

# Information and self-management needs of people living with bleeding disorders: a survey

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**Summary.** The aim of the study was to conduct a survey of information and self-management needs among members of the UK Haemophilia Society (HS). Of 1082 members mailed, 307 took part in the survey, the mean age was 52.4 years (SD 14.8), 85% were male, 96% white and 66% were living with haemophilia A. 90% felt that there is a lack of understanding amongst the public regarding bleeding disorders, 76% felt that health professionals understood their health and information needs and 32% had experienced problems managing anxiety and or depression. Results suggest that there was a 'stigma' attached to having a bleeding disorder and almost half are very careful about informing others that they have a bleeding disorder. Self-efficacy was relatively

high within the sample. Many respondents wanted to be kept informed about current research and the opportunity to participate in research. Women experienced a greater need for more information than men, particularly in the area of the 'medical management' and 'emotional' topics. Men appeared to need more information and or training on 'physical' aspects such as physiotherapy and joint replacement. The study provides an insight into the educational and self-management needs of those affected by bleeding disorders and highlights the importance of providing accessible information.

**Keywords:** haemophilia, patient education, self-efficacy, stigma, well-being

## Introduction

The number of people with haemophilia worldwide is estimated to increase from approximately 350 000 in 1990 to 440 000 by 2020 [1]. In the UK, there are approximately 7000 people living with haemophilia. There are several types of haemophilia with haemophilia A being the most common and resulting from a deficiency of clotting factor VIII. People with haemophilia can experience severe spontaneous bleeding into the joints. If left untreated, this can cause acute pain and severe joint damage leading to disability. Von Willebrand's disorder is believed to affect 1% of the population (<http://www.haemophilia.org.uk>), although approximately only 7000 people with this disorder have been identified in the UK [2].

There is little published literature focusing on the psychosocial impact of haemophilia. One exception is a study by Molleman & Van Knippenberg [3] investigating the origins and consequences of psychosocial problems among 43 patients with haemophilia in the Netherlands. Not surprisingly, severe haemophilia was associated with increased physical and psychological problems such as worry and depressive feelings. Stigmatization was found to have a negative effect on psychological well-being.

Access to good quality information about conditions, service provision and support are important to ensure that patients can make informed choices. Hussein & Partridge [4] state that information is needed in many formats, and as early as possible, with many patients reporting that this is not the case at present. Corben & Rosen [5] note that in order for patients to self-manage their long-term condition they must be provided with enough information. Furthermore, in recognition of the important role that the individual can play, there has been a rapid growth in reports of psycho-educational interventions for people living with long-term health condition [e.g. 6,7]. These courses are readily available in

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the community and provide support and information to participants. Provision of information to patients with bleeding disorders is important to enable them to be informed about the information and services that they desire [8]. Equally, self-management style interventions may enhance ability to cope with the demands of living with haemophilia and other bleeding disorders on a daily basis. However, there is little published research documenting the informational or self-management needs of people with haemophilia, von Willebrand's and other related bleeding disorders. Similarly, patient education or self-management programmes specifically for people with haemophilia have received scant research attention.

The aim of the study was to conduct a survey of information and self-management needs among members of the HS in the UK.

**Materials and methods**

*Sample and method*

Information packs containing an invitation letter, consent form and a questionnaire were mailed by the UK HS to 1082 of its members. Healthcare professionals, relatives, friends, unaffected carriers, children, retired professionals and the bereaved were excluded from the mailing. Respondents were entered into a prize draw. Respondents chose either to send their prize draw slip to the HS or to return it with their questionnaire to the Research Team.

*Materials*

Item generation was developed based on interviews with nine people living with haemophilia. This small but important group comprised eight males with haemophilia and one female with von Willebrand's; the age range was 28–84 years. The questionnaire comprised the following scales:

- (i) Demographics (e.g. age, gender, marital status);
- (ii) Type and severity of bleeding disorder, co-morbidity, age of diagnosis;
- (iii) Treatment centre type and region for management of condition.

*Health status.* A 10 cm horizontal Visual Analogue Scale (VAS) for health status anchored by 'worst imaginable health state' and 'best imaginable health state'. Scores ranged between 0 and 10 with higher scores representing more positive feelings about participants' own health status.

*Stigma, discrimination and disclosure.* Views about stigma, discrimination and disclosure related to having a bleeding disorder were assessed in 15 statements adapted from an HIV Stigma scale [9] and included 'yes' or 'no' responses (see Table 1).

*Psychological well-being.* Questions regarding psychological well-being and support including problems managing anxiety or depression, drug or alcohol problems and whether the respondent felt that they had support from family members. Response choices were 'yes' or 'no'.

**Table 1.** Views about stigma, discrimination and disclosure.

Statement	All respondents, % (n = 307)	HIV mono- or co-infected, % (n = 55)
1. There is a lack of understanding about people with bleeding disorders among the general public	90 (275)	93 (51)
2. In many areas of my life no one knows I have a bleeding disorder	52 (159)	47 (26)
3. I am very careful who I tell that I have haemophilia/a bleeding disorder	49 (149)	62 (34)
4. I regret having told some people I have haemophilia/a bleeding disorder	24 (74)	25 (14)
5. I work hard to keep my condition a secret	20 (60)	33 (18)
6. People's attitudes about bleeding disorders make me feel worse about myself	16 (50)	20 (11)
7. Some people who know I have a bleeding disorder have grown more distant	15 (47)	18 (10)
8. I would find it helpful to learn new skills and techniques to help me deal with other people's reactions better and to help me manage the stigma attached to having a bleeding disorder	15 (47)	13 (7)
9. I feel isolated and set apart from the rest of the world because of my bleeding disorder	15 (45)	25 (14)
10. It is easier to avoid new friendships than worry about telling someone I have a bleeding disorder	15 (45)	33 (18)
11. People have physically backed away from me when they learn I have a bleeding disorder	15 (45)	15 (8)
12. Generally, telling others I have haemophilia/a bleeding disorder has been a mistake	14 (42)	15 (8)
13. I find it hard to deal with people's reactions when I tell them I have a bleeding disorder	12 (36)	16 (9)
14. I have lost friends by telling them I have haemophilia/a bleeding disorder	10 (31)	16 (9)
15. I have stopped socializing with some people because of their reactions to my having a bleeding disorder	9 (26)	13 (7)

*Confidence* A 10 cm horizontal VAS for confidence in communicating with health professionals anchored by 'not confident at all' and 'completely confident'.

*Self-efficacy for managing disease and symptoms.* Self-efficacy, or confidence in managing aspects of a long-term health condition, was assessed using two self-efficacy sub-scales: managing disease (five items) and managing symptoms (five items), [10]. Each item is scored from one (not at all confident) to seven (totally confident) and for each sub-scale, scores are summed across the five items (range 5–35), with higher scores indicating greater self-efficacy. This scale has been used in self-management studies of other long-term health conditions [7].

*Generalised self-efficacy.* This was measured using the Generalised Self-Efficacy Scale (GSES) [11] as modified for use in the UK [12]. The GSES has established reliability and validity and was designed to examine the strength of an individual's belief in his or her ability to respond to new or difficult situations in general and to cope with any associated obstacles or setbacks.

*Information and self-management needs.* The needs related to bleeding disorders and related viruses were assessed in terms of medical management, lifestyle management, psychological and emotional issues and social, educational and employment issues. These topics represent key issues covered in many self-management programmes. Respondents were asked to indicate their preferred format for receiving information or training where applicable. Formats included self-management group; Face to Face with Haemophilia Professional; HS Leaflet; Newsletter/Magazine; Telephone Helpline; HS Website; Other Internet Sites; E-mail Alert; DVD or Video; CD Rom.

*Further information.* Respondents were given the opportunity to add written comments about the issues covered in the questionnaire.

### *Analysis*

Appropriate descriptive statistics were computed using SPSS version 12, SPSS Inc. Chicago, IL, USA [13].

## **Results**

### *Participant characteristics*

A total of 309 members responded, giving a response rate of 28.6%. Two questionnaires were excluded: one was largely incomplete and that other had been

completed by a spouse of a deceased partner who had a bleeding disorder. Of the remaining 307 respondents, the mean age was 52.4 (SD 14.8, range 18–86 years) and 85% were male. Most respondents ( $n = 296$ , 96%) were White. The majority (68%) were married or living with a partner and had formal educational qualifications (76%); the highest level of qualification most frequently (17%) reported was 'degree level'.

The majority of participants (66%,  $n = 201$ ) had haemophilia A. The mean age at diagnosis was 10.7 years (SD 16.7, range from 0 to 73 years). Three male participants did not report their condition. In terms of co-morbidity, 35% ( $n = 107$ ) were living with Hepatitis C. Seventy-six participants (25%) did not complete this question.

The majority of respondents (88%,  $n = 266$ ) were being managed through a Haemophilia Treatment Centre, 10% were managed by a Haematologist and 1% were managed by a general practitioner (GP) (four did not respond to the question). The range of scores on health status was from 0.4 to 10 with a mean of 6.0 (SD 2.3), indicating moderate global health.

Approximately one third of participants (31%) were in full time employment, 27% were retired and 19% had retired due to ill health. Haemophilia or other bleeding disorders were reported to have affected employment status for 58% ( $n = 171$ ) of respondents and 51% ( $n = 149$ ) felt that they had reduced their working hours because of their condition.

### *Managing stigma/discrimination and disclosure*

The majority of the sample (90%) felt that there is a lack of understanding among the general public regarding people with bleeding disorders. Almost half are very careful about informing others that they have a bleeding disorder and 52% indicated that, in many areas of their lives, no-one knows that they have a bleeding disorder. Results from HIV positive respondents are shown separately in Table 1. Percentages suggest that secrecy is an important issue for HIV positive respondents.

### *Communicating with healthcare professionals*

Seventy-six per cent ( $n = 226$ ) of participants felt that health professionals understood their health and information needs (see Table 2), although 17% ( $n = 50$ ) of respondents felt that they had encountered problems communicating with health professionals in the previous year. Reasons for this included feeling that health professionals did not listen to respondents' opinions regarding the treatment of their condition(s). Some respondents felt that health pro-

**Table 2.** Issues surrounding communication with healthcare professionals.

	% (n)
1. Do you feel that health professionals understand your health and information needs fully?	76 (226)
2. Do you make lists of things you would like to ask/raise before you go to visit your GP/Consultant?	53 (159)
3. Problems during the last 12 months in communicating with health professionals	17 (50)
4. Confidence in asking Doctor or Healthcare professional anything you want to (0 = not confident at all, 10 = completely confident)	Mean 6.0 (SD 2.3)

professionals lacked knowledge and understanding about bleeding disorders. Examples of comments written on the questionnaires are presented below.

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Doctor refused to accept that my own diagnosis of a bleed was really a bleed and not arthritis (M)  
 GP not understanding my condition (F)  
 Some doctors want to run your life and if you don't agree become distant and not helpful (M)  
 Some healthcare professionals simply will not listen to patients opinions' (M)  
 Doctor is supposedly professional but knows nothing of von Willebrand's (F)  
 Non-haemophilia trained staff have difficulty understanding implications of bleeding disorders (M)  
 The doctors don't communicate when you are co-infected (M)  
 Inability of health professional to contact my haematologist when my situation was critical (M)

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*Psychological wellbeing and social support*

Thirty-two per cent of respondents (n = 98) indicated that they had experienced problems managing anxiety and or depression over the previous 12 months. Most respondents felt anxious about their financial future. Some felt that anxiety and depression related to implications of treatment for Hepatitis C or HIV. Examples of comments written on the questionnaire are presented below.

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Depressed about future finances for family (M)  
 Very depressed by the pain I am always in (M)  
 Wondering what progress or worsening Hep C is causing and how long until live problems begin (M)  
 Often anxious and tearful, I feel isolated (F)  
 Money problems arising from absenteeism from work, resulting in anxiety and stress (M)  
 Get anxious about doctors not listening (M)

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Nine per cent (n = 27) reported having had a problem managing drug or alcohol problems over the previous 12 months. Alcohol was used in order to 'feel better' and reduce anxiety. Other problems were related to combination therapy and pain management.

A greater percentage of females compared with males reported having problems managing anxiety and depression (see Table 3). It was also noted that a greater proportion of females reported being in contact with other individuals who had a bleeding disorder, outside their family group. A large proportion of all respondents (90%) felt that that they received adequate support from members of their family or household.

*Self-efficacy*

The mean score for generalized self-efficacy (GSE) was 31.0 (SD 5.1). Published norms for GSE scores suggest a norm of 29.28, SD 4.6 [11] with typical mean values of between 28.7 and 30.23 for people with arthritis [12]. A mean score of 31.0 on the GSES suggests that respondents were confident that they can manage any issues and demands that occur in their lives in general. This confidence is reflected in specific self-efficacy scores for managing symptoms and disease (mean scores were 23.9, SD 5.6 and 27.4, SD 7.0 respectively).

*Information and self-management needs*

Overall, respondents expressed preferences for receipt of information via face-to-face contact with health professionals, or via the HS newsletter/magazine or leaflets. The Internet did not emerge as the preferred option for receipt of information although it was clear that in most topic areas the HS website was preferred to other websites. (Data for preference of format of information is not presented but is available from the authors).

*Medical management* The highest proportion of respondents wanted information on current research projects (57%), followed by joint damage and joint replacements (48%). Thirty-six per cent wanted information that would help them 'get the most from consultations with health professionals'. The lowest response was for information on Occupational Therapy (see Table 4).

Notable gender differences were observed for those requesting information on 'getting the most from health professionals' (63% females, 31% males). Also 57% of females compared with 29% males wanted information on 'bleeding disorders'. Higher propor-

**Table 3.** Psychological well-being and support.

	Total % (n) n = 307	Males % (n) n = 260	Females % (n) n = 47
1. Receive adequate support from other members of your family or household?	90 (276)	91 (237)	84 (39)
2. Problems managing anxiety and/or depression in the previous 12 months	32 (98)	31 (80)	38 (18)
3. In contact with any other individuals, outside your family who have a bleeding disorder?	31 (95)	33 (86)	19 (9)
4. Problems managing any drug or alcohol problems in the previous 12 months	9 (27)	10 (26)	2 (1)

**Table 4.** Information and self-management needs.

	Total Yes, %* (n) n = 307	Male, %† (n) n = 260	Female, %‡ (n) n = 47
<i>Medical management (Would you like information on:)</i>			
Current research projects	57 (174)	53 (139)	76 (35)
Joint damage/replacements	48 (146)	48 (125)	46 (21)
Getting the most from consultations with health professionals	36 (109)	31 (80)	63 (29)
Managing fatigue	35 (107)	34 (88)	41 (19)
Managing pain	35 (106)	34 (88)	39 (18)
Drug treatments	34 (104)	32 (83)	46 (21)
Opportunities to participate in research on new drugs/treatments	34 (103)	31 (82)	46 (21)
Bleeding disorders	33 (102)	29 (76)	57 (26)
Managing side effects of treatments	30 (90)	28 (71)	41 (19)
Physiotherapy	28 (87)	31 (80)	15 (7)
HIV/HCV	27 (84)	29 (75)	20 (9)
Occupational therapy	17 (52)	18 (46)	13 (6)
<i>Lifestyle management</i>			
Nutritional and healthy eating advice	38 (116)	34 (89)	59 (27)
Complementary and alternative therapies	36 (110)	33 (87)	50 (23)
Exercise	34 (105)	32 (83)	48 (22)
Stress Management	28 (86)	26 (69)	37 (17)
Relaxation and breathing techniques	24 (72)	21 (55)	37 (17)
Wills and living wills	23 (69)	22 (56)	28 (13)
Problem solving techniques	17 (53)	15 (39)	30 (40)
Life planning skills e.g. goal setting	16 (48)	15 (39)	20 (9)
<i>Psychological and emotional</i>			
Possible psychological effect of living with a bleeding disorder	34 (34)	30 (77)	57 (26)
Dealing with emotions	27 (27)	26 (69)	33 (15)
Emotional Changes	26 (26)	26 (68)	28 (13)
Improving self-confidence	24 (24)	21 (54)	39 (18)
<i>Social/employment/education</i>			
Benefits and entitlements	48 (147)	48 (125)	48 (22)
Information for family and friends	24 (73)	20 (52)	46 (21)
Transport	20 (62)	22 (56)	13 (6)
Managing at work	16 (50)	15 (39)	24 (11)
Talking about your condition with family and friends	15 (47)	13 (35)	26 (12)
Maintaining employment	15 (46)	14 (37)	20 (9)
Managing stigma/discrimination	14 (43)	14 (37)	13 (6)
Talking to colleagues about your condition	14 (42)	12 (30)	26 (12)
Finding employment	11 (35)	12 (30)	11 (5)
Managing at school/college/university	7 (21)	6 (15)	13 (6)

\*\*Percentage of all respondents; \*Percentage of all male respondents; † Percentage of all female respondents.

tions of females wanted information on the majority of topics listed under 'Medical Management'. Exceptions to this were for information on HIV/HCV, Physiotherapy and Occupational Therapy. This may be attributable to the lack of information surrounding women's bleeding disorders.

*Lifestyle management issues* The highest proportions of responses were noted for receipt of information and training about nutrition (38%), complementary therapies (36%), and exercise (34%). Least interest was shown in 'problem solving skills' (17%) and 'life planning skills' (16%). Higher percentages of females

indicated a preference for receiving information or training for all lifestyle management topics. The largest gender difference was observed for 'nutritional and health eating' information.

*Psychological and emotional issues* Overall, 34% of respondents expressed a need for information/training on the psychological effects of bleeding disorders. Once again, a higher proportion of females indicated that they would like information/training (57% females, 30% males).

*Social, emotional and educational issues* The pattern of responses in this section showed a clear need for information on benefits (48%). Least preference was shown for 'managing at school/college and university. This may be a reflection of the age of respondents, as few are currently attending a school, university or college. A notable gender difference was observed in relation to interest in receiving information for family and friends, with 46% of females compared with 20% of males interested in receiving information. Nine participants indicated that they would like information or training on 'other' including family planning, communicating with a partner regarding relationship problems and talking to children about what having haemophilia will mean to them.

*Self-management courses as a mode of delivery across all topics* Higher proportions of females than males showed interest in receiving information or training via a self-management course. Higher preferences for this mode of delivery were shown for lifestyle issues, psychological and emotional issues, relaxation and breathing techniques, and getting the most from consultations with health professionals. A total of 14 respondents had attended the Expert Patient Programme run by the HS (e.g. Living with Long-Term Illness, Get the Most of out Life, Making Changes).

## Discussion

Results show that there was a relatively high level of self-efficacy within the sample suggesting that respondents were confident that they can manage issues and demands that occur in the lives in general. Equally, specific self-efficacy scores for managing symptoms and disease were higher than those reported in a study comprising 171 participants (73% women) with a range of long-term health conditions including diabetes, myalgic encephalomyelitis, and osteoporosis even after they had completed a self-management programme [14] and were similar to those found in a study of cardiac patients comprising a predominantly

male sample (>70%) [15]. Hence, the results of this survey indicate that respondents are fairly confident that they can manage their condition on a daily basis. This may explain their relatively low uptake of self-management interventions.

Results suggest that there was a 'stigma' attached to having a bleeding disorder, HIV or HCV and many respondents did not discuss their condition with others. Secrecy appeared more of an issue for HIV positive respondents than for those who were not. However, most respondents felt that there is a general lack of understanding among the general public about bleeding disorders and people living with bleeding disorders. This suggests that more needs to be done in terms of raising public awareness. Although a minority reported problems, most respondents felt that health professionals understood their condition and needs.

Generally, the most preferred format for delivery of the majority of information and self-management topics was via HS leaflets and newsletters. However, the preferred option for 'medical information' was a face-to-face setting with a health professional. It is interesting to note that despite the advances in multimedia resources, respondents consistently preferred leaflets and newsletters rather than telephone help-lines, web-sites and DVDs. Self-management courses were desired by some, but it appears that there was a lack of understanding about what self-management programmes encompass. Indeed, only a small proportion of respondents had attended a self-management course, with many of the others suggesting that they did not know about the courses despite considerable publicity via the HS. The 14 respondents who had attended self-management programmes had valued the experience and reinforced the notion that some topics are best delivered in these courses including managing pain, managing fatigue, dealing with emotions and managing stigma/discrimination.

Gender differences were apparent with women experiencing a greater need for more information than men, particularly in the area of the 'medical management' and 'emotional' topics (e.g. stress management, dealing with emotions). Men appeared to need more information/training on 'physical' aspects such as physiotherapy and joint replacement. Many respondents wanted to be kept informed about current research and the opportunity to participate in research.

## Limitations of the survey

Most respondents were white, living with a partner, with formal educational qualifications and were

members of the HS. Thus, results have limited generalisability.

One limitation of the survey may have been respondent burden. It was clear from comments received that the survey questionnaire was not the first that some respondents had received. Furthermore, many reported that they had not been given any feedback from previous research participation. Given the anonymous nature of the survey, we do not have names and addresses of respondents and thus, we will not be able to mail debriefing sheets to respondents. Nonetheless, we will make every effort to disseminate findings in both professional and lay publications and via websites.

## Conclusion

In conclusion, the research highlights that having access to information is important not only for the patients but also for the wider community who still seem to live in fear of conditions they do not understand. Living with a bleeding disorder, like many other long-term conditions, impacts on many aspects of a person or their families' lives. Making informed choices from good quality information is essential.

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