

4.3 | Resilience

Resilience is resistance to adversity grounded in physiological or psychological coping mechanisms rather than external protective factors. Postmodern and multidisciplinary view of resilience is that it is the force which drives a person's ability to grow through adversity and disruptions, the ability to bounce back and cope with challenges.[33] Resilience is characterized by positive adaptation in the context of significant adversity or threat,[34] a way of responding to stress which facilitates adaptation to various stressors, such as injuries, tragic events, interpersonal problems, financial problems, or work- and health-related issues. Resilience ultimately helps to reduce the negative effects of the stressor.[35]

To promote psychological adjustment to their condition, PWHs should remain as active as possible, acknowledge and express their emotions in a way that allows them to take control of their lives, engage in self-management, and focus on potential positive outcomes of their condition.

Our results indicate that resilience is an important internal protective factor in coping with haemophilia. The force of resilience was apparent in all participants of our study. They describe strategies which help them cope with stress linked to their disease. These strategies are expressed in the form of attitudes to their disease and their perspective on negative experiences.

Attitudes to their disease, ie what PWHs say about themselves in relation to their health, show how they internally cope with their condition (see Table 3). The leitmotif of these attitudes is resilience in the sense of not giving up and fighting the challenges life throws at them. These results closely correspond to the findings of studies on patients with cancer, cardiovascular and other chronic physical diseases. Moreover, it seems that the more severe the impact of the disease, the higher is likely to be the patients' resilience, their efforts to reduce their disease's negative effects.[36] Our results correspond with another study which suggested a strong association between resilience and mental health in the somatically ill.[20] The profile of coping strategies in PWHs seems similar to that in other persons suffering from chronic pain.[37]

Family members who in some cases fail to cope with the health complications of PWHs become the source of negative experiences with relationships, but testimonies of men from our sample show that in all cases, they managed to complement this negative experience with a positive, reparative experience. They appreciate the positive aspects of new relationships, and this significantly contributes to their mental health.[38] In short, their resilience is apparent also with respect to negative experiences with relationships.

4.4 | Limitations, reliability, validity and subjects for further research

The main limitation of our study is linked to the fact that participants were recruited in collaboration with the Haemophilia Society Czech Republic and haemophilic centres in hospitals. We have thus worked with persons who were already actively engaged in haemophilia-related issues. Moreover, four of the five participants had haemophilia with inhibitors, the most severe form of the disease. Our conclusions therefore cannot be a priori generalized to the entire haemophiliac population, and they should be reconfirmed using a large sample.

Secondly, the age range of participants was rather broad, which means that the treatment they had received also varied. The older participants received in childhood poor treatment due to lack of information, poor medical facilities, and no appropriate medication or rehabilitation available in the past, especially prior to 1989. These persons are more affected by haemophilia than younger participants.

Thirdly, reliability and validity cannot be conclusively demonstrated in a qualitative research that relies on trustworthiness factors such as credibility, dependability, confirmability, transferability and authenticity.[39] Nevertheless, data analysis was performed systematically and the main subjects which emerged from it were checked independently by two authors.

More research is needed on the psychosocial mechanisms which help PWHs cope with their condition.

5 | CONCLUSION AND PRACTICAL IMPLICATIONS OF FINDINGS

Although four out of our study's five participants have the most severe form of haemophilia, they cope both with their health limitations and some negative relationship experiences and perceive their life as generally good. This attests to their resilience and good psychological health.

On the level of practical implication of our findings, we would recommend that haemophilic centres should learn about the supportive psychological mechanisms (especially resilience). They could then come up with a way of familiarizing PWHs with the potential of their own psychological resources.

It also seems that PWHs should be offered systematic care of their mental health both in the form of individual therapy and in the form of group therapy, which moreover presents an opportunity of sharing specific life experiences among PWHs. We therefore believe that each haemophilic centre should include in its team of experts a psychologist and a social worker. Their support and therapy could positively influence the processing of eventual traumatic experiences or deal with depressive tendencies before they develop into a full depression.

Another recommendation based on our findings is that support should be provided to persons who function as social support for people with haemophilia, especially their families, who deal with difficult situations linked to the disease. This can complicate relations

within families. Here, too, we would see the involvement of a psychologist and a social worker as desirable. We propose a preventive measure in the form of group therapy sessions of family members of PWHs, for instance in haemophilic centres. Likewise at the haemophilic centres, education for teachers could take place aimed at incorporation of children with haemophilia into their peer groups. For physicians, psychologists and other healthcare personnel, we recommend regular Balint groups.

Integration of psychosocial care into comprehensive haemophilia care would be, in our view, of crucial importance. It could help PWH cope with the difficulties and stress due to their disease by stimulating their coping mechanisms.

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DISCLOSURES

The authors stated that they had no interests which might be perceived as posing a conflict or bias.

AUTHORS' CONTRIBUTIONS

KR and JB wrote the manuscript and contributed equally. KR, IPS, ZM, TH, RB and PT conducted interviews with the patients and analysed the data. All authors reviewed and approved the manuscript.

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