Influence of optimism and resilience on quality of life & general health for haemophilia patients.

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Abstract

The purpose of this quantitative, cross-sectional study was to explore the effects of medical diagnosis (severity level, family history etc), optimism levels, resilience and age on the level of perceived quality of life and psychological distress experienced by patients with haemophilia in Ireland. Haemophilia is a hereditary bleeding disorder primarily affecting men. The purposive sample of 81 participants comprising of males ranging in age from 20 to 82 years, partook in an anonymous questionnaire, no treatment interventions were conducted. The SF-36, GHQ, LOT-r and BRS instruments were administered along with general demographic information relating to their bleeding disorder. No statistically significant correlation was found between bleeding disorder type or severity and QoL or psychological distress. Age and resilience were found to be positive predictors of QoL, similarly, age, resilience and optimism were found to be significant predictors of psychological distress. This may benefit tools for psychological interventions for patients.
Introduction

Haemophilia:

Haemophilia describes a group of inherited bleeding disorders in which there is a chronic defect in the clotting mechanism of the blood. Blood contains many proteins called clotting factors, and these work to stop bleeding. The lack of a clotting factor causes people with haemophilia to bleed for longer periods of time than people whose blood factor levels are normal. Most bleeding in haemophilia occurs internally, into the joints or muscles (Bolton-Maggs, 2006). Optimal care for severe haemophilia includes early and adequate factor replacement therapy for bleeding episodes and the provision of prophylaxis from an early age to prevent bleeding into joints and muscles resulting in consequent arthropathy if left untreated (Bolton-Maggs, 2006). There are two types of haemophilia, Haemophilia A (FVIII) and B (FIX). Haemophilia can be categorised further into three severity levels, mild haemophilia where a patient’s factor level is above 5%, moderate haemophilia where a patient’s factor level is between 1 – 5% and lastly severe haemophilia where the patient’s factor level is below 1% (Bolton-Maggs, 2006).

Treatment:

The categorisation of haemophilia is significant because of the correlation with bleeding patterns. Spontaneous bleeding episodes into the joints or muscles are mainly confined to those with severe haemophilia, patients with severe haemophilia are usually diagnosed within the first 2 years of life (Bolton-Maggs, 2006). Treatment for haemophilia is based on the replacement of the lacking factor/s by intravenous infusions when bleeding occurs. Treatment administered when bleeding occurs is known as on demand, the treatment in order to prevent bleeding episodes is called prophylaxis (von Mackensen & Gringeri, 2010). There are two regimes of prophylaxis, primary prophylaxis, known as the Malmo
protocol, which was pioneered in Sweden whereby, infusions are given several times weekly in order to maintain factor levels < 1%, to minimise bleeding episodes for patients with severe haemophilia (Blanchette et al., 2004) and secondary prophylaxis which is treatment to prevent recurrent bleeding into a particular joint or muscle to prevent further damage (Berntorp et al., 2003). The incidence of haemophilia in the general population is 1 in 10,000; it is not thought to vary between racial groups (Bolton–Maggs et al, 2004). Treatment for this disorder has dramatically improved in recent decades; originally, patients were treated with cryoprecipitate, this was followed by factor concentrates. Factor concentrates allowed patients to be treated for bleeding episodes more effectively resulting in less chronic arthropathy and better clinical results (Bolton–Maggs 2006). Plasma derived replacement therapy, which was considered the optimum treatment during the 1980’s, unfortunately led to high levels of contaminated blood products being disseminated resulting in the transmission of blood borne viruses such as Hepatitis C and HIV (Bolton–Maggs et al., 2003). Nowadays, prophylactic recombinant factor concentrates are used (Bolton–Maggs & Pasi, 2003). The life expectancy for people with haemophilia has increased significantly since the 1970’s, excluding an increase in deaths due to blood borne viruses throughout the 1980’s and 1990’s, this increase in life expectancy today is in no doubt attributed to an improvement in the quality of treatment received by people with haemophilia (Franchini & Mannucci, 2010).

Living with the condition:

The median life expectancy prior to treatment with cryoprecipitate was 16; currently the median life expectancy has reached an almost normal age of 63 years, in patients with severe haemophilia whom are not diagnosed with viruses (Aledort et al., 2012). Prior to the improvement in treatment, patients experienced low levels of education due to long periods at home or in hospital recovering from or treating bleeds, limited independence and poor employment opportunities (Aledort et al., 2012). With effective treatment available nowadays
for patients with haemophilia, disabilities can be minimised, surgery is more effective - including joint replacements for those with severe arthropathy, which has enabled patients on prophylaxis to lead a near normal lifestyle (Bolton-Maggs, 2006).

*Haemophilia Research:*

Haemophilia is a rare condition with a previously poor treatment prognosis until recent decades. Much of the research into haemophilia has focused on drug selection for treatment and the socio-economic justification for expensive treatment regimes per capita of population (Aledort et al., 2012). The collection of quality of life data has been, and will continue to be, of paramount importance for economic evaluations, cost effectiveness and the impact on health budgets (Aledort et al., 2012). Studies by Fischer et al., 2005 studying Health Related Quality of Life for patients with haemophilia, advocated for prophylaxis as the optimum treatment regime for children and adults with severe haemophilia (Fischer et al., 2005). Gringeri et al., 2006 reproduced the findings with reference to the importance of analysing the quality of life for patients with any disorder, emphasising the importance of Patient Related Outcomes (PRO) in relation to drugs and treatments undergoing clinical trials. A similar study has been completed by Naraine et al., 2002, which focused on the quality of life in relation to treatment efficacy for both adults with haemophilia. Talaulikar et al., 2006 discussed health related quality of life with specific reference to the psychosocial concerns of patients with haemophilia. The study explores differences between patients globally in relation to their perception of their general health and vitality levels, these patients in the Talaulikar et al., study were from Australia and Western Europe and were similar in relation to reported levels of bodily pain and physical function (Talaulikar et al., 2006).

In 2012 Cassis et al., undertook a systematic review of 24 pieces of literature, relating to haemophilia and its psychosocial implications for patients. Based on previous research,
there is a vast psychosocial impact for the patients and their families with the diagnosis of a chronic disorder (Cassis et al., 2012). The researchers stressed the need for further international research into the area of social and psychological implications with an aim to equip patients and their families with the essential education, coping mechanisms and support they may require in order to improve their quality of life (Cassis et al., 2012).

*Quality of life:*

Quality of life assessments have been recommended by the World Health Organisation (WHO) as a relevant medicinal parameter to assess health outcomes for people with various conditions (WHOQOL, 1993). Both clinicians and policymakers alike recognise the importance of studying quality of life for patients with chronic illnesses, in order to make clinical decisions and to put in place measures which can make positive changes in the lives of patients (Guyatt et al., 1993). According to the WHO, quality of life can be defined as the patients’ perceived wellbeing and function in terms of the physical, emotional, mental and social areas of their lives (Bullinger & von Mackensen, 2004).

The effects of living with a chronic condition have been studied and highlighted across various health related spectrums including cancer, chronic heart conditions, Alzheimers, Cystic Fibrosis and musculoskeletal conditions (Biegel et al, 1991), not just for the patients but the family dynamic as a whole. Sharpe & Rossiter, 2002 studied the effects of a chronic illness on siblings within an effected family; their results showed that there were significant negative feelings, depression and anxiety in siblings of a child with a chronic illness which were significantly higher than that of the control group. Their study emphasises that the entire family may be affected by a diagnosis of a chronic condition. The effect of a chronic condition on relationships between spouses has also been investigated in relation to interventions suitable for partners and the patient, the interventions suggested were support
networks for both parties and education (Reveson & Majerovitz, 1991). There is an abundant amount of literature focusing on the effects of various conditions on both the life of the patients and their families, it therefore is important for analysis of the quality of life for patients with haemophilia, with the aim of improving treatment regimes, psychological interventions and management of their condition from a holistic approach.

Despite the improvement in treatment for patients with haemophilia, recent research has shown that patients are reporting lower levels of quality of life than people without haemophilia based on their physical dysfunction, due to arthropathy and mental wellbeing due to pain and viral status (Bullinger & von Mackensen, 2004). Quality-of-life research has emerged as a primary measure of health outcomes because it allows the augmentation of traditional clinical indicators of health, with data gathered from the patient's perspective (Royal et al., 2002). There have been copious amounts of research in the area of the economic benefit of treating haemophilia with prophylaxis to improve the quality of life for patients (Schramm et al, 2003 & Farrugia et al, 2013). However the psychological impact of this chronic disorder on the quality of life of the adult population in Ireland has not been at the forefront of research in this area. Studies by von Mackensen et al, 2011, showed that the Health Related Quality of Life in elderly patients with haemophilia was negatively affected by their condition. Royal et al, 2002 conducted a European study on over 1,033 patients with haemophilia on varying treatments regimes; the purpose of the study was to focus on the economic benefits of on demand therapy v’s prophylactic therapy however their study revealed that patients on both forms of treatment scored significantly lower than the general population average (Royal et al, 2002). Their study suggested that further research into the area of quality of life for people with chronic conditions such as haemophilia, needs to be a focus for researchers in the future.
The area of quality of life and specifically haemophilia, will need considerable research and focus for elderly patients. The first generation of haemophilia patients are surviving into their 60's; information on the quality of life for elderly patients with haemophilia is scarce (Siboni et al., 2009). In a study completed by von Mackensen et al., they found that patients with haemophilia presented with significantly more psychological issues than their control group (von Mackensen et al., 2011). From both a physical, medical and psychological view it will become increasingly imperative that this cohort be monitored and assessed for quality of life in order to improve and alter the services available for this demographic (Siboni et al., 2009 & von Mackensen et al., 2011). For the purposes of this research the SF 36 Questionnaire will be used (Ware et al., 2000). The SF 36 Questionnaire focuses on three main areas in order to analyse the overall quality of life of an individual – physical, social and emotional health and wellbeing of the patient (Mc Horney et al, 1993).

*General Health Questionnaire:*

Patients suffering from a chronic somatic illness are more at risk of psychological distress than physically healthy people (Verhaak et al., 2005). Patients suffering from chronic illnesses such as heart disease, lung disease, neurological disease and arthritis are more likely to suffer from mental disorders, namely depression. For patients with a chronic disorder it has been suggested that psychiatric disorders may be a psychological reaction as a consequence of their medical condition, such as pain or treatment regimes, which may act as stressors for the patient (Verhaak et al., 2005). The burden of mental disorders is likely to have been underestimated because of an inadequate understanding of the relationship between mental illness and other health conditions. According to Prince et al., 2007 there can be no physical health without mental health. Mental disorders increase the risk for transmissible and non-transmissible diseases; mental disorders may also contribute to unintentional and intentional injury (Prince et al., 2007). Interestingly, many health conditions increase the risk of
developing a mental disorder (Prince et al., 2007). A chronic illness coupled with a mental disorder can complicate the patient’s ability to seek help in relation to treatment and diagnoses of mental disorders which in turn can significantly affect prognosis (Prince et al., 2007). There is a significant need for clinician’s and health care workers to develop psychosocial interventions that can be integrated into the management of chronic illnesses (Prince et al., 2007). In a study by Harter et al., 2006, they highlighted the importance of early detection of mental illness with a chronic somatic condition across various chronic conditions such as musculoskeletal, cardiovascular and cancer patients emphasising that early detection yielded a better prognosis for patients. Politi et al., 1994 found that the GHQ was shown to be both a reliable and valid test for general mental health on a group of 320, 18 year old males who were enlisted to join the army. The General Health Questionnaire can be used as a screening tool to identify participants who may be likely to suffer from a psychological disorder. As mentioned above, patients with haemophilia are presenting with more psychological issues than control groups. Therefore the General Health Questionnaire would be useful in order to detect any psychological distress as early as possible in order to intervene appropriately.

*Family History:*

Treatment for haemophilia in the past, led to serious joint arthropathy, physical disabilities, loss of range of motion and severe pain for some middle aged people with haemophilia (Szende et al., 2003). Furthermore, many patients were infected with blood borne viruses such as HIV and Hepatitis C, through contaminated blood products. Large amounts of research have also been compiled on this cohort, studies by Darby et al., 1997 and Qurishi et al., 2003 studied the progression of Hepatitis C in haemophilia patients and the effects of antiretroviral therapy on liver related mortality respectively. The emotional impact of witnessing a disease particular a fatal disease can have a negative effect on the perception
of the condition on family members (Walter & Emery, 2005). Tedgard et al., 1999 studied 105 carriers of the haemophilia gene. Prenatal diagnosis correlated highly with abortion following diagnosis coupled with a family history of haemophilia. Carriers who may have experienced the complications of haemophilia, through poor treatment or viral diagnoses were more likely to have an abortion on the confirmation of a haemophilia prenatal diagnosis. Subsequently, carriers who had a child with haemophilia abstained from having more children (Tedgard et al., 1999). Modern management and treatment of haemophilia with prophylaxis has reduced bleeding episodes and levels of arthropathy (Aledort et al., 2012) and has led to a significant increase in the life expectancy and the quality of life for people with haemophilia (Von Mackensen et al., 2012).

**Severity levels:**

Spontaneous bleeds into muscles and joints occur in patients with severe haemophilia, while patients with moderate or mild haemophilia rarely suffer spontaneous bleeding (Dijk et al., 2005). In relation to the particular diagnosis of haemophilia, severity levels may affect psychological distress and perceived quality of life (Triemstra et al., 1998). Malmo protocol in Sweden has been practised since 1958, with the aim of reducing the symptoms of severe haemophilia to a milder level of the disorder (Nilsson et al., 1992). Reducing the occurrence of bleeding episodes of a severe haemophilia patient to that of a moderate haemophilia patient, will prevent recurrent joint or muscle bleeds and thus reduce the level of arthropathy (Dijk et al., 2005). Elander et al., 2009, completed a study on 209 men with haemophilia, their study highlighted; using the SF-36, that pain intensity from joint arthropathy and acute bleeding pain had the highest influence on quality of life levels (Elander et al., 2009). Miners et al., 1999, conducted a study of 249 males using the SF-36 to analyse the quality of life of patients with varying severity levels of haemophilia and found that severe haemophilia patients reported a significantly lower quality of life levels than their mild or moderate
counterparts. Severe joint damage and disability which may be characteristic of a person with severe haemophilia is likely to increase levels of psychological distress and decrease levels of quality of life in comparison to patients suffering with mild or moderate haemophilia (Tiemstra et al., 1998). In contrast, Remor, 2011 reported that patients with mild or moderate haemophilia may have more treatment difficulties due to poor self-care skills in relation to the disorder and lack of experience with symptoms. This negative relationship with treatment may produce feelings of anxiety or depression for mild or moderate patients.

**Optimism & Resilience:**

It has also been identified in a number of health related research studies, that high levels of optimism and resilience have been linked to a higher level of perceived quality of life in patients with an illness either chronic or acute (Gotay et al, 2004 & Stanton et al, 2007). Scheier & Carver, 1992 suggested that there are mechanisms which we can adopt in order to cope more effectively with stress and thus manage a situation or indeed an illness better than somebody with lower levels of optimism. An individual with high levels of optimism will tend to live healthier lifestyles and attract supportive social relationships in comparison to those who live a more pessimistic lifestyle (Brissette et al., 2002). Achat et al., 2000 suggested that dispositional optimism has been linked to better health outcomes. Optimistic people are more likely to engage in positive and proactive problem solving behaviours thus increasing their ability to deal with negative or stressful situations (Achat et al., 2000). Studies relating to various physical illnesses, such as cancer, are demonstrating that even successful treatment can lead to psychological scars (Carver et al., 2005). Patients with higher levels of optimism are more likely to manage their psychological issues due to their illnesses, with more positive results than their pessimistic counterparts who engage with avoidant behaviours in relation to treatment and management of their condition (Carver et al., 2005).
Resilience is the capacity for people to maintain their mental health in the face of hardship, which can include physical illnesses (Stewart & Yuen, 2011). In the past decade, there has been a significant increase in the amount of literature published on resilience in relation to health and positive psychology (Stewart & Yuen, 2011). Stewart & Yuen found in their review of literature on resilience with reference to the physically ill, that there were several important factors contributing to resilience, a number of which included social support, adherence to treatment, pain perception, illness perception and self-efficacy. Mlinac et al., 2011 suggested that psychological resilience was correlated with learning from experience and effective coping skills. Tugade et al, 2004 studied a person’s ability to bounce back from negative events by using positive emotions as their coping mechanism, they found this greatly enhanced an individual’s ability to cope positively and react proactively to negative events and situations. Trivedi et al., 2011, similarly concluded that high levels of resilience can minimise the negative effect of stress, due to a chronic illness, and improve the psychological well-being of a patients (Trivedi et al., 2011).

Age:

As mentioned, the first generation of patients with haemophilia are reaching old age. The current main research avenues for this new area are focusing on establishing best medical practice and care. However, as previous research in other chronic conditions suggests psychological distress can increase for older patients and perceived quality of life levels can decrease. Costa & Mc Crae, suggested that old age is not necessarily a more stressful period in one’s life but there are significant stressors that accompany older age (Costa & Mc Crae, 1993). In a study by Sampogna et al., 2005 investigating people with psoriasis, a chronic dermatological condition, they found that psychological distress was increased in older patients and this distress had a significant impact on the quality of life levels of the patients they studied. Redekop et al., 2002 studied a group of patients with diabetes; their study
highlighted a significant decrease in the quality of life level for patients as they aged. Felton & Revenson, 1987 studied a group of middle and older aged men with chronic illnesses and the coping mechanisms they employ. They found that older men were less likely to cope by seeking information and using positive living techniques and more likely to attempt to minimise the impact of the disorder rather than cope with the disorder.

Pearlman & Uhlmann, 1988, suggested that the decrease in quality of life in elderly patients is a multi-faceted construct involving health care management but also psychosocial management. Social support has been implicated in the recovery of physical illness and psychological distress (Cohen & Syme, 1985). In a study Holahan et al., 1995 showed that patients suffering from cardiac disease reported less depressive episodes when effective coping strategies and social support were employed by the patients (Holahan et al., 1995). According to Sherbourne & Stewart, 1991, having emotional support from individuals can help patients to deal with negative consequences of their illness. Therefore, it may be important to include these types of interventions in the comprehensive care model for ageing patients with haemophilia.

Current Study

Reviewing the literature concerning quality of life, mental health, resilience, optimism and age for people with a chronic condition has uncovered some areas of haemophilia care which have not to date been explored. While quality of life has been explored in detail throughout innumerable studies in haemophilia, with specific reference to the economic weighting of patient reported outcomes, the Irish population with specific regards to the variables mentioned above have not been studied together. It is due to the improvement of treatment and increase in the perceived quality of life of patients which can now encourage
and inform clinicians and healthcare workers of the importance of psychosocial interventions for people with a manageable but chronic medical condition.

For the purpose of this study, with specific relevance to the participant’s particular medical condition, it is also hypothesised that the presence of a family history of the condition will have an effect on the psychological distress experienced by a person with haemophilia. It is also hypothesised that the presence of a family history of the condition will have an effect on the perceived levels of quality of life of a person with haemophilia.

It is hypothesised that the level of severity of the disorder will have an effect on the levels of psychological distress experienced by the participants. It is also hypothesised that the level of severity of the disorder will have an effect on perceived levels of quality of life of a person with haemophilia.

It is hypothesised that high levels of resilience and age will be positive indicators of the quality of life for people with haemophilia. Levels of resilience and age in relation to their effect on the quality of life for people with haemophilia have not been considered before. It is also hypothesised that high levels of resilience and age will be positive indicators of general mental health.

Lastly, it is hypothesised that high levels of optimism and resilience coupled with age will be indicators of levels of psychological distress experienced by a person with haemophilia. It is also hypothesised that high levels of optimism and resilience coupled with age will be indicators of the quality of life for people with haemophilia.
Method:

Participants:

Adult participants were sought with varying severity levels of haemophilia (mild, moderate and severe) from the database of the Irish Haemophilia Society (I.H.S.). Haemophilia predominantly affects males, as women are the genetic carriers of the condition on an affected X chromosome. Therefore the patients on the database of the I.H.S. with haemophilia are all male. All participants were asked to participate voluntarily; they were also informed (by means of a cover letter, appendix 2) of the nature and rationale of the study. The criterion for inclusion was age (participants had to be over the age of 18) and they must have a bleeding disorder. The severity of their bleeding disorder was not an exclusion factor. As the data gathered was from a rare medical disorder patient group a maximum of 204 participants were invited to participate in the research. 81 questionnaires were received and completed to date (N = 81). The participants ranged in age from 20 to 82 years (M = 44.56, SD = 14.79). Participants with FVIII deficiency accounted for 84% (N = 68), participants with FIX deficiency accounting for 16% (N = 13) of the sample. A more in depth analysis of the sample group will be discussed in the results section.

Design:

This study was a questionnaire based quantitative, cross-sectional design. It was also descriptive in nature; an opportunistic sample was sought.

Participants were sought from the database of the Irish Haemophilia Society. As put forward by Tabachnik and Fidell in 2007, in order to apply multiple regression analysis to data at least 15 participants per predictor variable must be used. For this research a minimum sample of 75 participants is necessary due to there being 5 predictor variables. The predictor variables for this piece of research are level of severity of haemophilia, family history, levels
of resilience, levels of optimism and age. The criterion variables for this research are quality of life and general mental health.

**Materials:**

General demographic information was sought from participants on page one of the questionnaire (appendix 3). This information covered areas relating to their medical condition such as family history, bleeding disorder type and severity, and number of bleeds annually. Information on social and peer support was also gathered.

In order to ascertain the levels of resilience, The Brief Resilience Scale, which assesses the ability of an individual to bounce back or recover from a stressor, was administered (BRS; Smith et al, 2008). This questionnaire is a 6 – item scale, with 3 negatively phrased items and 3 positively phrased items. The BRS is rated on a five-point Likert scale, with higher scores predicting higher levels of resilience; the maximum score for this test is 28. As studied by Smith et al, 2008, the BRS has been proven to be a reliable method of assessing resilience and the ability to bounce back from stress, they also highlighted that it may provide information about people dealing with health related stressors (Smith et al, 2008). Cronbach’s alpha for the BRS within the current sample was satisfactory at 0.83.

In order to measure the participant’s levels of optimism, the Revised Life Orientation Test (LOT-R; Scheier, Carver, & Bridges, 1994) was administered. This questionnaire is a 10-item scale with 3 positive items, 3 negative items and 4 null items. The LOT-R is rated on a five-point Likert scale; higher scores predict higher levels of optimism. The LOT-R measures dispositional optimism, which is a generalised expectation that more positive things will occur for participants rather than negative things (Burke et al., 2000). The maximum score for this test is 24. This test has been shown to have high test-retest reliability and high
internal consistency (Scheier et al., 1994). Cronbach’s alpha for the LOT-R within the current sample was satisfactory at 0.81.

In order to access participants over all general mental health the General Health Questionnaire-12 (GHQ-12: Goldberg & Williams, 1998) was administered. This is a self-report scale scored on a four point Likert Scale (0, 1, 2, 3, 4). Total possible scores range from a minimum of 0 to a maximum of 36, with higher scores indicating higher levels of psychological distress. Scores on the GHQ-12 from 11-12 are typical; scores greater than 15 suggest psychological distress; and scores greater than 20 suggest severe psychological distress. The GHQ has been used to identify minor psychiatric disturbances in clinical studies and psychiatric morbidity in large community based surveys (Pevalin, 2000). The GHQ has been used in various clinical groups such as urology and multiple sclerosis patients. A study conducted by Picardi et al., 2001 amongst dermatology patients demonstrated that the GHQ shows high reliability and internal consistency amongst various clinical groups as well as diverse cultures. Cronbach’s alpha for the GHQ-12 within the current sample was satisfactory at 0.91.

Finally in order to assess patient’s quality of life the SF 36 Health Status (Ware et al., 2000) questionnaire was administered. This test is a self-report scale, scored on a Likert Scale, covering 8 sections across the physical, emotional and social spectrums, higher scores predict higher levels of perceived quality of life. Scores are rated in terms of 0 – 100, 100 being optimum perceived health status. Brazier et al., 1992, confirmed the reliability and validity of this test for use in health perception of various medical populations. Cronbach’s alpha for the SF-36 within the current sample was 0.61.
Procedure:

The researcher is a full time employee of the patient organisation group – Irish Haemophilia Society. The researcher sought full permission from the CEO of the Irish Haemophilia Society (I.H.S) as the representative of the membership of the organisation (appendix I). Contact details for patients were gathered from the database of the I.H.S and a letter from the CEO of the Society and the researcher was sent to participants along with the questionnaire (appendix II). A questionnaire method was applied and no treatment interventions were conducted during the course of this research. The questionnaire was sent to participants by post; it was also available for distribution at educational conferences due to the demographic distribution of the sample group. A stamped addressed envelope was enclosed for participants, to return the questionnaire to the researcher in the offices of the I.H.S. A deadline date of one month from the posting date was highlighted on the letter. The questionnaire was completely confidential, with no identifiable information necessary or requested from participants. The resident counsellor employed by the I.H.S. was fully versed on the research and had any issues with the questionnaire arose after completion for the participants; contact details for her were included at the end of the questionnaire. Contact details were also included for the researcher and the CEO of the patient organisation, in the event patients had any questions or concerns regarding the questionnaire. Participants would have required a pen to complete the questionnaire; all other materials (introduction letter to questionnaire, questionnaire, stamped addressed envelope for return to researcher) were included in the package. The questionnaire took approximately 14 minutes to complete. After the data was collected and computed, the completed questionnaires were kept in a locked press in the I.H.S.
Analysis:

Analysis for the current study was carried out using Statistical Package for Social Sciences version 21 (SPSS-21). Preliminary analyses were initially conducted to assess for the presence of outliers and non-normality. All variables in the study satisfied the assumption of normality and no outliers were identified. Reliability analysis, Cronbach’s Alpha, was performed on each questionnaire to determine the internal reliability of each scale. Descriptive statistics were carried out to provide general information on the sample of participants. Pearson correlation coefficients were also performed in advance of the regression analysis to ensure test assumptions are satisfied. Also, correlation analysis was conducted to ensure that the predictor variables were significantly correlated with the criterion variables, and that the predictor variables were not highly associated with each other this is in line with the assumptions of multicollinearity. Independent t-tests were performed to identify whether there were any comparisons between the mean scores of the two distinct groups. One way between groups ANOVA’s were conducted to identify differences between groups in relation to their effect on predictor variables. A number of standard multiple regression analyses were performed to identify whether the predictor variables can explain the various criterion variables under investigation, and to highlight the unique independent effect of each predictor on the criterion variables. The Bonferroni method was applied 0.05 / 2, p = 0.03, and 0.05 / 3, p = 0.02 to both multiple regression models.
Results:

Descriptive Statistics:

Participants (N = 81) reporting a family history accounted for 64.2% (N = 52), participants reporting no family history of the disorder accounted for 35.8% (N = 29) of the sample. Participants that reported having severe haemophilia accounted for 50.6% of the collected data (N = 41), participants reporting moderate haemophilia accounted for 19.8% of data collected (N = 16) and lastly participants reporting mild haemophilia accounted for 29.6% of data collected (N = 24). Treatment regimes for participants varied between on demand treatment for bleeding episodes accounting for 58% of participants (N = 47), primary prophylaxis which would be considered the optimum level of treatment was reported at 27.4% of participants (N = 23) and lastly secondary prophylaxis was reported at 13.6% of participants (N = 11). Participants bleeding episodes in the last year were also recorded, 57.3% (N = 48) of participants reported 0 – 3 bleeds in a 12 month period, 23.5% (N = 19) of participants reported 4 – 7 bleeding episodes annually and lastly 8.6% (N = 7) of participants reported 8 – 10 bleeding episodes annually.

In relation to the tests applied participants (N = 81) scores ranged from 4 to 23 on the BRS scale (M = 14.69, SD = 4.18), maximum score on this test is 28. On the LOT-R scale measuring optimism participants scores ranged between 3 and 24 (M = 14.94, SD = 4.31), maximum score on this test is 24. On the GHQ scale measuring general mental health participants scores ranged from 6 to 33 (M = 12.72, SD = 5.98), as previously mentioned scores on the GHQ scale are typically between scores of 11 – 12. On the SF-36 Quality of Life survey participants scores ranged from 53 – 90 (M = 75.72, SD = 9.10), as previously mentioned SF-36 scores are rated from 0 – 100, 100 being optimum perceived health status.
**Difference Between Groups:**

An independent samples t-test was conducted to compare the presence of a history of haemophilia in a family (those who have a history of the disorder in their family and those who do not) on psychological distress. There was no significant difference in scores between the two groups \( t(75) = 1.60, p > 0.11 \), with participants with a history of haemophilia scoring \( (M = 13.44, SD = 6.58) \) and participants with no history of haemophilia reporting \( (M = 11.44, SD = 4.55) \). There was not a significant difference between the means (mean difference = 2.00, 95% CI: -0.48 to 4.47). Therefore the null hypothesis was accepted.

An independent samples t-test was conducted to compare the presence of a history of haemophilia in a family (those who have a history of the disorder in their family and those who do not) on quality of life. There was no significant difference in scores between the two groups \( t(52) = -0.37, p > 0.71 \), with participants with a history of haemophilia scoring \( (M = 75.42, SD = 8.74) \) and those with no family history scoring \( (M = 76.24, SD = 9.85) \). There was not a significant difference between the means (mean difference = -0.82, 95% CI: -5.22 to 3.58). Therefore the null hypothesis was accepted.

A one way between groups analysis of variance was conducted to explore the impact of the severity of diagnosis of haemophilia on psychological distress. Participants were divided into three separate groups according to the severity level of haemophilia (mild, moderate and severe). There was no statistically significant result between the three groups \( f(2, 80) = 2.11, p > 0.13 \). The effect size calculated using eta squared was 0.05. The mean score for mild haemophilia patients \( (M = 13.83, SD = 7.09) \) for moderate haemophilia patients \( (M = 14.43, SD = 8.17) \) and for severe patients was \( (M = 11.41, SD = 3.72) \). The test did not reveal a statistically significant result; therefore, the null hypothesis was accepted.
A one way between groups analysis of variance was conducted to explore the impact of the severity of the diagnosis of haemophilia on quality of life. Participants were divided into three separate groups according to the severity level of haemophilia (mild, moderate and severe). There was no statistically significant result between the three groups F(2, 80) = 2.48, p > .09. The effect size calculated using eta squared was 0.06. The mean score for mild haemophilia patients \( (M = 78.13, \ SD = 8.62) \), for moderate haemophilia patients \( (M = 77.70, \ SD = 10.30) \) and for severe haemophilia patients \( (M = 73.53, \ SD = 8.60) \). The test did not reveal a statistically significant result; therefore, the null hypothesis was accepted.

Multiple Regression Analysis:

Multiple regression analysis was performed to investigate the ability of resilience and age to predict the quality of life among patients with haemophilia. Preliminary analyses were conducted to ensure that no violation of the assumptions of normality, linearity and homoscedasticity. Additionally all correlations between the predictor variables in the study were examined. All correlations were weak ranging from \( r = -0.59 \) to 0.27. This indicates that multicollinearity was unlikely to be a problem. All predictor variables were statistically correlated with quality of life which indicates that the data was suitably correlated with the predictor variable for examination through multiple linear regression to be reliably undertaken. Since no \textit{a priori} hypotheses had been made to determine the order of entry of the predictor variables, a direct method was used for the multiple linear regression analysis. The two independent variables explained 10% of variance in quality of life \( F(2, 80) = 4.31, \ p < 0.03 \). Both predictors were significant, with resilience recording a higher Beta value \( (\beta = .26, \ p = 0.19) \), than age recording a Beta value of \( (\beta = -1.55, \ p = 0.13) \).

Multiple regression was performed to investigate the ability of optimism, resilience and age to predict the psychological distress (GHQ level) among patients with haemophilia.
Preliminary analyses were conducted to ensure that no violation of the assumptions of normality, linearity and homoscedasticity. Additionally all correlations between the predictor variables in the study were examined. All correlations were moderate ranging from $r = -0.59$ to -.53. This indicates that multicollinearity was unlikely to be a problem. All predictor variables were statistically correlated with psychological distress (GHQ) which indicates that the data was suitably correlated with the predictor variable for examination through multiple linear regression to be reliably undertaken. Since no $a priori$ hypotheses had been made to determine the order of entry of the predictor variables, a direct method was used for the multiple linear regression analysis. The three independent variables explained 40% of variance in psychological distress $F(3, 80) = 17.41$, $p < 0.02$. All 3 predictors were significant, with optimism recording the highest Beta value ($\beta = -0.44$, $p = 0.00$) than resilience recording a Beta value ($\beta = -0.26$, $p = 0.14$), and lastly age recording Beta value ($\beta = .23$, $p = 0.01$).
Discussion:

*Familial history of haemophilia on psychological distress and quality of life:*

The present study had several aims. The first hypothesis was to analyse whether there was a statistically significant effect on psychological distress based on whether patients had a history of haemophilia in their families. An Independent samples T-test was used to carry out this analysis. The results yielded no statistically significant relationship between patients having a familial history of haemophilia, in comparison to those patients with no familial history of haemophilia on the level of psychological distress experienced by participants within the current sample. Participants with a familial history did present with slightly higher mean scores, but this was not statistically significant. Based on previous research, in relation to the difficulties experienced in the past by patients and their families due to poor treatment, transmission of blood borne viruses (Tedgard et al., 1999 & Szende et al., 2003), the assumption of negative feelings towards haemophilia based on personal experience was reached. Due to no direct research having being completed on this variable to date, it may be possible for future research to replicate this hypothesis, perhaps, with a larger sample size in order to possibly achieve a statistically significant result.

The second hypothesis was to analyse whether there was a significant effect on the quality of life based on whether patients had a history of haemophilia in their families. An Independent samples T-test was used to carry out this analysis. The results yielded no statistically significant relationship between patients having a familial history of haemophilia in comparison to those patients with no familial history of haemophilia on the level of perceived quality of life reported by participants within the current sample. Participants with no familial history did present with slightly higher means, but this was not statistically significant. Due to no direct research having being completed on this variable to date, it may be possible for future research to replicate this hypothesis, perhaps, with a larger sample size.
in order to possibly highlight a statistically significant result. While the results for both tests reported was not statistically significant, the increases in the means may indicate an opportunity for future research.

*Level of severity of haemophilia on psychological distress and quality of life:*

The third hypothesis was to analyse whether there was a significant effect on the level of psychological distress experienced by a person with haemophilia in the current sample, based on the severity level of the participants’ haemophilia. A one way between groups ANOVA was used to carry out this analysis. Participants were spilt into three distinct groups according to their diagnosis – mild, moderate and severe. The results yielded no statistically significant relationship between the severity level of participant’s haemophilia diagnosis and psychological distress. Interestingly, however, the mean scores for this variable were lowest amongst the severe patients.

From previous research by Triemstra et al., 1998, in relation to the difficulties experienced by patients with severe haemophilia and the effects these difficulties may have on psychological distress, the assumption of higher levels of psychological distress for severe haemophilia patients relative to their mild or moderate counterparts was reached. However, as Remor, 2011 mentioned in his research for patients with a mild or moderate diagnosis they may present with more treatment difficulties due to a lack of experience with the condition which may lead to depressive symptoms. Although no specific research has looked at this area of haemophilia to date, with a larger sample size this analysis may yield some interesting results in relation to the coping mechanisms employed by people with severe haemophilia in comparison to their mild and moderate counterparts.

The fourth hypothesis was to analyse whether there was a significant effect on the perceived levels of quality of life for a person with haemophilia in the current sample, based
on the severity level of the participants’ haemophilia. A one way between groups ANOVA was used to carry out this analysis. Participants were spilt into three distinct groups according to their diagnosis – mild, moderate and severe. The results yielded no statistically significant relationship between the severity level of participant’s haemophilia diagnosis and perceived quality of life.

However, in agreement with previous research by Triemstra et al., 1998 and Elander et al., 2009, the means for the three groups were as expected, with severe haemophilia patients reporting the lowest quality of life level and mild haemophilia patients reporting the highest levels of quality of life. As with the previous hypothesis, no statistically significant result was found, however the mean levels may be an indication for a significant relationship between severity level and quality of life for future research.

The fifth hypothesis was to analyse whether resilience and age were statistically significant predictors of the quality of life of a person with haemophilia in the current sample. A multiple linear regression was used to carry out this analysis. The predictor variables (resilience and age) were shown to be statistically significant predictors of the quality of life of a person with haemophilia, demonstrating 10% of variance. Resilience was a better predictor of the perceived level of quality of life than age, with higher resilience levels correlating with higher scores in quality of life.

This result agrees with Tugade et al., 2004 whose research states that higher levels of resilience enable people to cope more effectively with and bounce back from negative situations and events quicker than people with lower levels of resilience. According to Tugade et al., 2004 people with higher levels of resilience demonstrate a higher perceived quality of life, higher satisfaction with life and fewer psychological issues. Mlinac et al., 2011, put forward the research by Hildon et al., 2009 in relation to a longitudinal study on
psychological resilience analysing the relationship the effects of negative and stressful situations both acute and chronic, such as deteriorating health,. They found that resilient participants had a more effective coping mechanism than those less resilient participants, who used avoidant coping mechanisms. The ability to bounce back from negative events and stress has been recognised to reduce psychological and medical comorbidities (Trivedi et al., 2011). A chronic illness can be stressful to manage; stress has also been shown to impact on a chronic illness (Trivedi et al., 2011). However, there are tools that patients with chronic illnesses can be taught in order to improve their resilience levels and in turn improve their quality of life (Trivedi et al., 2011). Age was also a significant predictor of quality of life for patients with haemophilia, with levels of quality of life decreasing with age. This replicates previous research by Sampogna et al., 2005 and Redekop et al., 2002, both studies identified a decrease in the quality of life for patients with chronic illnesses as they age. These pieces of research have supported the previous research in relation to an improvement in quality of life levels with higher resilience levels.

The sixth and final hypothesis was to analyse whether optimism, resilience and age were statistically significant predictors of the level of psychological distress in people with haemophilia. A multiple linear regression was used to carry out this analysis. The predictor variables (optimism, resilience and age) were shown to be statistically significant predictors of the levels of psychological distress experienced by a person with haemophilia, demonstrating 40% of variance. Optimism was the best predictor of the levels of psychological distress experienced by people with haemophilia followed by resilience and lastly age, while still significant was the weakest predictor of psychological distress amongst people with haemophilia in the current sample. Higher levels of optimism predict lower levels of psychological distress, similarly higher levels of resilience predict lower levels of
psychological distress and lastly psychological distress increases with age for patients in this sample.

This is in support of previous research in relation to levels of optimism, resilience and age on psychological distress levels. The research suggests the higher an individual’s level of optimism the lower their level of psychological distress, Carver et al., 2005 put forward that patients with chronic conditions are more likely to manage the psychological effects of their condition with positive outcomes than those with a lower level of optimism. Patients with high levels of optimism are more likely to seek treatment and engage with proactive steps in the management of their condition in comparison to patients with lower levels of optimism (Carver et al., 2005). Optimists are more likely to use effective coping mechanisms to help them to deal proactively with their condition whereas pessimistic patients are more likely to use avoidant behaviours in relation to the management of their conditions (Carver et al., 2005). Brisette et al., 2002 highlighted the important effect of an optimistic individual seeking healthier lifestyles and employing support mechanisms in social relationships which aid levels of psychological well-being. The new research and the literature available suggest that optimism can lead to improved health outcomes for patients with chronic conditions (Achat et al., 2000).

With relevance to resilience, the benefits of which have been discussed throughout this report, high levels of resilience can assist patients in coping effectively with stressors such as health related issues, thus reducing the negative psychological effects of the condition (Trivedi et al., 2011). This ability to bounce back from adversity allows patients to employ effective coping mechanisms, reducing stress and invariably enhancing the psychological well-being of the patient (Trivedi et al., 2011).
With reference to age, the levels of psychological distress increase with age. This is again in support of previous literature on the increasing stressors for older patients and their management of same (Costa & Mc Crac, 1993). Felton & Revenson, 1987, studied a group of middle and older aged men with chronic illnesses, they found that this age profile of men were less likely to seek positive coping mechanisms for this condition and thus increasing the impact of psychological issues related to their condition.

Limitations:

The results of the current study explored new areas of haemophilia research, it is therefore necessary to consider any possible limitations of the findings. While no significant findings were uncovered in relation to family history and severity of haemophilia on quality of life levels and psychological distress levels within this sample (N = 81), there may have been trends identified in the mean statistics which may yield significant results with future research. The research may have widened the parameters for future haemophilia based research in larger samples. The current research also supported previous research in the field of health psychology in relation to optimism, resilience and age as predictors of quality of life and psychological distress.

The SF-36 reported a Cronbach’s alpha score of 0.61 in the current sample. This is demonstrating slightly low reliability. For future haemophilia based research, a better Quality of Life instrument perhaps with distinct sections rather than one single quality of life outcome would be more suitable to this type of sample.

As with the majority of self-report questionnaires, participants may not always be truthful in their responses. Additionally there is the possibility that participants may interpret some questions incorrectly. Although steps were taken to control the latter, it cannot be definitively excluded from possible limitations.
**Strengths:**

Despite the possible limitations, there are a number of key strengths supporting the validity of the research. Standardised tests (SF-36, GHQ, LOT-r and BRS) were used which are considered to be reliable and valid measures of the hypotheses variables. The research replicated a significant amount of existing data, which is a favourable characteristic. The sample size received was 40% of the targeted population of patients registered on the database of the Irish Haemophilia Society which represents a high return rate for a posted questionnaire.

**Implications:**

The research may provide some interesting insights into psychological interventions that may be utilised as part of best practise for patients with haemophilia. Interventions in relation to increasing optimism and resilience levels may improve the quality of life and psychological distress levels for people with haemophilia. Also, as part of psychological interventions patients may be given, and encouraged to utilise, the tools to develop healthy and proactive coping mechanisms in order to improve their quality of life and psychological distress levels. In relation to the difficulties experienced by older men with chronic conditions peer support groups and psychological interventions at earlier stages - in order for patients to develop relationships with health care workers prior to the onset of middle age, as part of best practise may assist in help seeking behaviours for men with haemophilia as they age.

**Conclusion:**

The findings discovered emphasised some interesting areas of haemophilia care that were not previously analysed to date while not demonstrating significant results, the results may have highlighted some new areas of interest. The significant findings in relation to the
effect of resilience, optimism and age on quality of life and psychological distress levels may have some practical implications for clinical practices and theoretical implications for future research in the field.
References:


To Whom It May Concern:

Fiona Brennan, final year BA Hons. Psychology student in Dublin Business School, who is also a permanent employee of the Irish Haemophilia Society, has sought approval by the Irish Haemophilia Society to conduct a piece of research based on our Society.

The researcher will aim to identify the psychological quality of life for people with a chronic bleeding disorder. Areas addressed will include age, treatment regime, bleeding history and hospitalisation in the last 3 years, measurement of the participants’ levels of resilience and optimism which are indicators of the overall management of a person's Quality of Life. The WHO Quality of Life-BREF (WHOQOL-BREF) survey will also be administered.

I understand that this research will be carried out following sound ethical principles and that participant involvement in this research study is strictly voluntary and the content of same will be treated as confidential.

As the representative for the Irish Haemophilia Society and its members I am delighted to have the opportunity to take part in such research and will endeavour to participate actively with the researcher.

Should you have any queries with the information above, I would be delighted to speak to you further in relation to this matter.

Yours Sincerely,

Brian O’Mahony
Chief Executive
Irish Haemophilia Society
Appendix 2:

28th November 2013

Dear Member,

Our staff member Fiona Brennan is conducting research in the Department of Psychology, in Dublin Business School. The research aims to explore the quality of life for people with haemophilia. According to current research overall quality of life can be positively enhanced by high levels of resilience; optimism and social support. It is the aim of the research to analyse these points in relation to a chronic condition.

You are invited to take part in this study; participation involves completing and returning the attached anonymous survey. While the survey asks some questions that might cause some minor negative feelings, it has been used widely in research. If any of the questions do raise difficult feelings for you, contact information for support services are included on the final page of the survey.

Participation is voluntary, anonymous and confidential; you will note that you are not required to fill out your name when completing the survey. Thus responses cannot be attributed to any one participant. For this reason, it will not be possible to withdraw from participation after the questionnaire has been collected.

The questionnaires will be securely stored and data from the questionnaires will be transferred from the paper record to electronic format and stored on a password protected computer. Access to the returned surveys will be limited to Fiona Brennan.

It is important that you understand that by completing and submitting the questionnaire that you are consenting to participate in the study. Please return the survey, in the stamped addressed envelope by Monday January 6th, 2014.

Should you require any further information about the research, please contact Fiona Brennan, [redacted]. If you have any concerns about the survey please do not hesitate to contact me on (01) [redacted] or at [redacted]

Thank you for taking the time to complete this survey.

Yours Sincerely,

Brian O’Mahony
Chief Executive
Irish Haemophilia Society

Yours Sincerely,

Fiona Brennan
Undergraduate Research
Appendix 3:

**Personal:**

**Age:** _______  **Is there a history of bleeding disorders in your family?** _______

1. **What type of bleeding disorder do you have?**
   - Haemophilia A (FVIII) ☐
   - Haemophilia B (FIX) ☐
   - Von Willebrand disease ☐

2. **What is the severity of your bleeding disorder?**
   - Mild ☐
   - Moderate ☐
   - Severe ☐

3. **What is your current treatment?**
   - ☐ On-Demand – (When needed and only when you suspect that you have a bleed)
   - ☐ Primary Prophylaxis – (With a preventive aim and infused regularly several times a week during the whole year to prevent bleeds from occurring)
   - ☐ Secondary prophylaxis – (Treated in order to prevent recurrent bleeding in a target joint and given regularly or prior to specific activities)

4. **Please give a brief description of your treatment regime during your life to date?**
   - Example: From age 0 to age 15 - Treatment regime On-Demand
   - From age 15 to age Present - Treatment regime Prophylaxis
   - From age _______ to age _______ - Treatment regime _______
   - From age _______ to age _______ - Treatment regime _______
   - From age _______ to age _______ - Treatment regime _______

5. **Have you ever been diagnosed with inhibitors?**
   - ☐ Yes ☐ No

6. **How many bleeds did you have in the past year (1st January 2013 – 31st December 2013)?**
   - ☐ 0 - 3 bleeds/year ☐ 4-7 bleeds/year ☐ 8-10 bleeds/year
   - ☐ 10-15 bleeds/year ☐ 15-30 bleeds/year ☐ More than 30 bleeds/year

7. **Is your mobility reduced because of your bleeding disorder?**
   - ☐ Yes ☐ No
   - If yes, is your mobility reduced in any joints? ☐ Yes ☐ No, If yes, which joint(s): ________________________________

8. **Approximately how many I.H.S events or meetings have you attended in the past 5 years?**
   - ☐ None ☐ 1 - 5 ☐ 6 – 10 ☐ 11 – 15

9. **Outside of your family members do you have regular (once a month or more) contact with other people with a bleeding disorder?**
   - ☐ Yes ☐ No

10. **In relation to your involvement with the I.H.S how many times have you been in contact with the Society in the past year (1st January 2013 – 31st December 2013)?**
    - ☐ Never ☐ 1 – 5 ☐ 6 - 10 ☐ 10+
Please answer the following by the extent to which you are in agreement with the statement using the scale provided below:

0 = Strongly disagree  
1 = Disagree  
2 = Neutral  
3 = Agree  
4 = Strongly agree

☐ In uncertain times, I usually expect the best.  
☐ Its easy for me to relax.  
☐ If something can go wrong for me, it will.  
☐ I’m always optimistic about my future.  
☐ I enjoy my friends a lot.  
☐ It’s important for me to keep busy.  
☐ I hardly ever expect things to go my way.  
☐ I don’t get upset too easily.  
☐ I rarely count on good things happening to me.  
☐ Overall, I expect more good things to happen to me than bad.  
☐ I tend to bounce back quickly after hard times.  
☐ I have a hard time making it through stressful events.  
☐ It does not take me long to recover from a stressful event.  
☐ It is hard for me to snap back when something bad happens.  
☐ I usually come through difficult times with little trouble.  
☐ I tend to take a long time to get over set – backs in my life.

Please read the questions below and tick the response that applies to you best.

1. Have you recently been able to concentrate on what you’re doing?

<table>
<thead>
<tr>
<th>Better than usual</th>
<th>Same as usual</th>
<th>Less the usual</th>
<th>Much less than usual</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2. Have you recently lost much sleep over worry?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>No more than usual</th>
<th>Rather more than usual</th>
<th>Much more than usual</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
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</tbody>
</table>


3. Have you recently felt that you are playing a useful part in things?

<table>
<thead>
<tr>
<th>More so than usual</th>
<th>Same as usual</th>
<th>Less so than usual</th>
<th>Much less so than usual</th>
</tr>
</thead>
</table>

4. Have you recently felt capable of making decisions about things?

<table>
<thead>
<tr>
<th>More so than usual</th>
<th>Same as usual</th>
<th>Less so than usual</th>
<th>Much less so than usual</th>
</tr>
</thead>
</table>

5. Have you recently felt constantly under strain?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>No more than usual</th>
<th>Rather more than usual</th>
<th>Much more than usual</th>
</tr>
</thead>
</table>

6. Have you recently felt you couldn’t overcome your difficulties?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>No more than usual</th>
<th>Rather more than usual</th>
<th>Much more than usual</th>
</tr>
</thead>
</table>

7. Have you recently been able to enjoy your normal day to day activities?

<table>
<thead>
<tr>
<th>More so than usual</th>
<th>Same as usual</th>
<th>Less so than usual</th>
<th>Much less so than usual</th>
</tr>
</thead>
</table>

8. Have you recently been able to face up to your problems?

<table>
<thead>
<tr>
<th>More so than usual</th>
<th>Same as usual</th>
<th>Less the usual</th>
<th>Much less than usual</th>
</tr>
</thead>
</table>

9. Have you recently been feeling unhappy or depressed?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>No more than usual</th>
<th>Rather more than usual</th>
<th>Much more than usual</th>
</tr>
</thead>
</table>

10. Have you recently been losing confidence in yourself?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>No more than usual</th>
<th>Rather more than usual</th>
<th>Much more than usual</th>
</tr>
</thead>
</table>

11. Have you recently been thinking of yourself as a worthless person?

<table>
<thead>
<tr>
<th>Not at all</th>
<th>No more than usual</th>
<th>Rather more than usual</th>
<th>Much more than usual</th>
</tr>
</thead>
</table>
12. Have you recently been feeling reasonably happy, all things considered?

<table>
<thead>
<tr>
<th>More so than usual</th>
<th>Same as usual</th>
<th>Less the usual</th>
<th>Much less than usual</th>
</tr>
</thead>
</table>

Please answer each of the following questions – some questions may look like others but each one is different. Please take time to read and answer each question carefully by ticking the box that best represents your response.

1: In general, would you say your health is:

<table>
<thead>
<tr>
<th>Excellent</th>
<th>Very Good</th>
<th>Good</th>
<th>Fair</th>
<th>Poor</th>
</tr>
</thead>
</table>

2: **Compared to one year ago, how would you rate your health in general now?**

<table>
<thead>
<tr>
<th>Much better now than one year ago</th>
<th>Somewhat better now than one year ago</th>
<th>About the same as one year ago</th>
<th>Somewhat worse now than one year ago</th>
<th>Much worse now than one year ago</th>
</tr>
</thead>
</table>

3: The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

<table>
<thead>
<tr>
<th>Vigorous Activities, such as running, lifting heavy objects, participating in strenuous sports</th>
<th>Yes, limited a lot</th>
<th>Yes, limited a little</th>
<th>No, not limited at all</th>
</tr>
</thead>
<tbody>
<tr>
<td>Moderate activities, such as moving a table, pushing a vacuum cleaner, bowling or playing golf</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lifting or carrying groceries</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Climbing several flights of stairs</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Climbing one flight of stairs</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bending, kneeling or stooping</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Walking more than a mile</td>
<td></td>
<td></td>
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<tr>
<td>Walking several hundred yards</td>
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<td></td>
<td></td>
</tr>
<tr>
<td>Walking one hundred yards</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bathing or dressing yourself</td>
<td></td>
<td></td>
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</tr>
</tbody>
</table>


4: How much of the time during the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

<table>
<thead>
<tr>
<th></th>
<th>All of the time</th>
<th>Most of the time</th>
<th>Some of the time</th>
<th>A little of the time</th>
<th>None of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cut down on the amount of time you spent on work or other activities</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accomplished less than you would like</td>
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<td></td>
<td></td>
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</tr>
<tr>
<td>Were limited in the kind of work or other activities</td>
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<tr>
<td>Had difficulty performing the work or other activities (for example it took extra effort)</td>
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</tbody>
</table>

5: How much of the time during the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

<table>
<thead>
<tr>
<th></th>
<th>All of the time</th>
<th>Most of the time</th>
<th>Some of the time</th>
<th>A little of the time</th>
<th>None of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cut down on the amount of time you spent on work or other activities</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Accomplished less than you would like</td>
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<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did work or other activities less carefully than usual</td>
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</tbody>
</table>

6: During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbours or groups?

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>Slightly</th>
<th>Moderately</th>
<th>Quite a bit</th>
<th>Extremely</th>
</tr>
</thead>
</table>

7: How much bodily pain have you had during the past 4 weeks?

<table>
<thead>
<tr>
<th></th>
<th>None</th>
<th>Very Mild</th>
<th>Mild</th>
<th>Moderate</th>
<th>Severe</th>
<th>Very Severe</th>
</tr>
</thead>
</table>

8: During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)?

<table>
<thead>
<tr>
<th></th>
<th>Not at all</th>
<th>Slightly</th>
<th>Moderately</th>
<th>Quite a bit</th>
<th>Extremely</th>
</tr>
</thead>
</table>
9:  These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks.....

<table>
<thead>
<tr>
<th></th>
<th>All of the time</th>
<th>Most of the time</th>
<th>Some of the time</th>
<th>A little of the time</th>
<th>None of the time</th>
</tr>
</thead>
<tbody>
<tr>
<td>Did you feel full of life?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have you been nervous?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have you felt so down that nothing could cheer you up?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have you felt peaceful and calm?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did you have a lot of energy?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have you felt downhearted or depressed?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did you feel worn out?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have you been happy?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Did you feel tired?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

10:  How much of the time during the past 4 weeks, has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives etc.)?

<table>
<thead>
<tr>
<th></th>
<th>All of the time</th>
<th>Most of the time</th>
<th>Some of the time</th>
<th>A little of the time</th>
<th>None of the time</th>
</tr>
</thead>
</table>

11:  How TRUE or FALSE is each of the following statements for you?

<table>
<thead>
<tr>
<th></th>
<th>Definitely true</th>
<th>Mostly true</th>
<th>Don’t know</th>
<th>Mostly false</th>
<th>Definitely false</th>
</tr>
</thead>
<tbody>
<tr>
<td>I seem to get sick a little easier than other people</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I am as healthy as anyone I know</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>I expect my health to get worse</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>My health is excellent</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Support Services:

Irish Haemophilia Society  01 657 9900 / 087 232 0255

Anne Duffy Nurse / Counsellor

1st Floor Cathedral Court,

New Street, Dublin 8