THE RELATIONSHIP OF SELF-COMPASSION AND

HOPE WITH QUALITY OF LIFE FOR

INDIVIDUALS WITH BLEEDING DISORDERS

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Abstract:

Individuals with bleeding disorders experience a number of physical and psychosocial stressors in their lives (Bullinger & von Mackensen, 2008; Forsyth, Cassis, Iorio, & Querol, 2011; Hill, 2015; Poon, 2013; Rolstad, 2014; Trzepacz, Vannatta, Davies, Stehbens, & Noll, 2003; Williams & Chapman, 2011). However, little research has been conducted to explore the psychological factors that influence quality of life for such individuals. The purpose of this study was to explore the relationship of self-compassion and hope with quality of life in a sample of individuals who have bleeding disorders (n = 86). Self-compassion and hope were significantly and positively related to overall quality of life for these patients and were significant predictors of quality of life when considered together. However, hope was the only significant individual predictor of quality of life, which may be explained in part by the shared variance between self-compassion and hope. Focusing psychological interventions and education around the topics of self-compassion and hope may be beneficial for this unique patient population to enhance their overall quality of life.

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CHAPTER I

The Relationship of Self-Compassion and Hope with

Quality of Life for Individuals with Bleeding Disorders

Individuals living with bleeding disorders face difficulties beyond the scope of general living. Hemophilia and Von Willebrand's disease are two such bleeding disorders. Children, adolescents, and adults can all be diagnosed with these diseases and may experience many biopsychosocial stressors in their daily lives.

Hemophilia is a rare bleeding disorder characterized by an inability to clot blood properly due to insufficient production of factor or clotting agent. Hemophilia causes an increased risk of internal bleeding due to injury usually in the joints and muscles, which can be immensely painful. In severe cases internal bleeding can occur spontaneously and can be life threatening. The gene for hemophilia is located on the X chromosome; therefore, it is more commonly diagnosed in males. Surgeries and dental procedures are often complicated by the symptoms of bleeding disorders and proper treatment must be prepared in advance. Hemophilia is usually treated throughout one's life time and often involves infusing or injecting synthetic factor into the body, as well as consistent medical visits. Carriers of the gene can also experience symptoms of hemophilia without being diagnosed with the disease. Physiological, psychological, social, and educational/occupational issues are common in individuals with hemophilia (Hill, 2015; Williams & Chapman, 2011), which can affect their quality of life throughout the lifespan.

Von Willebrand's disease is similar to hemophilia, but occurs in males and females equally (National Hemophilia Foundation, n.d.). Common symptoms associated with Von

Willebrand's disease include excessive mucosal bleeding in the mouth and nose area, menorrhagia, or excessive bleeding during menstrual cycles, and bruising. Individuals diagnosed with severe Von Willebrand's may experience bleeding in the joints and muscles, similar to hemophilia, and must treat their symptoms with infusions of factor, or blood clotting agent. Many of the struggles individuals with hemophilia face are also possible for individuals with Von Willebrand's disease due to the similar nature of these illnesses. There are numerous other bleeding disorders that share similar complications and symptoms with hemophilia and Von Willebrand's disease, such as Platelet Disorders and hemophilia F13; however, these are the two most common.

Quality of life for individuals diagnosed with bleeding disorders can be impacted in many ways. For the purpose of this study, quality of life will be defined using Varni, Seid, and Rode's (1999) conceptualizations of health-related quality of life (HRQOL) described as the patients' perception of their disease and the impact of treatment on their physical, mental, and social functioning. Bleeding disorders can cause a great deal of stress in the lives of those diagnosed with one. For example, children living with hemophilia experience a multitude of unique difficulties compared to non-hemophilic children including, but not limited to, invasive and painful treatments, peer victimization associated with limitations brought on by their bleeding disorder, rigid treatment schedules, pain due to bleeding, and activity restrictions (Williams & Chapman, 2011). Children with bleeding disorders may also have more issues with their emotional well-being than children without hemophilia (Poon, 2013). These biopsychosocial experiences have the potential to impact quality of life for these individuals (Trzepacz, Vannatta, Davies, Stehbens, & Noll, 2003).

While children and adults are developmentally different, the struggles children face may also impact adults with bleeding disorders. Pain is one issue most patients with bleeding disorders experience. Bleeding in joints and muscles can be extremely painful, which is likely to have an impact on the quality of life for individuals with hemophilia and Von Willebrand's disease. Elander, Robinson, Mitchell, and Morris (2009) found that negative thoughts about pain were a main influence on the mental health of persons diagnosed with hemophilia. Pain is a symptom of hemophilia and Von Willebrand's disease that does not discriminate based on age. However, research shows that pain associated with bleeding disorders affect adults and children in different ways. Poon (2013) found that, during a bleeding event, children's mental quality of life was more greatly affected than their physical quality of life. The restriction that bleeding imposes on children may affect their social relationships and further their sense of belonging, self-esteem, and mental quality of life. The opposite was found in adults; adults experienced significantly lower physical quality of life compared to their mental quality of life during a bleeding episode. Adults' mental health was affected more by days missed at work due to medical reasons, possibly due to increased levels of work related stress. In fact, adult men diagnosed with hemophilia often have occupational stress associated with feeling discriminated against on the basis of their diagnosis, missing work due to medical appointments or bleeding episodes, and difficulty finding jobs that assist in managing bleeding disorder symptoms, such as pain (Forsyth, Cassis, Iorio, & Querol, 2011).

Another factor associated with well-being or quality of life for individuals with bleeding disorders is social support. Social interactions have the potential to influence the development of children and adolescents with chronic illnesses and these peer relationships have been shown to be of particular importance for those with chronic illnesses, such as bleeding disorders (La

Greca, Bearman, & Moore, 2002). Children, adolescents, and adults with bleeding disorders may experience ridicule, stigmatization, and social rejection for having a bleeding disorder (Williams & Chapman, 2011). In a study of 298 adolescents and children diagnosed with hemophilia from six different countries, two of the most influential factors on quality of life were life satisfaction and social support (Bullinger & von Mackensen, 2008), further emphasizing the importance of positive social functioning in this population.

In conjunction with social, physical, and occupational issues, emotional struggles are not foreign to individuals with bleeding disorders. For example, individuals with hemophilia have been shown to report lower levels of self-esteem (Canclini et al., 2003) and more difficulties with emotional well-being than non-hemophiliac individuals (Trzepacz et al., 2003). These emotional concerns may be due to constant reminders of the societal stigmatization associated with their diagnosis. Barlow, Stapley, and Ellard (2007) found that individuals with hemophilia and Von Willebrand's disease experience anxiety and depressive symptoms associated with the daily stressors of managing illness-related symptoms. These individuals reported social stigmatization, common public misunderstanding about their disease, and discrimination in academic and occupational situations. Avoiding feelings of rejection on the basis of one's bleeding disorder is another emotional struggle for individuals diagnosed with hemophilia (Rolstad, 2014). These stressors can contribute to emotional concerns and can affect these individual's overall well-being and quality of life.

There are many factors that may assist in alleviating the burden of having a bleeding disorder, two of which may be self-compassion and hope. While research has been conducted on self-compassion or hope with quality of life in individuals with chronic illnesses, no researchers

to date have explored the relationship of self-compassion and hope with quality of life for individuals with bleeding disorders.

Self-Compassion

Self-compassion is defined as the ability to be touched by and open to one's own suffering, the desire to ease one's suffering, and to heal oneself with kindness (Neff, 2003b). It also refers to the capacity to be understanding and to express kindness and caring toward oneself, as well as avoiding judgmental attitudes towards one's potential failures. Due to the potential physical and psychological pain, as well as the inability to be physically active, individuals with bleeding disorders may experience judgmental attitudes towards themselves. Self-compassion may combat the negative effects of self-judgment for individuals with bleeding disorders. Additionally, the components of self-compassion that address a common human experience and avoidance of isolating behaviors may also enhance the social functioning of individuals with bleeding disorders, as this is a potential concern for this population.

Neff (2003a) identified three main positive features of self-compassion that may contribute to people's ability to cope with stressful life events: self-kindness, common humanity, and mindfulness. Neff also identified three negative components of self-compassion (counterparts): self-judgment, isolation, and over-identification. Self-kindness refers to the idea that we can be understanding and non-critical of ourselves during challenges, while self-judgment encourages a critical approach towards one's self. Common humanity refers to the concept that all humans experience painful and difficult experiences and isolation encourages feelings of being alone in one's suffering. Lastly, mindfulness refers to creating a balanced emotional perspective, as opposed to over-identifying with said emotions (over-identification),

especially when experiencing negative emotions. The goal is to not be overwhelmed by anger, sadness, or other powerful emotional states (mindfulness).

Individuals diagnosed with bleeding disorders encounter many stressful life events. In fact, hemophilia patients experienced significantly higher levels of stress and lower quality of life than non-affected individuals (Barlow et al., 2007). Whether from treatment management or social struggles, stress is something many people diagnosed with bleeding disorders experience. Ineffective management of and coping with stress can result in poor psychological and physical well-being (Evers et al., 2013). If self-compassion is a factor that can decrease levels of stress, it should be emphasized in the treatment of individuals, especially individuals who experience large amounts of stress for extended periods of time, such as those who have been diagnosed with a bleeding disorder.

Self-compassion has been associated with psychological well-being (Bluth & Blanton, 2015; Muris et al., 2005; see Neff, 2009, for a review). Neff and McGehee (2010) found that self-compassion was associated with less anxiety and depression and more positive social relationships. For individuals diagnosed with bleeding disorders, social relationships can be particularly difficult given people's reactions to their bleeding related struggles, resulting in rejection and/or isolation. Emphasizing self-compassion with these individuals may alleviate some of the stress or anxiety associated with social isolation. In another study, self-compassion was associated with fewer symptoms of depression and anxiety in individuals diagnosed with various chronic illnesses including: hypertension, congestive cardiac failure, rheumatoid arthritis, psoriasis, osteoporosis, allergic disease, hyperthyroidism, Crohn's disease, asthmatic bronchitis, and glaucoma (Pinto-Gouveia et al., 2014). In addition to psychological well-being, researchers have also studied self-compassion and physical well-being.

Self-compassion has been associated with the ability to accept pain related to one's chronic illness (Costa & Pinto-Gouveia, 2011). Those with higher levels of self-compassion were shown to have more acceptance of their pain than those with less self-compassion. Chronic pain is a symptom many individuals with chronic illnesses experience, especially those with bleeding disorders. This pain may affect their ability to accept their diagnosis (Williams & Chapman, 2011). Self-compassion has also been associated with less intrusive pain and higher levels of activity engagement (Ziemer, 2014) as well as to predict diagnosis-related shame (Brion, Leary, & Drabkin, 2014). In addition, self-compassion was associated with fewer negative emotions, self-pity, and shame, and more self-care and greater optimism. As the research supports, self-compassion is associated with many factors that may positively affect quality of life and deter negative influences of well-being on various chronic illness populations.

Being compassionate towards oneself may be an important coping strategy when coping with one's chronic illness. Sirois et al., (2015) examined two samples diagnosed with chronic illnesses (i.e., irritable bowel disease and arthritis) and found that those who were self-compassionate tended to use adaptive coping (e.g. active strategies, positive reframing, and acceptance) rather than maladaptive coping strategies (i.e., behavioral disengagement and self-blaming). These adaptive coping strategies were also associated with lower levels of stress and were linked to coping efficacy. Another factor that may impact the quality of life for individuals diagnosed with bleeding disorders is hope.

Hope

Hope is a psychological construct that may promote resilience in individuals diagnosed with chronic illness, such as bleeding disorders. "Hope is a positive motivational state that is based on an interactively derived sense of successful (a) agency (goal-directed energy), and (b)

pathways (planning to meet goals)" (Snyder et al., 1991, p. 287). As described in the definition, the two components that encompass hope are pathways and agency. Pathways refer to the influence of the past, present, and future on goals. Agency is the motivational piece of hope theory. It is the perceived ability to use one's pathways to attain one's goals. Hope can have a strong impact on emotional well-being. For example, hope has been related to success in academics, athletics, physical health, psychological adjustment, and psychotherapy (Marques, Gallagher, & Lopez, 2017; Rasmussen, O'Byrne, Vandament, & Cole, 2018; Snyder, 2002; Snyder et al., 1997; Harney, 1990).

According to hope theory, hope has two essential roles in people's lives: primary and secondary prevention (Snyder et al., 2000b). Primary prevention occurs before a problem arises. Enhancing one's primary abilities influences and encourages overall positive functioning and life satisfaction. It is a preventative measure that impacts the individual's ability to handle an issue before it arises. For individuals with bleeding disorders, primary prevention may psychologically prepare them before bleeding episodes and medical complications, creating less stress, especially when such a situation arises. Harney (1990) found that individuals who reported being more hopeful were more likely to engage in preventative behaviors (e.g. physical exercise for bleeding disorder patients) than those who had less hope. Secondary prevention is present after a problem occurs. This allows an individual to cope in the midst of challenging or difficult situations. Secondary prevention can also engage strengths an individual already possesses. An example of secondary prevention for an individual with a bleeding disorder may be quickly responding to a bleed/pain by infusing factor or blood clotting agent.

Research shows that there is a relationship between hope and quality of life in individuals with chronic illnesses. Chammas (1999) discovered that hope was positively related to quality of

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life among hospitalized patients with Human Immunodeficiency Virus (HIV) and Acquired Immunodeficiency Syndrome (AIDS). In the past, individuals with bleedings disorders have been at risk for contracting HIV due to injections and infusions. Further, Germann et al. (2015) found that hope and quality of life were related to less depression and anxiety in cancer patients. These researchers found that when depression, anxiety, or hope changed, these changes predicted quality of life. Hope was also found to mediate the relationship between depression and anxiety and quality of life. Based on these findings, it would appear that hope is a powerful factor that influences multiple aspects of people's well-being and for individuals with bleeding disorders, increasing hope, when they experience many stressors, may very well enhance their quality of life.

Hope may be an especially important factor to consider when treating individuals with bleeding disorders. In one study, children diagnosed with chronic illnesses (including cystic fibrosis, hyperthyroidism, cancer, cardiomyopathy and congestive heart failure, familial adenomatous polyposis, head injury, and kidney failure) reported lower levels of hope than those who were not diagnosed with a chronic illness (Venning, Eliott, Whitford, & Honnor, 2007). Social interaction difficulties predicted less hopefulness in both children with and without chronic illness. This is important to note because individuals diagnosed with bleeding disorders may have difficulties in social situations due to the limitations brought on by their disease, such as stigmatization or peers not understanding the implications of a bleeding disorder. Increasing or encouraging hope in individuals with bleeding disorders may lessen the burden of their limitations (e.g. constant pain, questions of the future, and social isolation) and increase their quality of life and disease management. In fact, Barlow and Ellard (2004) agreed that

interventions involving hope were effective in disease management planning for individuals diagnosed with chronic illness.

Purpose of this Study

Self-compassion and hope may be important positive psychology factors that influence the quality of life for individuals diagnosed with bleeding disorders. It is expected that the results of the present study will be useful to health care professionals, including medical doctors and psychologists, who interact with and treat patients with bleeding disorders. If self-compassion and hope are found to be positively related to and predictive of quality of life for individuals with bleeding disorders, then it would be beneficial to implement psychological interventions, education, and assessment geared towards self-compassion and hope to help relieve some of the stressors and difficulties associated with having a bleeding disorder.

The purpose of this present study was to explore the bivariate and linear relationships between and among self-compassion, hope, and quality of life among individuals diagnosed with bleeding disorders. These findings could guide the development of positive psychology interventions for people with bleeding disorders. The current study also contributed to the literature and knowledge of the bleeding disorder community and further developed a better picture of how to support these individuals.

Research Questions and Hypotheses

Research Question 1. What is the relationship between Self-Compassion and Overall Quality of Life for individuals diagnosed with bleeding disorders?

Hypotheses 1. Overall Quality of Life was expected to be significantly and positively correlated with the Self-Kindness, Common Humanity, and Mindfulness subscales of the Self-Compassion scale as well as the Overall Self-Compassion score for this sample of individuals

diagnosed with bleeding disorders. Overall Quality of Life was expected to be significantly and negatively correlated with the Self-Judgment, Isolation, and Over-Identification subscales of the Self-Compassion Scale for this sample of individuals diagnosed with bleeding disorders.

Research Question 2. What is the relationship between Hope and Overall Quality of Life for individuals diagnosed with bleeding disorders?

Hypotheses 2. Hope was expected to be significantly and positively correlated with Overall Quality of Life for this sample of individuals diagnosed with bleeding disorders.

Research Question 3. What is the linear relationship of Self-Compassion and Hope with Overall Quality of Life for individuals diagnosed with bleeding disorders?

Hypotheses 3. Overall Self-Compassion and Hope were expected to significantly and positively predict Overall Quality of Life for this sample of individuals diagnosed with bleeding disorders.

Research Question 4. What is the linear relationship of Self-Compassion and Hope with Psychosocial Quality of Life for individuals diagnosed with bleeding disorders?

Hypotheses 4. Overall Self-Compassion and Hope were expected to significantly and positively predict Psychosocial Quality of Life for this sample of individuals diagnosed with bleeding disorders.

Research Question 5. What is the linear relationship of Self-Compassion and Hope with Physical Quality of Life for individuals diagnosed with bleeding disorders?

Hypotheses 5. Overall Self-Compassion and Hope were expected to significantly and positively predict Physical Quality of Life for this sample of individuals diagnosed with bleeding disorders.

CHAPTER III

Methods

Participants

A total of 91 individuals with bleeding disorders were recruited for this study. However, five participants were omitted from the data analyses due to incomplete data responses or ineligibility. Therefore, the final sample included 86 participants of which 33 were females (38.4%) and 53 were males (61.6%). Participants ranged in age from 15 to 65 years old, with a mean age of 29.7 years old and a standard deviation of 14.42 years. Individuals fell into one of three age groups based on which Quality of Life inventory was appropriate for their age; these three groups included Teen (15-18), Young Adult (19-26), and Adult (26-65). A total of 22 participants were Teens (25.6%), 25 were Young Adults (29.1%), and 39 were Adults (45.3%). Participants identified their racial identity(ies) as follows: 58 were White/Caucasian (67.34%), 11 were Bi-racial (12.8%), five were Native American (5.8%), four were African American (4.7%), four were Hispanic/Latino (4.7%), two were Asian American (2.3%), one was Asian Indian (1.2%), and one identified as Multi-racial (1.2%). A total of 36 participants identified as a student (41.9%) and a total of 51 participants reported that they were employed at time of survey completion (59.3%). Participant annual family income ranged from less than $10,000 to more than $100,000, with a mean income of $55,300 (sd = 22,000).

In terms of bleeding disorders for this sample, 38 individuals were diagnosed with hemophilia A (44.2%), five were diagnosed with hemophilia B (5.8%), 38 individuals were diagnosed with Von Willebrand's disease (44.2%), two individuals were diagnosed with

hemophilia F13 (2.3%), one individual was diagnosed with Afibrinogenemia F1 (1.2%), one individual was diagnosed with Immune Thrombocytopenic Purpura (1.2%), and one individual was diagnosed with Asprine Like Platelet Disorder (1.2%). A total of 40 participants identified their diagnosis as Mild (46.5%; based on physician's assessment at the time of diagnosis), 12 were Moderate (14%), and 32 were Severe (37.2%). Two participants did not report the severity of their condition. It should be noted that the researchers of this study consulted with the healthcare providers at the two recruitment sites to ensure the appropriateness of including all of these participants in the data analyses given the different types of bleeding disorders and conditions they identified.

Most participants (n = 76) were recruited in-person during their annual or semi-annual bleeding disorder comprehensive appointment in one of two clinics in the Midwest United States (U.S.). Seven participants were recruited from an additional hematology clinic in the Midwest U.S. and completed the online version of the study. Three participants were recruited via acquaintances of the Primary Investigator and completed the online survey. See Table 1 for full participant demographic details.

Measures

Participants completed a demographic questionnaire and three measures including the Self-Compassion Scale (Neff, 2003a), the Adult Hope Scale (Snyder et al., 1991), and the PedsQL Inventory - Core Generic (Varni et al., 1999). Measures were completed in person using a pencil and paper method or on-line using a Qualtrics survey. The pencil and paper version and online version of the survey were identical. The order of the questionnaires was randomized to control for any potential ordering effects.

Self-Compassion Scale (SCS; Neff, 2003a). The purpose of the SCS is to assess thoughts, emotions, and behaviors associated with self-compassion in individuals fifteen and older (Neff, 2015). The SCS is a 26-item scale that assesses six components of self-compassion (i.e. three positive and three negative components): Self-Kindness ("I try to be loving toward myself when I'm feeling emotional pain"), Common Humanity ("I try to see my failings as part of the human condition"), Mindfulness ("When something painful happens I try to take a balanced view of the situation"), Self-Judgment ("I'm disapproving and judgmental about my own flaws and inadequacies"), Isolation ("When I think about my inadequacies it tends to make me feel more separate and cut off from the rest of the world"), and Over-Identification ("When I'm feeling down I tend to obsess and fixate on everything that's wrong"). Participants were asked to rate each item using a 5-point Likert-type scale ranging from 1- Almost Never to 5- Almost Always. Statements were presented in both positively ("When something painful happens, I try to take a balanced view of the situation") and negatively ("I am intolerant and impatient towards those aspects of my personality I don't like") directed ways. A total self-compassion score was obtained, as well as, six subscale scores including: Self-Kindness, Self-Judgment, Common Humanity, Isolation, Mindfulness, and Over-Identification. All of the negative subscale items (i.e., Self-Judgment, Isolation, and Over-Identification) were reverse scored before calculating total and subscale scores. The individual subscales were computed by finding the mean for each set of subscale questions and the total score was computed by finding the grand mean of all scale items.

Over the course of multiple studies, the SCS has shown acceptable reliability and validity (Neff, 2003a). Three studies assessed psychometrics of the SCS with two undergraduate samples and one Buddhist sample. The three samples produced similar results. The components

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of self-compassion were analyzed using exploratory factor analysis. Items with loadings at 0.40 or higher were included in the final version of the scale. The final versions of the subscales were analyzed using confirmatory factor analysis. Items on the three components of self-compassion did not fit a one-factor model and items were modeled to load on a second correlated factor. Correlated factors included: Self-Kindness and Self-Judgment, Common Humanity and Isolation, and Mindfulness and Over-Identification (Neff, 2003a).

The three-week test-retest reliability estimate for the Overall Self-Compassion scale was .93. The three-week test-retest reliability estimates for the six subscales were: .88 for Self-Kindness, .88 for Self-Judgment, .80 for Common Humanity, .85 for Isolation, .85 for Mindfulness, .88 for Over-Identification. Internal consistency reliability estimates for all six subscales were as follows: .78 for Self-Kindness, .77 for Self-Judgment, .80 for Common Humanity .79 for Isolation, .75 for Mindfulness, .88 for Over-Identification (Neff, 2003).

Researchers calculated the internal consistency reliability estimates for the current sample. The internal consistency reliability estimate for the Overall Self-Compassion score for this sample was .92. The internal consistency reliability estimates for the six subscales for this sample were as follows: .84 for Self-Kindness, .80 for Self-Judgment, .76 for Common Humanity, .78 for Isolation, .76 for Mindfulness, .82 for Over-Identification.

The convergent and divergent validity of the SCS has been well-established. The convergent validity of the SCS is evident in that self-compassion, as measured by the SCS, is positively related to self-esteem, self-acceptance, self-determination, basic psychological needs, social connectedness, life satisfaction, and emotional intelligence (Diener, Emmons, Larsen, & Griffin, 1985; Lee & Robbins, 1995; Salovey, Mayer, Goldman, Turvey, & Palfai, 1995; Rosenberg, 1965). Divergent validity is evident in that self-compassion, as measured by the SCS,

was negatively related to thought suppression, narcissism, self-criticism, depression, and trait anxiety as well as neurotic perfectionism (Beck, Ward, Mendleson, Mock & Erbaugh, 1961; Blatt, Quinlan, Chevron, & Zuroff, 1982; Slaney, Mobley, Trippi, Ashby, & Johnson, 1996; Speilberger, Gorsuch, & Luschene, 1970; Raskin & Hall, 1979; Wegner & Zanakos, 1994; Zung, 1965). Adequate content validity was found. People with high levels of self-compassion tended to experience fairly equal levels of kindness toward self and others. Those with low self-compassion reported being more kind to others than to themselves (Neff, 2003a).

There is evidence of adequate discriminant validity of the SCS. A Buddhist sample reported higher levels of self-compassion compared to undergraduate student samples (Neff, 2003a). The Buddhist participants also scored significantly higher on the positive self-compassion subscales (Self-Kindness, Common Humanity, and Mindfulness) and significantly lower on the negative self-compassion subscales (Self-Judgment, Isolation, and Over-Identification) compared to the undergraduate sample. The differences in SCS scores between the undergraduate and Buddhist samples revealed that the SCS distinguished between groups in a theoretically consistent pattern, which also suggests that the SCS does indeed measure what it intends to measure.

Adult Hope Scale (AHS; Snyder et al., 1991). The AHS consists of 12 items. Participants rate each item using an 8-point Likert scale, ranging from 1- Definitely False to 8- Definitly True. There are four Agency items, four Pathway items, and four filler items. To address goals as a whole, there is one item referencing the past ("I've been pretty successful in life"), two referencing the present ("I energetically pursue my goals" and "I meet the goals that I set for myself"), and one referencing the future ("My past experiences have prepared me well for my future"). The Agency subscale items address participants' determination to complete

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personal goals (e.g., I energetically pursue my goals). The Pathway subscale items assess participants' ability to overcome challenges and meet their goals (e.g., "I can think of many ways to get out of a jam"). An Overall Hope score was obtained by adding the eight items and omitting filler items. Potential Overall Hope scores range from zero to 64. Scores for Agency and Pathway subscales can be calculated by adding up the respective four items each; however, the subscales were not utilized in the analyses of the current study.

Test-retest reliability of the AHS was examined in four undergraduate college samples. The 3-week test-retest reliability estimate was .85 (Anderson, 1988); the 8-week test-retest reliability estimate was .73 (Harney, 1990); and two 10-week test-retest reliability estimates were .76 and .82 respectively (Gibb, 1990; Yoshinobu, 1989).

The internal consistency reliability of the AHS was examined using a series of tests involving six separate college samples, as well as one inpatient and one outpatient sample engaged in psychological treatment. Cronbach alphas for these samples ranged from .74 to .84 for the Overall Hope score (Snyder, et al., 1991). The Agency subscale Cronbach alphas ranged from .71 to .76 and the Pathway subscale Cronbach alphas ranged from .63 to .80. Internal consistency scores were found to be acceptable for all of the samples in the original study.

For the current study sample, the internal consistency reliability estimate for the overall AHS score was .86. Since the overall score was only used in this study, additional analyses for the two subscales of the AHS were not conducted.

The AHS has two theorized components: Agency and Pathways. Principle-components factor analyses with oblique rotations were conducted on the AHS (eight-items). The four Agency items had high loadings on Factor 1 but not on Factor 2. The four Pathway items had high loadings on Factor 2 but not on Factor 1. The inpatient sample demonstrated that one

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Pathway item loaded on Agency factor. The two factors accounted for 52% to 63% of the variance in hope scores across samples. The two-factor model appears to be appropriate (Snyder et al., 1991).

Agency and Pathway subscales have been significantly correlated with one another in multiple samples: six college student samples, $r = .38$ to .46; an outpatient sample, $r = .57$; an inpatient sample, $r = .46$ (Snyder, et al., 1991). According to these analyses, Agency and Pathway items are related, but are also distinct constructs.

Researchers have examined the convergent validity of the AHS when compared to other questionnaires that were developed to measure theoretically similar constructs. Hope has been significantly and positively correlated with optimism, expectancies for attaining goals, general desire for control, perceptions of problem solving abilities, self-esteem, social desirability, and self-presentation (Gibb, 1990; Holleran and Snyder, 1990; Roth, Harris, & Snyder, 1988; Roth, Snyder, & Pace, 1986;). In addition, divergent validity for the AHS is noted in that hope has been significantly and negatively correlated with depression and hopelessness (Gibb, 1990).

PedsQL Inventory - Core Generic Form (PedsQL; Varni et al., 1999). Quality of life may be associated with individuals' perceptions of their best physical and emotional state possible within the limits of their medical condition. Quality of life was measured within the conceptualization of Health-Related Quality of Life (HRQOL) as defined by Varni et al. (1999). Participants' HRQOL was assessed taking into consideration their medical diagnosis using the PedsQL Inventory - Core Generic Form. This inventory measures generic health-related quality of life. This inventory is appropriate to use with patients who have chronic health conditions. Both self-report and parent-report versions of this inventory are available; however, for the current study, only the self-report versions was used.

The PedsQL Inventory-Core Generic Form is a 23-item inventory that includes assessment of physical, mental, social, and school/work domains. For the purpose of this study, three versions of the self-report form were given based on the age of the participants: Teen (15-18 years old), Young Adult (19-25 years old), and Adult (>26 years old). Each version addresses the same items; however, some of the wording is slightly modified to reflect the experiences of participants based on their developmental level. For example, one item on the adult form reads "I hurt or ache", while the same item on the young adult form reads "I hurt or feel pain". Each item is prompted with "In the past ONE month, how much of a problem has this been for you…" Eight items assess problems with the participants' physical health and activities (e.g., "It is hard for me to run"). Five items address problems with feelings or emotion (e.g. "I feel afraid or scared"). Five items assess social issues (e.g., "I have trouble getting along with other adults"). Five items refer to school or work problems (e.g., "It is hard to pay attention at work or school"; all examples taken from the adult form). Participants rate each item using a 5-point Likert scale, ranging from 0-Never to 4- Almost Always.

All items were reverse scored and transformed (0=100, 1=75, 2=50, 3=25, 4=0). The Overall Quality of Life score was calculated by finding the mean of all the items (after reversed and transformed and then adding up all items and dividing by total items answered). The individual physical functioning, emotional functioning, social functioning, and academic/occupational functioning subscale scores were calculated by finding the mean score of each subscale items (add items from individual subscale and divide by total items answered from subscale items). The psychosocial health summary score was created by calculating the mean of the emotional, social, and school/work subscale scores. Lastly, the physical health summary score is the physical functioning subscale. Varni et al. (1999) endorse the use of means for the

Overall Quality of Life score and the subscales scores. Higher scores indicated a higher quality of life; lower scores indicate lower levels of quality of life.

The PedsQL is a reliable and valid measure of quality of life (Varni et al., 1999). Varni et al. (1999) used a sample of pediatric cancer patients and their parents to assess psychometrics for this measure. The internal consistency reliability estimates for the patient and parent version of the PedsQL were .93 and .93 respectively (Varni et al., 1999). These scales were negatively correlated with emotional distress. Scale inter-correlations support a multidimensional model, with positive medium to large effect sizes between patient and parent forms and small to medium effect sizes between scales. A factor analysis was conducted on the 15 core items comprising the PedsQL Inventory. Three factors accounted for 52% of the total variance in quality of life scores: physical, psychological, and social functioning.

For this current sample, the internal consistency reliability estimates for the Overall PedsQL Inventory score was .93. The internal consistency reliability estimates for the individual subscales for the current sample were as follows: .91 for Physical functioning, .82 for Emotional functioning, .77 for Social functioning, .85 for School/Work functioning, and .90 for Psychosocial functioning (which is a combination of the Emotional, Social, and School/Work subscale items). For the purposes of this study, the Physical and Psychosocial functioning subscales as well as the Overall PedsQL Inventory (Overall Quality of Life) score was utilized.

Demographic Questionnaire. The purpose of the demographic questionnaire was to acquire information from the participants about their age, gender, race/ethnicity, bleeding disorder diagnosis, diagnosis severity (i.e., mild, moderate, severe), the education level of participant, their family income level, their age when first diagnosed, student/employment status, and any other chronic medical conditions identified above and beyond their bleeding disorder.

Procedure

    In-Person Recruitment. Participants recruited in-person were approached during their annual or semi-annual bleeding disorder comprehensive clinic visit. Eligible individuals were provided with information about the study and addressed questions as needed. Potential participants were also informed that for every survey completed, $5 would be donated to the National Hemophilia Foundation. Informed consent and PHI (personal health information) consent was then obtained from those who decided to participate. Participants aged 15 to 17 years of age were required to have a parent or guardian complete the informed consent and PHI consent forms, in addition to their own assent forms for this study. Participants aged 18-65 years of age completed the informed consent and PHI consent forms for this study independently. Copies of the informed consent and PHI forms were provided to those who requested them.

    After signing all appropriate consent/assent forms, participants completed the demographic questionnaire. Next, participants completed a randomized order of the three study measures: the SCS, AHS, and PedsQL Inventory - Core Generic Form.

    After completion of the study materials, participants were thanked for their time, given a Thank You page with the researchers' contact information, and they continued with the remainder of their medical appointment. At the end of the study, the Primary Investigator donated a total of $455 to The National Hemophilia Foundation.

    Online Recruitment. Participants were also recruited online (n = 10). A Qualtrics survey identical to the survey used in the in-person recruiting process was created and activated. The online survey only allowed those 18 and older to participate due to the researcher's inability to accurately verify parental/guardian informed consent for minor participants.

Various Facebook bleeding disorder-related groups were contacted in an effort to recruit individuals with bleeding disorders who were eligible to participate in this study. One group gave permission to post on their Facebook page, but no one from that group participated in this study. A URL to the study Qualtrics survey was provided within the post. In addition, over 40 hematology clinics across the United States were contacted by the Primary Investigator. One Midwest Clinic Director sent the Qualtrics survey link via email to all their patients through their clinic portal (n = 7). Lastly, a few participants (n = 3) were recruited via email who were acquaintances of the researchers of this study.

The following is the procedure for those recruited online. Individuals who participated online followed the URL via email to the Qualtrics survey for this study. Participants were pre-screened with two items. The first question asked participants to enter their age. The second asked if they have been diagnosed with Von Willebrand's disease or hemophilia. If the individual met the criteria for the study, they continued to the informed consent page. Participants were encouraged to print a copy of the consent form for their records. After agreeing to the consent form (by clicking Next), the participants completed the demographic questionnaire followed by the SCS, the AHS, and the PedsQL Inventory. These three measures were randomly ordered to control for any potential ordering effects. After completing the online survey, the participants were reminded of the donation that would be made on their behalf at the completion of the study and were shown a Thank You page with the researchers' contact information.

CHAPTER IV

FINDINGS

Missing Data

Due to incomplete data or ineligibility to participate in the study, five participants' data were excluded from the final analyses. If more than two items on any subscale measure was missing, those participants' data were omitted from the final analyses. This is consistent with the recommendations from the authors of the measures (Neff, 2003a; Snyder et al., 1991; Varni et al., 1999). If only one item was missing on a scale, the mean of that scale replaced the missing item value; this was the case for only one participant on one data point.

Descriptive Statistics for the Main Study Variables

Descriptive statistics (i.e., means, standard deviations, potential score ranges, and actual score ranges) were calculated for the overall scores for the main study variables including Overall Quality of Life, Psychosocial Quality of Life, Physical Quality of Life, Overall Self-Compassion, and Overall Hope. See Table 2.

The mean score for Overall Quality of Life for this sample of individuals with bleeding disorders was 75.9 (sd = 16.6) with participants' scores ranging from 33.9 to 100 (possible range is 0 to 100). The mean score on Psychosocial Quality of Life was 77.1 (sd = 16.2) with participants' scores ranging from 38.3 to 100 (possible range is 0 to 100). Finally, the mean score on Physical Quality of Life was 72.4 (sd = 23.3) with participants' scores ranging from 15.6 to 100 (possible range is 0 to 100). Higher scores indicate a higher quality of life and lower scores

indicate a lower quality of life. Of interest, many of the participants scored in the moderate to high range regarding their overall quality of life.

The Overall Self-Compassion mean score has a potential range of 0 to 5. The mean score of Overall Self-Compassion for this sample of individuals with bleeding disorders was 3.4 (sd = 0.7) with actual scores ranging from 2.1 to 5.0. Higher scores indicate more self-compassion and lower scores indicate less self-compassion.

The Overall Hope score has a potential range of 0 to 64. The mean score of Overall Hope was 53.3 (sd = 7.0), with actual scores ranging from 33 to 64. Higher scores indicate more hope and lower scores indicate less hope.

Assumptions Tested in the Analyses to Follow

The assumption of linearity and bivariate normality were assessed by the examination of scatterplots addressing the relationship of x and y variables. The scatterplots revealed adequate relationships between the variables, with an absence of unusual patterns or skewedness. Independence was met for the analyses given the independent nature of the procedure and data collection methodology.

Homogeneity of variance was addressed by examining the regression error plots for each regression analysis conducted. Plots illustrated minimal concerns among consistency of spread across points. Regression error plot histograms were examined for each regression to assess the assumption of normality of residuals. The histograms illustrated a general consistency of distribution of what would be expected of a normal curve; however, there was some irregularity toward the center of the distribution. This may be due to the small sample size within this study.

Multicollinearity was also assessed between the predictor variables in the regression models. A Pearson correlational analysis revealed a moderate correlation between self-

compassion and hope ($r = .61$, p $< .001$). Due to the strength of this relationship, further analysis was conducted to assess for the presence of multicollinearity. The VIF and Tolerance values in the regression analyses were examined and both were acceptable and supported the absence of multicollinearity (Tolerance $> .333$ and VIF < 3).

Correlational Analyses

Research Question 1. What is the relationship between Self-Compassion and Overall Quality of Life for individuals diagnosed with bleeding disorders?

Hypotheses 1. Overall Quality of Life was expected to be significantly and positively correlated with the Self-Kindness, Common Humanity, and Mindfulness subscales of the Self-Compassion Scale as well as the Overall Self-Compassion score for this sample of individuals diagnosed with bleeding disorders. Overall Quality of Life was expected to be significantly and negatively correlated with the Self-Judgment, Isolation, and Over-Identification subscales of the Self-Compassion Scale for this sample of individuals diagnosed with bleeding disorders.

To answer this question, researchers conducted a Pearson correlational analyses to assess the bivariate relationships among Overall Self-Compassion, the positive and negative components of self-compassion (Self-kindness, Common Humanity, Mindfulness, Self-judgment, Isolation, and Over-identification) and Overall Quality of Life. There was a significant and positive relationship between Overall Quality of Life and Overall Self-Compassion ($r = .39$, p $< .001$) for these individuals with bleeding disorders. The researchers of this study did not statistically control for Type I error for the number of correlational analyses conducted with this sample given the exploratory nature of this study, the fact that this is a new area of research (i.e., exploring positive psychological variables associated with quality of life for patients who have bleeding disorders), and given the greater concern to minimize Type II error.

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Overall Quality of Life was also significantly related to most of the Self-Compassion subscale scores for these patients with bleeding disorders. There was a significant and positive correlation between Overall Quality of Life and Self-Kindness ($r = .37$, p < .001). However, there was not a significant relationship between Overall Quality of Life and the other two positive Self-Compassion components: Common Humanity ($r = .01$, p > .05) and Mindfulness ($r = .20$, p > .05). Further, there were significant and inverse bivariate relationships between Overall Quality of Life and each of the negative Self-Compassion components including Self-Judgement ($r = -.44$, p < .001), Isolation ($r = -.35$, p < .001), and Over-Identification ($r = -.45$, p < .001). These results partially supported the hypotheses for research question 1.

Research Question 2. What is the relationship between Hope and Overall Quality of Life for individuals diagnosed with bleeding disorders?

Hypotheses 2. Hope was expected to be significantly and positively correlated with Overall Quality of Life for this sample of individuals diagnosed with bleeding disorders.

To answer research question two, researchers conducted one correlation analysis. There was a significant and positive relationship between Hope and Overall Quality of Life for these individuals with bleeding disorders ($r = .44$, p < .001), supporting the hypothesis for research question two.

See Table 3 for the correlation matrix for all of the main study variables. The subscales of the Quality of Life measure were included in this matrix given that some of the regression analyses to follow included those subscales as criterion variables.

Regression Analyses

Research Question 3. What is the linear relationship of Self-Compassion and Hope with Overall Quality of Life for individuals diagnosed with bleeding disorders?

Hypotheses 3. Overall Self-Compassion and Hope were expected to significantly and positively predict Overall Quality of Life for this sample of individuals diagnosed with bleeding disorders.

To answer this research question, a multiple regression analysis was conducted to explore the linear relationship of Self-Compassion and Hope with Overall Quality of Life. Self-Compassion and Hope were found to be significant predictors of Overall Quality of Life for this sample when these variables were considered together, $F(2, 83) = 11.45$, $p < .001$. The multiple correlation coefficient ($R2$) for this model was .22, indicating that approximately 22% of the variance in Overall Quality of Life was accounted for by the linear combination of Overall Self-Compassion and Hope. Participant's Overall Quality of Life scores increased 4.71 for each Self-Compassion unit increase and .74 for each Hope unit increase. See Table 4 for these multiple regression findings. Examination of the standardized beta weights revealed that Hope ($\beta = .31$, t = 2.54, $p < .05$) was the only significant individual contributor of Overall Quality of Life for this sample.

Research Question 4. What is the linear relationship of Self-Compassion and Hope with Psychosocial Quality of Life for individuals diagnosed with bleeding disorders?

Hypotheses 4. Overall Self-Compassion and Hope were expected to significantly and positively predict Psychosocial Quality of Life for this sample of individuals diagnosed with bleeding disorders.

To answer this research question, researchers conducted a multiple regression analysis to explore the linear relationship of Overall Self-Compassion and Hope with Psychosocial Quality of Life. Self-Compassion and Hope were found to be significant predictors of Psychosocial Quality of Life for this sample when these variables were considered together, $F(2, 83) = 10.31$,

$p < .001$. The multiple correlation coefficient ($R2$) for this model was .20, indicating that approximately 20% of the variance in Psychosocial Quality of Life can be accounted for by the linear combination of Overall Self-Compassion and Hope. Participant's Psychosocial Quality of Life scores increased 5.22 for each Self-Compassion unit increase and .61 for each Hope unit increase. Examination of the standardized beta weights revealed that hope ($\beta = .26$, $t = 2.13$, $p < .05$) was the only significant individual contributor to Psychosocial Quality of Life for individuals with bleeding disorders. However, Self-Compassion was approaching significance ($\beta = .23$, $t = 1.90$, $p = .06$) as an individual predictor of Psychosocial Quality of Life. See Table 5.

Research Question 5. What is the linear relationship of Self-Compassion and Hope with Physical Quality of Life for individuals diagnosed with bleeding disorders?

Hypotheses 5. Overall Self-Compassion and Hope were expected to significantly and positively predict Physical Quality of Life for this sample of individuals diagnosed with bleeding disorders.

To answer this research question, researchers conducted a multiple regression analysis to explore the linear relationship of Overall Self-Compassion and Hope with Physical Quality of Life for this sample. Self-Compassion and Hope were found to be significant predictors of Physical Quality of Life when these variables were considered together, $F (2, 83) = 8.16$, $p < .001$. The multiple correlation coefficient ($R2$) for this model was .16, indicating that approximately 16% of the variance of Physical Quality of Life could be accounted for by the linear combination of Overall Self-Compassion and Hope. Participant's Physical Quality of Life scores increased 3.20 for each Self-Compassion unit increase and 1.12 for each Hope unit increase. Examination of the standardized beta weights revealed that Hope ($\beta = .34$, $t = 2.67$, $p <$

.01) was the only significant individual contributor to Physical Quality of Life for individuals

with bleeding disorders. See Table 6.

CHAPTER V

DISCUSSION

In this study, Overall Self-Compassion and Hope were significantly related to Quality of Life in individuals who have bleeding disorders. While both Overall Self-Compassion and Hope together significantly predicted Overall Quality of Life as well as Physical and Psychosocial Quality of Life for individuals with bleeding disorders, Hope was the only significant individual predictor of these Quality of Life scales for this sample. This, in part, could be explained by the shared variance between Self-Compassion and Hope. These findings indicate that positive qualities, such as being kind to oneself and being more hopeful, can have a positive impact on the quality of life for individuals who have bleeding disorders. Having a higher quality of life can also have a positive impact on how compassionate patients with bleeding disorders are towards themselves and how hopeful they are in general about their goals and their lives. These findings will be discussed in more depth.

Self-Compassion and Quality of Life for Individuals with Bleeding Disorders

Self-Kindness, a positive component of self-compassion, was significantly and positively correlated with Overall Quality of Life for individuals with bleeding disorders. Therefore, as Self-Kindness increases for individuals with bleeding disorders, Overall Quality of Life also increases. This finding is especially important given the complicated nature of bleeding disorders. Since individuals with bleeding disorders often experience physical pain and manage increased emotional, social, occupational/academic stressors (Barlow, Stapley, and Ellard, 2007; Forsyth et al., 2011; Poon 2013; Trzepacz et al., 2003; Williams & Chapman, 2011), it appears

that the presence of self-kindness may allow one to accept these sufferings and implement understanding towards one's situation. Employing kindness towards oneself may ultimately lessen these burdens, and in turn, enhance one's quality of life.

The other two positive components of self-compassion, Common Humanity and Mindfulness, were not found to a have a significant relationship with Overall Quality of Life for this sample of individuals with bleeding disorders. Common humanity is the idea that one is not alone in their suffering. Due to the rarity of bleeding disorders, feeling like no one else understands one's situation is a reality for many individuals with these illnesses. Further, it is possible that being mindfulness will only draw attention to the struggles individuals with bleeding disorders endure, especially the physical pain, making it more difficult to maintain or increase one's quality of life. Therefore, for these reasons, it makes sense that Mindfulness and Common Humanity are not significantly related to the Quality of Life of individuals with bleeding disorders. While Common Humanity and Mindfulness were not found to be individually related to Quality of Life in individuals with bleeding disorders, Overall Self-Compassion was related to Quality of Life. This may be an area for researchers to further explore—what aspects of Mindfulness and Common Humanity either do or do not relate to Quality of Life or overall functioning for individuals with bleeding disorders?

Overall Quality of Life for individuals with bleeding disorders was significantly and inversely related to the three negative components of self-compassion—Self-Judgment, Isolation, and Over-Identification. This indicates that the more one judges oneself, isolates oneself, or over-identifies with one's thoughts and emotional states, quality of life declines for individuals who have bleeding disorders. Judging oneself, for example, thinking poorly of one's situation or even placing blame/shame on oneself for the symptoms of their disease may decrease

the ability for patients with bleeding disorders to feel they can manage or cope with their struggles and, in turn, can negatively affect their quality of life. Individuals with bleeding disorders may experience unique social difficulties due to their bleeding disorder (Williams & Chapman, 2011). Therefore, isolating oneself from social contexts may limit one's ability to seek relational support in times of struggle and/or pain, ultimately wearing away at one's quality of life. In fact, research has shown that social support is one of the most important factors influencing quality of life in individuals with chronic illnesses (Bullinger & von Mackensen, 2008). Therefore, seeking out relational support when needed and avoiding isolating behaviors may increase self-compassion and quality of life in individuals with bleeding disorders.

Lastly, Over-identification is the concept that one over-identifies with their thoughts and emotional states. Individuals who have bleeding disorders may experience increased mental health concerns (Canclini et al., 2003; Elander et al., 2009; Poon, 2013; Trzepacz et al., 2003), making over-identification with one's thoughts and emotions an important factor in understanding their quality of life. In fact, individuals with bleeding disorders may experience anxiety and depression associated with the daily stressors related to their illness (Barlow et al., 2007; Trzepaczet al., 2003). Therefore, if one over-identifies with their emotions, especially depression and anxiety, it is reasonable to expect that their mental health may suffer and ultimately lower their quality of life.

In addition to the subscales of the Self-Compassion Scale, Overall Self-Compassion was significantly and positively related to Overall Quality of Life in individuals with bleeding disorders. Therefore, as Overall Self-Compassion increases, their Overall Quality of Life also increases. This finding is in line with previous research. Self-compassion has been associated with less intrusive pain (Ziemer, 2014) as well as the ability to accept one's pain related to a

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chronic illness (Costa & Pinto-Gouveia, 2011). Individuals with bleeding disorders often experience significant amounts of pain due to bleeding in their muscles and joints and pain can have a significant influence on the mental health of individuals with bleeding disorders (Elander et al., 2009). Self-compassion has also been associated with fewer symptoms of depression and anxiety in individuals with various chronic illnesses (Pinto-Gouveia et al., 2014) and increased levels of activity engagement (Ziemer, 2014), which may enhance mental and social functioning. In conclusion, results from this and previous studies support that self-compassion has the potential to enhance the quality of life for individuals who have bleeding disorders.

Hope and Quality of Life for Individuals with Bleeding Disorders

Hope was also significantly and positively related to Overall Quality of Life in individuals diagnosed with bleeding disorders. This finding is congruent with previous research exploring hope and quality of life among individuals with other chronic illnesses (Chammas, 1999). Hope is the concept that individuals are motivated to reach their goals (agency) and have the means or experience to reach those goals (pathways). It is important to note that individuals with chronic illnesses may already have lower levels of hope than those who have not been diagnosed (Venning et al., 2007). Therefore, there are many areas of life for individuals with bleeding disorders that hope may positively influence. Two essential roles of hope are primary and secondary prevention (Snyder et al., 2000b). Prevention and treatment are highly important in the lives of individuals with chronic illnesses. Preventing bleeding episodes, preparing for treatments, and enacting treatments are vital to the functioning of those diagnosed with bleeding disorders, and hope has the potential to positively affect one's ability to engage in such behaviors. In fact, hope has been associated with engagement in preventative behaviors related to one's medical condition (Harney, 1990), making hope a valuable component of wellness for

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those with bleeding disorders, especially in terms of enhancing one's quality of life. Hope may

further impact the emotional/mental functioning of these individuals, as hope has been related to

less depression and anxiety for individuals who have chronic illnesses (Germann et al., 2015).

Both self-compassion and hope appear to have the potential to increase quality of life for

individuals with bleeding disorders and lessen the daily stressors and struggles they may

experience.

Self-Compassion and Hope for Individuals with Bleeding Disorders

Few researchers have explored the relationship between hope and self-compassion,

especially within samples of patients with chronic illnesses, and this is the first study of its kind

to explore these constructs among individuals who have bleeding disorders. Self-Compassion

and Hope were moderately and positively correlated with one another. Theoretically, when an

individual implements kindness toward oneself, believes in common humanity, and engages in

mindfulness, it is probable that they also feel more hopeful that they can effectively attain their

goals. If an individual is judgmental towards their experiences and decisions, isolates, and over-

identification with one's emotions/thoughts it is also realistic that they would experience

difficulty believing they could reach their goals and have limited hope for their future. Based on

these findings, if a person with bleeding disorders is more hopeful and goal-oriented, whether it

be related to their bleeding disorder or to other aspects of their lives, they also tend to be more

compassionate towards themselves.

Due to the complimentary nature of Self-Compassion and Hope, as well as the

associations of Self-Compassion and Hope with various areas/aspects of functioning, it makes

sense that these variables were predictive of Overall, Psychosocial, and Physical Quality of Life

for individuals with bleeding disorders. This indicates that not only does self-compassion and

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hope predict overall functioning of quality of life, but it has predictive power within the smaller components of quality of life functioning as well. Self-compassion and hope appear to have great potential to positively influence the physical, emotional, social, and occupational/academic aspects of functioning for individuals with bleeding disorders. It should be noted that Hope was the only significant individual predictor of Overall, Psychosocial, and Physical Quality of Life for these individuals with bleeding disorders, which may be, in part, due to the shared variance between Self-Compassion and Hope.

Implications for Practice with Individuals Diagnosed with Bleeding Disorders

Findings from this study are valuable to consider for those working with individuals diagnosed with a bleeding disorder. For health care providers (i.e., physicians, psychologists, counselors, social workers, etc.) who work with the bleeding disorders population, implementing interventions and psychoeducational opportunities related to self-compassion and hope may enhance patients' quality of life. Introducing interventions about the process of promoting self-kindness and confronting self-judgments may allow individuals with bleeding disorders to be more understanding of their struggles related to their medical condition and their lives in general. For example, cognitive-behavioral strategies may be employed to address internal judgments and/or over-identification/personalization tendencies, to acknowledge common errors/mistakes in thinking about one's disease, and to restructure automatic thoughts and core beliefs that are negative, unrealistic, and unhelpful in nature (Beck, 2011). Addressing cognitive processes, such as self-kindness, self-judgment, and over-identification is especially important for individuals with bleeding disorders as the symptoms associated with these illnesses may have a negative impact on their mental health (Elander et al., 2009) as well as their quality of life. Enhancing self-compassion may reduce the likelihood of depression and anxiety (Pinto-Gouveia et al.,

2014), which are more prevalent in those with bleeding disorders (Barlow et al., 2007; Trzepaczet al., 2003) compared to other patient populations. Further, reducing one's tendencies to over-identify with one's thoughts and emotions may allow individuals to limit self-judgement and embrace self-kindness. Instead of believing "depression is a part of who I am", they can identify that depression is something that they can change and it is not a fixed state of being. Providers can educate individuals about the effects of over-identification and provide tools and interventions to balance awareness of one's emotions/thoughts and not over-identify with them.

Additionally, due to the social struggles many individuals with bleeding disorders experience (Williams & Chapman, 2011), reducing the likelihood of social isolation is an important component of self-compassion that health care providers can address, especially given the fact that social support is one of the most important predictors of quality of life for individuals with bleeding disorders (Bullinger & von Mackensen, 2008). Providers can support individuals with bleeding disorders by providing them with information on various bleeding disorder or chronic illness support groups in the community or may even be able to connect those who are patients in their clinic(s) to gain additional relational support. Health care providers may also problem-solve with these individuals where they can gain more familial, social, or psychological support from sources wherein they already have connections rather than starting from scratch.

Due to the many struggles individuals with bleeding disorders experience, it may be difficult at times to believe one can attain their goals or find the means to accomplish them. Individuals with chronic illnesses may already have lower levels of hope than those without a diagnosis (Venning et al., 2007). Barlow and Ellard (2004) posited that interventions around hope for individuals with chronic illnesses would be effective in disease management planning.

Managing and planning for one's bleeding disorder can be vital given the unpredictable nature of bleeding episodes. Being more hopeful (i.e., believing in your ability to achieve your goals and findings ways to get there) may boost actual goal attainment for individuals with bleeding disorders and in turn improve their overall quality of life. Providers may instill hope in those they work with utilizing a problem-solving approach and identifying ways in which individual are capable of reaching their goals. Providers may also offer concrete resources that make their patients' goals more realistic in nature. Such resources may include information about scholarships and Individualized Education Plans for students, additional disability support, and networks within the community that offer symptom-conscious employment. In addition, providers may also use strength-based approaches when working with individuals with bleeding disorders. Since the struggles these individuals experience may make it difficult to be hopeful, providers can point out the strengths of their patients and support them in seeing that they are capable of reaching their goals despite their difficulties. For example, providers may identify times in which a person was able to attain a goal, such as treatment management, and reinforce the ways in which this person was able to do this.

Assessing for self-compassion and hope when working with individuals with bleeding disorders could identify these variables as protective factors, with an emphasis on supporting patients' growth in one or both areas to enhance their quality of life. Identifying aspects of their quality of life that may affect patients' functioning can also be very helpful in the management of their disease process and in supporting their overall well-being. In fact, administering these measures (i.e., SCS, AHS, and PedsQL) would take only a few minutes and providers can then customize their interventions that focus on certain aspects of clients' experience based on these assessment findings. Providers may also elect to give these measures consistently throughout

treatment to reassess and monitor progress as they continue to support patients in their journey toward self-compassion and hope as buffers for their quality of life.

Self-compassion and hope hold abundant potential as variables that can positively affect the quality of life in those with bleeding disorders. By bringing awareness to individuals through assessment, education, and intervention, providers can create opportunities to enhance the quality of life in those they work with each time they see them.

Limitations and Recommendations for Future Research

The researchers of this study plan to conduct further analyses to explore demographic group differences (e.g., age, gender, race) as well as level of severity of bleeding disorder group differences regarding their quality of life as well as their levels of self-compassion and hope. Further research is needed to explore other cultural and psychosocial factors that may be contributing to the quality of life of individuals with bleeding disorders. Self-efficacy in treatment, diagnosis-related shame, and/or resilience may be other psychological factors introduced into future research studies related to quality of life for those with bleeding disorders. Obtaining a more detailed picture of factors related to or predictive of quality of life for these individuals will give providers more information in how to best support them and their functioning. In addition to exploring factors related to quality of life in this population, there is also the opportunity to address barriers that may inhibit client's ability to obtain, maintain, or implement these factors. Examples of such barriers may be access to psychological/medical care, access to support systems, and the cost of services for individuals with medical conditions. Additionally, research could embrace a qualitative inquiry approach to explore in depth the unique experiences of individuals with bleeding disorders, especially related to self-compassion, hope, and quality of life.

While this study was the first of its kind to explore the relationships of self-compassion and hope with quality of life for individuals with bleeding disorders, due to the rarity of bleeding disorders and the limited recruiting resources of the researchers, the sample size was one of the main limitations of this study. It would be beneficial to expand future research to broader geographic locations to obtain a larger sample of participants. Larger sample sizes would allow researchers to identify potential differences between bleeding disorder diagnoses or severity levels. For examples, researchers could explore the effect of symptom severity on levels of self-compassion, hope, and/or quality of life. Individuals with more severe symptomology may have a more difficult time embracing self-compassion and hope; in this case, severity may be a confounding factor, which would be important for providers to recognize when supporting their patients.

Once health care providers begin to implement assessment, education, and intervention around the topics of self-compassion and hope for individuals with bleeding disorders, research can focus on the effectiveness of these interventions used with this unique medical population. By understanding the effectiveness of the services, support, and education that providers utilize, researchers can identify and explore which interventions are most useful and impactful in enhancing the self-compassion, hope, and quality of life among individuals who have bleeding disorders. Providers can then support their patients in using evidence-based treatments to help them cope better with their bleeding disorders and their lives in general.

Strengths of the Study

There are many strengths of the current study that supported the validity of the findings. First, the support received from the providers and staff at the two recruitment clinics were cooperative and this support helped in informing patients about the study and encouraging their

participation without undue pressure. It was clear in the communications with these providers and staff that their genuine care for their patients and desire to support their quality of life was a motivating factor in encouraging patients to participate in this study.

Additionally, the participants themselves were enthusiastic about contributing to a greater cause by participating in this research project. This may be due to the research emphasis present in the clinics used for data recruitment and the possibility that these patients may be more comfortable with and invested in participating in research.

Participants in this study were also relatively diverse with regards to their age, gender, race/ethnicity, and severity of diagnosis, which broadens/enhances the generalizability of findings to other patients with bleeding disorders and makes the sample size more robust and representative of this population in general.

Lastly, the use of standardized measures and the more than adequate internal consistency reliability estimates for the self-compassion, hope, and quality of life scores for this sample strengthens the methodology and validity of this study.

Conclusion

Health care providers who work with individuals diagnosed with bleeding disorders can support them by considering the positive psychology factors that influence their quality of life. The researchers of this study found that self-compassion and hope have relational and predictive value when it comes to quality of life for individuals with bleeding disorders. Recommendations were offered for providers to implement assessment, education, and intervention with their patients in the areas of self-compassion and hope to enhance their quality of life. For those diagnosed with bleeding disorders, the symptoms associated with one's diagnosis can bring about struggles in physical, emotional, social, and occupational/academic functioning, but by

focusing on self-compassion and hope, health care providers have the opportunity to enhance their patients' overall quality of living, which may have a number of positive rippling effects for their patients' medical treatment, relationships with others, views of their chronic illness, and their accomplishments in life in general.

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APPENDIX A

EXTENDED REVIEW OF THE LITERATURE

Bleeding disorders, including hemophilia and Von Willebrand's disease, are rare chronic illnesses that affect individuals all around the world. Hemophilia (type A and B) occurs in approximately 1 in 5,000 live births (National Hemophilia Foundation, n.d.). The most common bleeding disorder is Von Willebrand's disease, which occurs in 1% of the general population. Hemophilia is a rare bleeding disorder when blood cannot properly clot due to insufficient production of factor or clotting agent. Hemophilia severity (mild, moderate, or severe) is based on the amount of factor or clotting agent a person produces naturally. Bleeding can occur internally or externally following an injury and on rare occasions can occur spontaneously. Bleeding, or "bleeds", can cause a great deal of pain for those who experience hemophilia. Bruising, joint pain and swelling, and bleeding in the joints and muscles, are all common symptoms of hemophilia. In severe cases, hemophilia can be life threatening. Surgeries and dental procedures are often complicated by the symptoms of hemophilia and proper treatment must be prepared in advance. The National Hemophilia Foundation explains that hemophilia is a recessive gene carried on the X chromosome. Therefore, males are more often diagnosed with hemophilia than females. Males inherit an X chromosome form their mother and a Y chromosome from their father; if their mother is a carrier and the son inherits that gene on his X chromosome then he will have hemophilia. A son cannot inherit hemophilia from the father because they receive the fathers Y chromosome. If a daughter inherits the hemophilia gene from the mother's X chromosome, she will only be a carrier and will not have hemophilia, but she

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may pass the carrier gene down to a son and he would have hemophilia. It is very rare that a female is diagnosed with hemophilia. Carriers of hemophilia may also show symptoms of the disease. Hemophilia is usually treated throughout one's life time and often involves infusing or injecting synthetic factor into the body, as well as consistent medical visits. Physiological, emotional, social, and educational/occupational issues are common in individuals with hemophilia (Hill, 2015; Williams & Chapman, 2011). The restrictions associated with hemophilia, due to precautions, treatment, or pain may impact many components of daily living for those diagnosed with it.

Another bleeding disorder is Von Willebrand's disease. Unlike hemophilia, Von Willebrand's is diagnosed equally in both women and men. Von Willebrand's is characterized by bruising, mucosal bleeding in the mouth and nose, as well as menorrhagia, or extended and intensified menstrual cycles. Individuals diagnosed with severe Von Willebrand's may experience bleeding in the joints and muscles, similar to hemophilia, and must treat their symptoms with infusions of blood clotting agent.

Biopsychosocial stressors are common for individuals diagnosed with bleeding disorders such as hemophilia and Von Willebrand's disease. Individuals with bleeding disorders are often restricted in activity level, which can be especially stressful for children who want to play actively or engage in a sport. These restrictions can also result in social difficulties. In one qualitative study, boys, ages six to thirteen, diagnosed with hemophilia and their parents reported a recurring theme of wanting to be "normal" (Williams and Chapman, 2011). Participants noticed differences between themselves and others their age and idolized the notion of normality. The researchers noted that the children with hemophilia had a heightened sense of being different due to the rarity of their condition. Participants felt socially stigmatized by their diagnosis and

made consistent attempts to conceal their medical diagnosis from peers. Hemophilia can inhibit children from taking part in physical social activities, which could lead to them being bullied. Hiding their condition is one way children might try to appear normal. William and Chapman (2011) emphasized the need for interventions that foster peer relationships and medical self-management that facilitates healthy social development in children with hemophilia, and more broadly for children with bleeding disorders.

Similar results were found in another study of 298 pediatric hemophilia patients, eight to sixteen years of age, from six different European countries including Germany, Italy, France, Spain, The United Kingdom, and The Netherlands (Bullinger and von Mackensen, 2008). Participants from Germany, Italy, France, and Spain completed the KINDL-R (a generic self-report quality of life measure) that covers six dimensions of quality of life. These participants also completed the HAEMO-QOL (a hemophilia-specific quality of life measure) to assess up to eleven domains (e.g. coping, locus of control, life satisfaction, social support) contributing to their quality of life. While results varied from country to country, participants from Germany, Italy, and France reported that life satisfaction impacted their quality of life. In addition to life satisfaction, participants from Germany reported that social support was a major factor contributing to quality of life. The researchers explained that deficits in social support may lead to lower levels of quality of life. While results varied from country to country, this research assists in getting a broader picture of factors that may influence quality of life in individuals diagnosed with bleeding disorders. In summary, individuals diagnosed with bleeding disorders may face social challenges due to isolation or inability to engage and these social difficulties may impact their quality of life.

Research shows that emotional difficulties also impact the quality of life of these individuals. Individuals with hemophilia report more issues in relation to their emotional well-being than those without hemophilia (Trzepaczet al., 2003). In one study, a total of 40 male adolescents diagnosed with hemophilia and 40 comparison non-hemophiliac males, ages 8 to 15, were recruited to participate in a study to examine the emotional, behavioral, and social functioning of adolescents with and without hemophilia. The adolescents themselves, their parents, and their teachers assessed the participants' emotional well-being by completing a battery of questionnaires including: the Children's Depression Inventory, the Roberts Apperception Test for Children, the Loneliness and Social Dissatisfaction Questionnaire, the Self-Perception Profile for children, and the Vocabulary and Block Design subtests of the Wechsler Intelligence Scale for Children-Revised. Adolescents diagnosed with a bleeding disorder had significantly higher scores on the Children's Depression Inventory compared to peers and they also rated themselves lower on Scholastic Competence, Athletic Competence, and Global Self-Worth than their peers. Parents of the participants with hemophilia reported higher levels of Somatic Complains, Total Internalizing Problems, and Anxious/Depressed Behavior compared to parents of the non-hemophiliac adolescents. No differences were found in behavioral or social functioning between participants with and without hemophilia. These research findings emphasize that individuals diagnosed with hemophilia should not be assumed to experience social or behavioral issues as a result of their disease; however, issues of depression and anxiety, academic competence, desire to be physically active, internalizing problems, and self-worth were present. All of these factors contributing to emotional well-being should be considered when treating individuals with bleeding disorders.

Furthermore, individuals with bleeding disorders report lower levels of self-esteem (Canclini et al., 2003; Limperg et al., 2017) and quality of life as well as experience more stress than non-hemophiliacs (Barlow et al., 2007). In a qualitative study, men with hemophilia reported that they feel a need to carefully assess the negative effects of divulging their diagnosis to friends, co-workers, and partners to avoid rejection, misunderstandings, and/or discrimination (Rolstad, 2014). They also reported feeling overwhelmed or dispirited about their diagnosis and felt the threat of falling into a powerless victim role. Due to this fear of rejection or discrimination, creating personal and professional relationships can be difficult for individuals with bleeding disorders, which can result in a great deal of stress. In one way or another, most individuals diagnosed with bleeding disorders have some level of stress associated with their chronic illness.

Two factors that have contributed to stress in individuals with hemophilia and Von Willebrand's disease are social stigmatization and lack of public knowledge about bleeding disorders (Barlow et al., 2007). Individuals with hemophilia and Von Willebrand's reported discrimination in educational and occupational settings, which can contribute to stress and impact quality of life. Occupational settings can introduce another level of emotional distress for individuals with bleeding disorders. Forsyth et al. (2011) found that men with hemophilia have concerns with occupational discrimination on the basis of their diagnosis, missing multiple days of work for medical appointments or medical leave, and finding appropriate jobs that accommodate their medical needs. It can be difficult for individuals with bleeding disorders to find conducive work that considers their joints, pain, and abilities. For example, standing for long hours or lifting heavy objects could be extremely painful for an individual with hemophilia and jobs that require such activity should be avoided. Limperg and colleagues (2017) found that

95 young adult Dutch males diagnosed with bleeding disorders had slightly lower scores on the total, physical, and school/work quality of life subscales, measured by the Peds Quality of Life Inventory, compared to healthy peers. However, despite physical limitations, sometimes individuals with bleeding disorders work at physically-demanding jobs and avoid disclosing their condition to colleagues for fear of discrimination or stigmatization (Rolstad, 2014).

Emotional, social, medical, academic, and physical struggles are also evident for others who have chronic conditions. In a qualitative study, Hill (2015) studied eleven adolescents, ages 15-19, who were diagnosed with a chronic physical condition including Diabetes, Celiac Disease, Muscular Dystrophy, Crohns Disease, and Ehlers Danlos Syndrome. Emotions such as anger, guilt, hopelessness, and sadness were common among the participants. Some participants endorsed high levels of pain and impaired mobility. Participants in the study also shared stressful experiences of constant medical appointments, hospitalizations, and consistent medical treatments/procedures. Multiple school absences and the need for specific accommodations were indicated as stressful school experiences according to the participants in the study. Social difficulty was reported for every single participant in the interviews, including feeling isolated, being unable to perform physically in comparison with peers, and friends not understanding their illness. Despite the difficulties mentioned all participants alluded to specific strengths they possessed, such as determination and having a positive attitude. This positive outlook highlights the resilience many individuals with chronic illnesses possess. All the difficulties reported by the participants in this study (Hill, 2015) can be issues faced by individuals with bleeding disorders. Similar to these participants, emotional distress, as well as pain, impaired mobility, and psychosocial stressors are common experiences for individuals with bleeding disorders (Elander et al., 2009; Williams & Chapman, 2011)

As mentioned above, many individuals with hemophilia experience physical pain. Mental and physical aspects of pain may impact these individuals' quality of life. In a cross-sectional study of 209 males with hemophilia who experience chronic arthritic joint pain and acute bleeding pain, Elander et al. (2009) explored factors related to participants' physical and mental health-related quality of life (Elander et al., 2009). Health-related quality of life and factors associated were measured by the Hemophilia Pain Coping Questionnaire, the Chronic Pain Acceptance Questionnaire, and the RAND Health Survey. Physical quality of life was most impacted by the severity of pain, whereas mental quality of life was most influenced by negative thoughts. Negative thoughts partly mediated the impact of pain intensity on mental quality of life. In a later study by Elander and colleagues, reduction of negative thoughts predicted better mental quality (Elander, Morris, & Robinson, 2013), which further supports the powerful effect negative cognitions can have on one's well-being.

Furthermore, Poon (2013) studied mental and physical quality of life in a group of 261 participants (136 adults and 125 children) diagnosed with hemophilia. Participants completed the SF-12 Health Survey Version 1 or the PedsQL 4.0 Generic Core Form to measure quality of life. Participants also completed a survey created by the researchers that assessed joint pain and range of motion. Children were impacted more mentally when experiencing acute events, such as missing school, whereas adults were more likely to have a negative impact on their physical quality of life. Poon (2013) explained that children's decrease in mental quality of life may reduce their social interactions and could impact their self-esteem. Pain may have contributed to a decline in adults' physical quality of life because of continuous joint damage.

Similar results were found in another study in which mental quality of life in hemophilia participants was explored. A total of 711 adults diagnosed with hemophilia completed the Dutch

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Self-Assessment Questionnaire, which assessed four psychological characteristics: anxiety, anger, depression, and optimism (Triemstra et al., 1998). Participants also completed an activities of daily living index, The Multidimensional Health Locus of Control Scale, a social experiences checklist, a global life satisfaction index, and questions created by the researchers investigating appraisal and severity of disease. These researchers found that the psychological characteristics (e.g. anxiety, anger, depression, and optimism) predicted well-being and were also shown to partly mediate the negative effects (i.e. perceived seriousness, level of disability) of the participants' bleeding disorder on well-being.

As evidenced by the literature, individuals diagnosed with bleeding disorders may face a number of difficulties on a daily basis, which can affect their quality of life. Whether their issues stem from physiological, emotional, social, and/or academic/occupational issues, a great deal of stress can result. Two positive psychology factors that may be beneficial to consider when treating individuals diagnosed with bleedings disorders are self-compassion and hope, both of which will be explored in relation to quality of life for individuals with bleeding disorders. Researchers have explored biopsychosocial factors related to quality of life in individuals with hemophilia and chronic illnesses, but no research to date has been conducted to explore self-compassion and hope as predictors of quality of life for individuals with bleeding disorders.

Self-Compassion

Self-compassion is a relatively new concept in Western culture. Eastern cultures have embraced and valued the notion of self-compassion for centuries and it has been slowly migrating into Western values. Research on self-compassion has become increasingly studied over the years and the well-known Self-Compassion Scale was developed by Neff in 2003. Researchers have explored the relationship between self-compassion and well-being and have

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found a consistent association between these two variables in the general population (Neff, 2003b; Neff, 2004; Neff & McGehee, 2010). Self-compassion is associated with adaptive functioning, as well as positive mental health (Neff, 2004; Sirois et al, 2015). Increased happiness, optimism, and social connectedness, and decreased depression, anxiety, rumination, and neurotic perfectionism have all been associated with self-compassion (See Neff, 2009, for review).

Neff (2003a) defined self-compassion as having three main components, each having an inverse component: self-kindness versus self-judgment, common humanity verses isolation, and mindfulness versus over-identification. Neff has defined these constructs following the values of Buddhist writings. Self-kindness is having a genuine, kind understanding towards oneself in the face of hardship or struggle, whereas self-judgment encourages a critical approach towards one's experiences. Common humanity is viewing one's experience as part of a larger whole of human existence; as opposed to feeling one's life is completely separate and isolated. Lastly, mindfulness is a balance and awareness of positive and negative emotion, as opposed to over-identifying with negative emotions.

Self-compassion has been associated with psychological well-being in multiple studies (see Neff, 2009, for review). Self-compassion has the potential to contribute many benefits in non-clinical, as well as clinical populations. Symptoms of depression and anxiety are common in both populations and research has shown that self-compassion may assist in decreasing depressive and anxious symptoms. In a study of 132 non-clinical adolescents aged 12-17 years old, depression and anxiety symptoms were lower for individuals with higher levels of self-compassion (Muris et al., 2015).

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One particular population that may benefit from self-compassion is individuals diagnosed with chronic illnesses. Symptoms of depression and anxiety are not foreign to individuals with chronic illnesses (Pinto-Gouveia et al., 2014), especially those with bleeding disorders (Barlow et al., 2007; Trzepacz et al., 2003). Higher self-compassion has been associated with fewer symptoms of depression and anxiety in chronic illness populations (Pinto-Gouveia et al., 2014).

Self-compassion has been shown to effect depression and anxiety as well as impact the quality of life of those who live with chronic illnesses (Germann et al., 2015). In a study of 63 cancer patients, 68 patients with chronic illnesses (including hypertension, congestive cardiac failure, rheumatoid arthritis, psoriasis, osteoporosis, allergic disease, hyperthyroidism, Crohn's disease, asthmatic bronchitis, and glaucoma), and 71 healthy participants, lower self-compassion was significantly associated with increased depression and stress, as well as lower quality of life in both of the patient samples (Pinto-Gouveia et al., 2014). For participants with chronic illnesses, self-judgment most accurately predicted symptoms of depression, stress, and quality of life. The researchers of this study emphasize the need for interventions that develop skills related to self-compassion in hopes of improving the psychological adjustment and well-being for individuals with chronic illnesses.

In addition to depression and anxiety, stress can have a large impact on the lives of individuals with and without chronic illnesses. Psychological and physical well-being can be influenced by ineffective management of stress for individuals with chronic illnesses (Evers et al., 2013). Chronic illnesses, such as bleeding disorders, can create a great deal of stress for those diagnosed with it and coping with theses stressors deserves heightened attention. Neff, Kirkpatrick, and Rude (2007) proposed that the three positive components of self-compassion (i.e., self-kindness, common humanity, and mindfulness) can decrease stress levels when faced

with uncontrollable events by regulating the negative emotions that may arise in such instances. Stressful events can facilitate negative self-evaluations and mood, but self-compassionate individuals may view stressors as less threatening, resulting in appropriate and adaptive coping to reduce stress (Sirois, Kitner, & Hirsch, 2015).

Adaptive coping during stress is characterized by direct behavioral changes or cognitively changing the judgment assigned to said stress (Lazarus & Folkman, 1984). Individuals with chronic illnesses, such as those with bleeding disorders, may be burdened by constant and longitudinal stressors that ebb with daily life. These individuals may require multiple coping strategies to manage pain, treatments, and relationships (to name a few stressors; Gignac, Cott, & Badley, 2000).

In a study of individuals diagnosed with chronic Irritable Bowel Syndrome (IBS) or arthritis, higher self-compassion was associated with increased implementation of adaptive coping strategies (Sirois et al., 2015). Adaptive coping strategies included positive cognitive restructuring (positive reframing), actively coping, and acceptance of one's illness. Self-compassion was also negatively associated with maladaptive coping, such as behavioral disengagement, avoidance, denial, and self-blame. Maladaptive coping can impact the well-being of individuals with chronic illnesses; for example, self-blame has been associated with poor adjustment in a study of individuals diagnosed with chronic tinnitus (Sirois, Davis, & Morgan, 2006).

Self-blame may be common in individuals with chronic illnesses, due to the lack of control one feels from spontaneous or unexpected symptomology and/or treatment. Bleeding disorders may encompass spontaneous bleeding or unexpected pain that can cause a great deal of stress, and possibly maladaptive coping. Thompson, Sobolew-Shubin, Galbraith, Schwankovsky,

& Cruzen (1993) found that individuals in low control circumstances, such as those diagnosed with chronic illnesses, would blame themselves for not being able to change an aspect of their disease. In other words, an individual who encounters an illness-related difficulty that is not easily controlled may internalize their struggle and engage in self-blaming thoughts and behaviors. This act of self-blame can be a maladaptive coping strategy, which may be remedied by increasing one's self-compassion given the circumstances of having a chronic illness.

Acceptance is an adaptive coping strategy associated with self-compassion (Sirois et al., 2015). Individuals with chronic illnesses are faced with the task of accepting one's illness. While some may practice acceptance, those who have low levels of acceptance have been shown to report higher levels of self-judgment, isolation, and over-identification, the three negative components of self-compassion based on a sample of patients suffering from chronic pain (Costa & Pinto-Gouveia, 2011). Those with higher levels of self-compassion were shown to have more acceptance of their pain. Chronic pain is a symptom many individuals with chronic illnesses, especially bleeding disorders face regularly and, as research shows, this pain may have an influence on their ability to accept their diagnosis (Williams & Chapman, 2011). In a study of adults with chronic pain, such as arthritis, fibromyalgia, migraines, and degenerative disc disease (to name a few), participants engaged in three 20-minute sessions (spaced one week apart) of either self-compassion or self-efficacy focused writing (Ziemer, 2014). For example, one of the self-compassion prompts asked the participant to write about their experience with pain from a self-compassionate perspective (briefly defined self-compassion) and to discuss what the participant would compassionately say to a friend. One of the self-efficacy prompts asked the participant to write about their experienced pain from a self-efficacy perspective (briefly defined self-efficacy) and to discuss their confidence in coping with and managing their pain. Those in

the self-compassion condition reported significantly less intrusive pain than those in the self-efficacy condition. Also, regardless of condition, when participants' self-compassion scores increased, lower illness intrusiveness (i.e. lifestyle disruptions brought about by one's illness) was reported and higher levels of activity engagement were present. In summary, self-compassion can influence those affected by pain in a positive way.

Research has shown that self-compassion is valuable in many different areas of one's life, especially those affected by chronic illness. In a study of individuals diagnosed with Human Immunodeficiency Virus (HIV), self-compassion predicted the level of diagnosis-related shame the participants felt (Brion, Leary, & Drabkin, 2014). Self-compassion was associated with fewer negative emotions, such as less stress, self-pity, and shame. Those who were self-compassionate also engaged in greater self-care and sought out interactions with other individuals. In this study, self-compassion was associated with greater optimism, as well as less rumination.

As evidenced by the research literature, self-compassion can be a powerful and valuable construct and skill in the lives of individuals with chronic illnesses. However, no research to date has been conducted to explore self-compassion in those with bleeding disorders. Many of the variables affected by self-compassion, such as chronic pain, maladaptive or adaptive coping, psychological and physical well-being, and depression and/or anxiety symptoms may be experienced by individuals with bleeding disorders. Interventions that emphasize self-compassion may positively influence individuals with bleeding disorders and may improve their quality of life. Self-compassion is not the only construct that has been shown to improve the lives of those affected by chronic illness. Hope also plays an important role.

Hope

Hope can be a powerful emotion and a positive psychological construct in the lives of the general population, but especially for those who have been diagnosed with chronic illnesses, specifically bleeding disorders. Hope is another variable that will be explored in relation to quality of life for patients with bleeding disorders in the present study.

Over the past few decades, the research literature on hope in general has increased exponentially. Hope has been studied as a resilience factor, as well as a predictive factor for various outcomes. Hope has been largely researched by Snyder and colleagues (e.g. Snyder et al., 1992; Snyder et al., 1997; Snyder et al., 2000; Snyder, Cheavens, & Michael, 1999) and for the purpose of this study, hope will be conceptualized using their definition of hope.

While hopefulness is indeed an important emotion, hope will be characterized within a goal-oriented framework; therefore, goals are important when defining hope (Snyder et al., 1991). Goals are defined as the objectives of mental action sequences and are considered the cognitive element that grounds hope theory (Snyder et al., 2000). Hope is comprised of two main elements: agency and pathways (Snyder et al., 1991). Agency refers to the sense of one's determination to accomplish a goal in the past, present, and future. Pathways refer to one's ability to create plans that will successfully meet particular goals. Agency fuels hope by a perception that one is determined to accomplish a goal, while pathways provide the means to accomplish said goal. Formally, hope is defined as a mutual sense of successful agency and pathways or determination and plans to meet goals (Snyder et al., 1991).

Individuals who have high agency usually also perceive pathways; however there are instances when one may be determined to reach a goal (agency), but cannot develop a plan (pathway) to reach said goal. Snyder and colleagues (1991) emphasize that in instances without

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both agency and pathway, goals are unlikely to be met; therefore, both are needed for successful goal attainment. With this in mind, both agency and pathways are needed to define hope (a goal-directed variable). Hope has been the topic of high volumes of research literature and has been related to optimism, expectancies for attaining goals, general desire for control, perceptions of problem solving abilities, self-esteem, social desirability, and self-presentation (e.g. Gibb, 1990; Holleran & Snyder, 1990; Roth, Harris, & Snyder, 1988; Roth, Snyder, & Pace, 1986). Higher levels of hope have been associated with successful goal-oriented outcomes in many different fields including academics, athletics, and coping (see Snyder et al., 1999, for review).

General samples exhibiting high or low levels of hope have been shown to demonstrate certain trends within the research literature—participants with higher levels of hope tend to report more adaptive coping and more wellness-oriented outcomes compared to participants with lower levels of hope. For example, those who have high hope are more likely to maintain agency and pathways when stressors arise, while low hope individuals' agency and pathways weaken when faced with a barrier (Snyder et al., 1991). Also, those with higher levels of hope set higher, more challenging goals (Anderson, 1988), as well as a higher number of goals compared to those with lower levels of hope (Lazarus & Folkman, 1984). Higher hope individuals are more likely to view goals in a positive perspective and tend to focus on the perception that they will be successful in attaining their goals compared to those with lower levels of hope. In addition, those who have higher hope have more problem-solving strategies that have accumulated from experiences of successful past behaviors (Magaletta & Oliver, 1999) compared to those with lower levels of hope. By using strategies that have been proven to work, these individuals are also reducing the likelihood that other problems or difficulties will arise. All of the aforementioned research findings may apply to individuals who have been diagnosed with

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chronic illnesses especially within the framework of goals associated with treatment and illness management.

In relation to illness management or treatment, the goals of individuals with chronic illnesses, especially those with bleeding disorders, would benefit from two types of prevention present in hope. The two types of prevention associated with hope are primary and secondary prevention, both of which should be beneficial when used by individuals with bleeding disorders. Primary prevention refers to thoughts or behaviors that could decrease the likelihood that future problems will arise (Snyder et al., 2000). Primary prevention aims to prevent injury or sickness before it even occurs. This can come in the form of preventative treatment and avoidance of certain dangerous behaviors or places. Individuals with higher levels of hope usually implement primary prevention in the form of establishing clear goals, identifying pathways to reach goals, and motivating themselves to implement said pathways compared to individuals with lower levels of hope (Snyder, 2000).

Primary prevention can be especially useful to those who have bleeding disorders. Individuals with bleeding disorders are often faced with unexpected bleeding episodes or pain, which can cause a great deal of stress. Breznitz (1999) argued that "anticipatory stress" may relate to tolerating pain and should be explored in those who have low hope and high stress. This is important to note when considering primary prevention in low hope individuals with bleeding disorders. Such individuals may anticipate symptoms related to their disorder, which may increase levels of stress and in turn affect their ability to engage in primary prevention. Planning treatment in case of a bleeding episode or avoiding intense physical activity would be examples of primary prevention in an individual with a bleeding disorder.

Secondary prevention is the second type of prevention that may be useful for individuals with chronic illnesses to implement. Secondary prevention is action taken after a problem has appeared (Snyder et al., 2000). The main goal of secondary prevention is to eliminate, reduce, or contain a stressor once it happens. An example of a stressor common within the bleeding disorder community may be a bleeding episode in a joint. Individuals with high hope tend to use strategies or behaviors that have worked in reducing or eliminating a problem in the past (Snyder, 1994; Synder et al., 1991). If an individual has a joint bleed, they may infuse with synthetic factor to stimulate a clotting sequence in the joint. Those with higher levels of hope may use infusing as a form of secondary prevention, while those with lower levels of hope may be overwhelmed by their bleeds and have difficulty responding or treating them.

Another example of secondary prevention may be to call on close friends or social support when faced with a stressor. Individuals with higher levels of hope usually have friendships that serve as a support during difficult times compared to those with lower levels of hope (Crothers & Schraw, 1999). This may be particularly important to note in relation to individuals with bleeding disorders because peer relationships are of particular importance for individuals with chronic illnesses (La Greca et al., 2002) and research has shown that difficulties with social isolation and social ridicule are present in those with bleeding disorders (Williams & Chapman, 2011). Increasing hope in individuals with bleeding disorders may increase positive social relationships which can serve as a form of secondary prevention in the face of stressors.

A good deal of research has been done exploring hope among patients with various chronic illnesses, but scant research has been published on hope for individuals with bleeding disorders. Individuals who experience symptoms associated with their bleeding disorder, such as bleeding episodes or chronic pain, may adopt a perspective of hopelessness, but those with

higher levels of hope are more likely to find benefits within their experiences of stressors

compared to those with lower levels of hope (Affleck & Tennen, 1996). In other words,

individuals who experience higher levels of hope may be more optimistic and positive in their

struggles associated with their bleeding disorder compared to those with lower levels of hope. In

a study of adults diagnosed with fibromyalgia those who endorsed more hope reported more

benefits from their experience of living with a chronic illness than those with less hope (Affleck

& Tennen, 1996). High hope was also associated with greater pain tolerance and adaptive coping

when faced with stressors resulting from one's chronic illness.

Stress due to one's chronic illness can arise at different times throughout one's life. Some

illnesses are acquired as one ages (e.g. cancer), while others are congenital (i.e. the individual is

born with illness). While bleeding disorders are congenital, it is common that they present as

acquired. Some individuals who have bleeding disorders do not experience symptoms until later

in life. In these instances, individuals may react as if their illness is acquired, rather than

congenital. In one study, children and adolescents (ages 8-17) with and without chronic illnesses

completed the Children's Hope Scale created by Snyder and colleagues (1997; Venning et al.,

2007). Chronic illnesses represented in the sample included Cystic Fibrosis, craniometaphysical

dysplasia, cancer (Lymphoma), cardiomyopathy, congestive heart failure, serious burns,

hypothyroidism, kidney failure, and head injury. The children with both acquired and congenital

chronic illnesses reported lower hope than those participants without chronic illnesses. Hope was

lowest for participants who reported having an acquired illness compared to those with

congenital illnesses. These findings suggest that the onset of one's chronic illness has an impact

on their level of hope. This is important to note for individuals with bleeding disorders because

these disorders can appear congenital or acquired, both of which impact hope and may, in turn, impact quality of life.

Hope may also impact the physiological quality of life of patients with chronic illnesses. In a longitudinal clinical study of 2428 middle aged men, Everson and colleagues (1996) found that low hope is related to fewer biological and behavioral risk factors. The researchers found that hopelessness was associated with mortality, after controlling for biological, socioeconomically, and behavioral risk factors, as well as perceived health, depression, prevalence of disease, and social support. Participants with moderate or high levels of hopelessness were at a significantly increased risk of mortality compared to those participants with lower hopelessness scores. High hopelessness predicted incident myocardial infarctions, and moderate hopelessness was associated with incident cancer. In a second study by Everson and colleagues (1997), the progression of carotid arthrosclerosis in 942 middle aged men from Finland was associated with hopelessness. Participants with low levels of hope reported the greatest levels of illness progression, as well as the fastest progression of illness. All of the mentioned findings indicate that hope is a powerful predictor of various health outcomes, and the influence of hope should be emphasized in other chronic illness samples, including those with bleeding disorders.

Delmar et al., (2005) illustrated the power and influence of hope in a qualitative study of 18 participants, ages 18-75, diagnosed with chronic illness including type I Diabetes, colitis ulcerosa, and coronary occlusion. Delmar and colleagues did not operationally define hope in this study, but allowed participants express hope through their phenomenological experiences of what they considered hope. Results were analyzed in a three part method: naïve reading, structural analysis, and critical interpretation. Participants explained that living with a chronic

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illness can be difficult to accept and coping with associated limitations can be especially

stressful. Participants indicated that having a chronic illness that is not immediately visible to

others can make it difficult to reach out for help, but despite all the reported difficulties,

participants endorsed the power of hopeful thinking. Many of the participants expressed hope for

the future, hope about their health and healing, hope about treatment, and hope for a normal life.

Hope is powerful in facilitating the management of difficult situations related to chronic

illnesses. This research highlights hope as an influential trait, but also illustrates that participants

were fluctuating between hope and doubt. Emphasizing hope within treatment may stabilize the

consistency of hopefulness and strengthen one's ability to cope with illness-related difficulties.

Similar to self-compassion, hope has been associated with lower levels of depression and

anxiety in chronic illness samples. In a study of emotional predictors of quality of life in

adolescent cancer patients (i.e., leukemia, lymphoma, and neurological tumors), participants

completed the Children's Depression Inventory (CDI), the Children's Hope Scale (CHS), the

Spielberger State Trait Anxiety Inventory (STAI) or the Spielberger State Trait Anxiety

Inventory for Children (STAIC) and The Pediatric Quality of Life Inventory_3.0 Cancer Module

(PedsQL) (Germann et al., 2015). Participants were assessed across time and changes in hope,

depression, and anxiety were significant predictors of changes in quality of life over time. More

specifically, the changes in quality of life that did not occur due to depression and anxiety

changes were attributed to hope, suggesting that hope may mediate the effects of changes in

quality of life. As expected, hope was also found to be negatively associated with depression and

anxiety. In summary, hope was found to be a predictor of improved quality of life in adolescents

diagnosed with cancer. Similarly, Evangelista, Doering, Dracup, Vassilakis, & Kobashigawa

(2003) found a significant negative relationship between hope, anxiety, and depression in heart transplant patients. Hope independently predicted mood states and quality of life.

In another study, a group of 89 childhood cancer survivors (ages 17 to 31) completed the Chinese Cancer-Related Rumination Scale (CCRRS) and the Chinese versions of the Beck Depression Inventory (BDI), the Beck Anxiety Inventory (BAI), and the Adult Hope Scale (AHS) to assess hope as it relates to adjustment post-cancer (Yuen, Ho, & Chan, 2014). Hope was correlated with lower levels of depression and anxiety and participants who reported higher levels of hope were more likely to have better psychological adjustment post-cancer (i.e., engaged in positive rumination, or positive thoughts, related to their cancer) than those with lower levels of hope).

Researchers have also investigated how the components of hope theory (agency and pathways) interact with depression and anxiety. Arnau, Rosen, Finch, Rhudy, & Fortunato (2007) recruited 522 undergraduate college students to explore the relationship between hope and anxiety and depression. They found that the agency component of hope had a statistically significant negative effect on levels of anxiety. Therefore, hope may serve as a protective factor for depression.

While Snyder and colleagues' hope theory will be used to conceptualize and measure hope in the present study, other researchers have used the Herth Hope Index in their studies. In one study, a total of 113 Brazilian adolescents and young adults with type I diabetes completed the Herth Hope Index and the Hospital Anxiety and Depression Scale to explore the relationship between hope and depression (Santos et al., 2015). The Herth Hope Index is comprised of three components: inner sense of temporality (i.e., setting goals, positive outlook, potential for each day), inner positive readiness and expectancy (i.e., sense of direction, value in life), and

interconnectedness with self and others (i.e., feeling alone, comfort in faith, inner strength, give and receive love/care; Herth, 1992). The second and third factors of hope, inner positive readiness and expectancy and interconnectedness with self and others, were negatively associated with depression in those patients with diabetes. Participants who had greater social connectedness and value in life also had lower levels of depression.

As research supports, hope is a positive psychology variable that can have a significant impact on many aspects of one's daily living for both individuals with and without chronic illnesses. Hope can serve as a protective factor against depression and anxiety and it has been shown to strengthen social connectedness. Implementing both primary and secondary forms of prevention in regards to hope has the potential for numerous benefits and can be especially valuable to individuals who have chronic illnesses. Overall, hope is important when considering the quality of life in individuals with chronic illnesses and further research is needed on this topic, specifically involving individuals with bleeding disorders.

In conclusion, individuals diagnosed with bleeding disorders face illness-related stressors on a daily basis. Individuals with hemophilia and Von Willebrand's disease may encounter social, academic/occupational, emotional, psychological, or physiological difficulties that can impact their quality of life. It is hypothesized that the presence of the two positive psychology constructs, self-compassion and hope, may positively enhance these individuals' quality of life. Self-compassion has been associated with adaptive functioning and positive mental health (Neff, 2004; Sirois et al., 2015), as well as negatively associated with depression and anxiety (Muris et al., 2015; Neff & McGehee, 2010; Pinto-Gouveia et al., 2014). Specifically within chronic illness populations, self-compassion has been shown to decrease intrusive pain (Ziemer, 2014) and increase optimism (Brion et al., 2014). Similarly to self-compassion, hope has been

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associated with optimism (Affleck & Tennen, 1996) and negatively associated with depression

and anxiety (Arnau et al., 2007; Germann et al, 2015; Evangelista et al., 2003; Yuen et al., 2014)

in some samples of individuals with chronic illnesses. Self-compassion and hope can be

powerful variables and can impact quality of life in many ways, especially for individuals with

chronic illnesses, such as bleeding disorders. No researchers to date have explored the

relationship of self-compassion and hope with quality of life for individuals with bleeding

disorders, which is the focus of the present study.

APPENDIX B

TABLES

Table 1

Participant Demographic Data: Frequencies, Percent, Cumulative Percent, and Mean

	n	Percent (%)	Mean	Standard Deviation
Age Group	86	100	29.65	14.4
Teen (15-18)	22	25.6		
Young Adult (19-26)	25	29.1		
Adult (27-65)	39	45.3		
Race				
White/Caucasian	58	67.4		
Black/African American	4	4.7		
Hispanic/Latino	4	4.7		
Asian American	2	2.3		
Native American	5	5.8		
Bi-racial	11	12.8		
Asian Indian	1	1.2		
Multi-Racial	1	1.2		
Gender				
Male	53	61.6		
Female	33	38.4		
Diagnosis				
Hemophilia A	38	44.2		
Hemophilia B	5	5.8		
Von Willebrand's	38	44.2		
Hemophilia F13	2	2.3		
Afibrinogenemia F1	1	1.2		
Immune Thrombocytopenic Purpura	1	1.2		
Asprine Like Platelet Disorder	1	1.2		
Severity of Diagnosis				
Mild	40	46.5		
Moderate	12	14.0		
Severe	32	37.2		
Unknown	2	2.3		
Student				
Yes	36	41.9		
No	50	58.1		
Employed				
Yes	51	59.3		
No	35	40.7		
Income			$55,300	$22,000
$0-10,000	2	2.3		
$10,000-20,000	5	5.8		
$20,000-30,000	11	12.8		
$30,000-40,000	8	9.3		

$40,000-50,000	12	14.0
$50,000-60,000	6	7.0
$60,000-70,000	6	7.0
$70,000-80,000	8	9.3
$80,000-90,000	4	4.7
$90,000-100,000	4	4.7
$100,000+	17	19.8
Unknown	3	3.5
Survey Modality		
In Person	76	88.4
Online	10	11.6

Table 2

Descriptive Statistics for Main Study Variables

Variable	Mean	SD	Actual Score Range	Possible Score Range
O-QOL	75.92	16.62	33.91-100.00	0-100
PS-QOL	77.09	16.18	38.33-100.00	0-100
P-QOL	72.40	23.32	15.63-100.00	0-100
O-SC	3.45	.72	2.05-5.00	0-5
O-H	53.3	7.00	33.00-64.00	0-64

Note. O-QOL = Overall Quality of Life; PS-QOL = Psychosocial Quality of Life; P-QOL =

Physical Quality of Life; O-SC = Overall Self-Compassion; O-H = Overall Hope

Table 3

Correlation Matrix for Self-Compassion, Hope, and Quality of Life Scores*

Variable	O-QOL	PS-QOL	P-QOL	O-SC	O-H	SK	SJ	CH	I	M	O-ID
O-QOL	1	.97**	.84**	.39**	.44**	.37**	-.44**	.01	-.35**	.20	-.45**
PS-QOL	-	1	.67**	.39**	.41**	.34**	-.43**	.-.01	-.40**	.19	-.46**
P-QOL	-	-	1	.30**	.40**	.35**	-.35**	.04	-.18	.19	-.31**
O-SC	-	-	-	1	.61**	.85**	-.83**	.59**	-.81**	.79**	-.81**
O-H	-	-	-	-	1	.59**	-.41**	.38**	-.45**	.57**	-.46**
SK	-	-	-	-	-	1	-.62**	.59**	-.52**	.74**	-.53**
SJ	-	-	-	-	-	-	1	-.25*	.76**	-.50**	.78**
CH	-	-	-	-	-	-	-	1	-.20	.62**	.13
I	-	-	-	-	-	-	-	-	1	.62**	.84**
M	-	-	-	-	-	-	-	-	-	1	-.49**
O-ID	-	-	-	-	-	-	-	-	-	-	1

Note. $*p < .05$; ** $p < .01$; O-QOL = Overall Quality of Life; PS-QOL = Psychosocial Quality of Life; P-QOL = Physical Quality

of Life; O-SC = Overall Self-Compassion; O-H = Overall Hope; SK = Self-Kindness; SJ = Self-Judgment; CH = Common

Humanity; I = Isolation; M = Mindfulness; O-ID = Over-Identification

Table 4

Regression Findings for Self-Compassion and Hope as Potential Predictors of Overall Quality of Life for Individuals with Bleeding Disorders (n = 86)

Variable	*B*	*SE B*	*β*	*p*
Constant	20.36	12.40		.11
O-SC	4.71	2.81	.21	.10
O-H	.74	.29	.31	.01

Note. O-SC = Overall Self-Compassion; O-H = Overall Hope; B = Unstandardized Coefficient Beta; SE B = Unstandardized Coefficients Standard Error; β = Standardized Coefficients Beta; p = Significance

Table 5

Regression Findings for Self-Compassion and Hope as Potential Predictors of Psychosocial Quality of Life for Individuals with Bleeding Disorders (n =86)

Variable	*B*	*SE B*	*β*	*p*
Constant	26.65	12.20		.03
O-SC	5.22	2.76	.23	.06
O-H	.61	.29	.26	.04

Note. O-SC = Overall Self-Compassion; O-H = Overall Hope; B = Unstandardized Coefficient Beta; SE B = Unstandardized Coefficients Standard Error; β = Standardized Coefficients Beta; p = Significance

Table 6

Regression Findings for Self-Compassion and Hope as Potential Predictors of Physical Quality of Life for Individuals with Bleeding Disorders

Variable	B	SE B	β	p
Constant	1.49	17.96		.934
O-SC	3.20	4.06	.10	.43
O-H	1.12	.42	.34	.01

Note. O-SC = Overall Self-Compassion; O-H = Overall Hope; B = Unstandardized Coefficient Beta; SE B = Unstandardized Coefficients Standard Error; β = Standardized Coefficients Beta; p = Significance

APPENDIX C

INFORMED CONSENT AND SURVEY FORMS

PARTICIPANT CONSENT/ASSENT FORM

PROJECT TITLE: The Relationship of Self-Compassion and Hope with Quality of Life for

Individuals with Bleeding Disorders

INVESTIGATOR(S):

Darci Klein, M.S. – Oklahoma State University and OU Bleeding and Clotting Disorders Clinic – darcik@okstate.edu

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405-271-3661
The Jimmy Everest Center for Cancer and Blood Disorders Clinic
OU Children's Physicians Building, 10th Floor, Suite 10000
Oklahoma City, OK 73104

Please read this document and contact one of the investigators to ask any questions that you may have BEFORE agreeing to take part in this research.

PURPOSE:
The purpose of this study is to look at factors that relate to quality of life in individuals diagnosed with bleeding disorders.

PROCEDURES:
Please only complete this survey if you are 15-65 years old and are diagnosed with hemophilia or von Willebrand's disease.

Participation in this study includes completing four questionnaires. The questionnaires should take approximately 10-15 minutes to complete. For participating in this study we will donate $5 to The National Hemophilia Foundation in your name.

RISKS OF PARTICIPATION:
There are no foreseeable risks in participating in this study. If you encounter any problems or have any questions, please do not hesitate to ask the researchers.

BENEFITS OF PARTICIPATION:
Your participation in this study will help us understand patients like you better who have a bleeding disorder. It may also help us to better treat patients like you in a medical setting.

CONFIDENTIALITY:
Your participation in this study is completely voluntary and confidential. The data associated with this study will be kept private and will not be connected to your identity in any way. Any

written results of this research will discuss group findings and will not include information that will identify you. Research records will be stored on a password protected computer in a locked office and only researchers and individuals responsible for research oversight will have access to the records. Data will be kept for at least five years after the study has been completed.

DONATION:
Once the study is complete, we will donate $5 to The National Hemophilia Foundation in your name. We appreciate your participation in this study and this donation will go to an organization that does a great deal to support the bleeding disorder community.

CONTACTS:
You may contact any of the researchers at the above addresses and phone numbers, should you desire to discuss your participation in the study and/or request information about the results of the study.

PARTICIPANT RIGHTS:
I understand that my participation is voluntary, that there is no penalty for refusal to participate, and that I am free to withdraw at any time.

CONSENT DOCUMENTATION:
If desired, please request a copy of this consent/assent form for your records.

By signing below I acknowledge that I have been fully informed about the procedures listed here and I give my consent/assent to participate in this study.

Participant Signature   Date

If the participant is below the age of 18 a guardian must consent to their participation in this study. By signing below I acknowledge that I, the minor's guardian, have been fully informed about the procedures listed here and I give my consent for them to participate in this study.

Guardian's Signature (if applicable)   Date

PROJECT TITLE: The Relationship of Self-Compassion and Hope with Quality of Life for

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CONTACTS:
You may contact any of the researchers at the above addresses and phone numbers, should you desire to discuss your participation in the study and/or request information about the results of the study.

PARTICIPANT RIGHTS:
I understand that my participation is voluntary, that there is no penalty for refusal to participate, and that I am free to withdraw at any time.

CONSENT DOCUMENTATION:
If desired, please request a copy of this consent/assent form for your records.

If you are 15 to 17 years of age please obtain your parental guardians permission before continuing in this study. If you continue below you agree that you have obtained your guardian's permission to complete this study.

By clicking the continue button below you agree to participate in this study and fully understand all of the mentioned information above.

Study Information

INVESTIGATOR(S):

Darci Klein, M.S. – Oklahoma State University and OU Bleeding and Clotting Disorders Clinic – darcik@okstate.edu

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You may contact any of the researchers at the above addresses and phone numbers, should you desire to discuss your participation in the study and/or request information about the results of the study.

The purpose of this study is to look at factors that relate to quality of life for individuals diagnosed with bleeding disorders. Participation in this study involves completing four questionnaires. The questionnaires should take approximately 10-15 minutes to complete. Upon completion of the questionnaires, you will be compensated with $5 cash to thank you for your participation.

RISKS AND BENEFITS OF PARTICIPATION:
No risks that we know of will come from participating in this study greater than what you would encounter in everyday life. If you encounter any problems or have any questions, please do not hesitate to ask the researchers.

Your participation in this study will help us understand patients like you better who have a bleeding disorder. It may also help us to better treat patients like you in a medical setting.

CONFIDENTIALITY:
This study is completely voluntary and anonymous. The records and data associated with this study will be kept private and will not be connected to your identity in anyway. Any written results will discuss group findings and will not include information that will identify you. Research records will be stored on a password protected computer in a locked office and only researchers and individuals responsible for research oversight will have access to the records. Data will be kept for at least five years after the study has been completed.

Thank you for your participation!

Your participation in this study is greatly appreciated and will assist us in better understanding individuals who have been diagnosed with bleeding disorders.

For your participation, we would like to donate $5 to the National Hemophilia Foundation on your behalf. This donation will be made after this study is complete.

If you have any questions regarding the study please do not hesitate to contact one of the researchers.

Darci Klein, M.S. – Oklahoma State University and OU Bleeding and Clotting Disorders Clinic
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Thank you again!

Demographic Form

Please fill out the following information. Fill in the blanks where appropriate or circle the options that apply to you.

1. **What city and state do you live in?** _____

2. **What is your age:** _____

3. **What is your race (choose all that apply):**
__ White/Caucasian
__ African American
__ Hispanic/Latino
__ Asian American
__ Native American
 __ Pacific Islander
___ Other:_____

4. **What is your gender?** _____

5. **Are you currently a student?**
Yes
No

If yes, are you in middle, high school, or college? _____
If applicable, what grade are you in? _____
If you are in college, what year are you in college? _____

6. **Are you currently working/employed?**
Yes
No

7. **What is your diagnosis:**
___ Hemophilia A
___ Hemophilia B
___ Von Willebrand's disease
___Other:_____

8. **Severity of bleeding disorder:**
___Mild
___Moderate
___Severe

9. Over the past three months, how severe do you feel your bleeding disorder has been?

___Very Severe

___Moderately Severe

___Average

___Slightly Severe

___Not Severe

10. In the past three months how much pain you have experienced due to your bleeding disorder.

___A lot of pain

___Moderate pain

___Mild pain

___No pain

11. At what age were you diagnosed with your bleeding disorder? _____

12. Do you have any other chronic medical conditions?

___Yes

___No

If yes, please list: _____

13. What is your total household income? Circle one.

$0- 10,000

$10,000-20,000

$20,000-30,000

$30,000-40,000

$40,000-50,000

$50,000-60,000

$60,000-70,000

$70,000-80,000

$80,000-90,000

$90,000-100,000

$100,000 or more

14. How many people live in your household? _____

15. Do you or any individuals in your household use any of the following? (Circle all that apply)

Well fare

Free or reduced lunches

Food stamps

Social Security Income

Disability Income

TANF Support

WIC Support

Section 8 Housing

16. How did you hear of this study?

___In medical appointment

___Facebook group

___Online support group

___Friend or Family

___Other: _____

17. Do you attend annual or semi-annual medical appointments for your bleeding disorder?

___Yes

___No

If yes, where do you attend appointments? _____

PedsQL™

Adult Quality of Life Inventory

ADULT REPORT (26 and older)

DIRECTIONS

On the following page is a list of things that might be a problem for you. Please tell us **how much of a problem** each one has been for you during the **past ONE month** by circling:

0 if it is **never** a problem
1 if it is **almost never** a problem
2 if it is **sometimes** a problem
3 if it is **often** a problem
4 if it is **almost always** a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

*In the past **ONE month**, how much of a **problem** has this been for you …*

ABOUT MY HEALTH AND ACTIVITIES *(problems with…)*	Never	Almost Never	Some-times	Often	Almost Always
1. It is hard for me to walk more than one block	0	1	2	3	4
2. It is hard for me to run	0	1	2	3	4
3. It is hard for me to do sports activity or exercise	0	1	2	3	4
4. It is hard for me to lift something heavy	0	1	2	3	4
5. It is hard for me to take a bath or shower by myself	0	1	2	3	4
6. It is hard for me to do chores around the house	0	1	2	3	4
7. I hurt or ache	0	1	2	3	4
8. I have low energy	0	1	2	3	4

ABOUT MY FEELINGS *(problems with…)*	Never	Almost Never	Some-times	Often	Almost Always
1. I feel afraid or scared	0	1	2	3	4
2. I feel sad or blue	0	1	2	3	4
3. I feel angry	0	1	2	3	4
4. I have trouble sleeping	0	1	2	3	4
5. I worry about what will happen to me	0	1	2	3	4

HOW I GET ALONG WITH OTHERS *(problems with…)*	Never	Almost Never	Some-times	Often	Almost Always
1. I have trouble getting along with other adults	0	1	2	3	4
2. Other adults do not want to be my friend	0	1	2	3	4
3. Other adults tease me	0	1	2	3	4
4. I cannot do things that others my age can do	0	1	2	3	4
5. It is hard to keep up with my peers	0	1	2	3	4

ABOUT MY WORK/STUDIES *(problems with…)*	Never	Almost Never	Some-times	Often	Almost Always
1. It is hard to pay attention at work or school	0	1	2	3	4
2. I forget things	0	1	2	3	4
3. I have trouble keeping up with my work or studies	0	1	2	3	4
4. I miss work or school because of not feeling well	0	1	2	3	4
5. I miss work or school to go to the doctor or hospital	0	1	2	3	4

PedsQL™

Adult Quality of Life

Inventory

YOUNG ADULT REPORT (19 to 25)

DIRECTIONS

On the following page is a list of things that might be a problem for you. Please tell us **how much of a problem** each one has been for you during the **past ONE month** by circling:

0 if it is **never** a problem
1 if it is **almost never** a problem
2 if it is **sometimes** a problem
3 if it is **often** a problem
4 if it is **almost always** a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

*In the past **ONE month**, how much of a **problem** has this been for you …*

ABOUT MY HEALTH AND ACTIVITIES *(problems with…)*	Never	Almost Never	Some-times	Often	Almost Always
1. It is hard for me to walk more than one block	0	1	2	3	4
2. It is hard for me to run	0	1	2	3	4
3. It is hard for me to do sports activity or exercise	0	1	2	3	4
4. It is hard for me to lift something heavy	0	1	2	3	4
5. It is hard for me to take a bath or shower by myself	0	1	2	3	4
6. It is hard for me to do chores around the house	0	1	2	3	4
7. I hurt or feel pain	0	1	2	3	4
8. I have low energy	0	1	2	3	4

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ABOUT MY FEELINGS (problems with…)	Never	Almost Never	Some-times	Often	Almost Always
1. I feel afraid or scared	0	1	2	3	4
2. I feel sad or blue	0	1	2	3	4
3. I feel angry	0	1	2	3	4
4. I have trouble sleeping	0	1	2	3	4
5. I worry about what will happen to me	0	1	2	3	4

HOW I GET ALONG WITH OTHERS (problems with…)	Never	Almost Never	Some-times	Often	Almost Always
1. I have trouble getting along with other young adults	0	1	2	3	4
2. Other young adults do not want to be my friend	0	1	2	3	4
3. Other young adults tease me	0	1	2	3	4
4. I cannot do things that others my age can do	0	1	2	3	4
5. It is hard to keep up with my peers	0	1	2	3	4

ABOUT MY WORK/STUDIES (problems with…)	Never	Almost Never	Some-times	Often	Almost Always
1. It is hard to pay attention at work or school	0	1	2	3	4
2. I forget things	0	1	2	3	4
3. I have trouble keeping up with my work or studies	0	1	2	3	4
4. I miss work or school because of not feeling well	0	1	2	3	4
5. I miss work or school to go to the doctor or hospital	0	1	2	3	4

PedsQL™

Adult Quality of Life

Inventory

TEEN REPORT (13-18)

DIRECTIONS

On the following page is a list of things that might be a problem for you. Please tell us **how much of a problem** each one has been for you during the **past ONE month** by circling:

0 if it is **never** a problem
1 if it is **almost never** a problem
2 if it is **sometimes** a problem
3 if it is **often** a problem
4 if it is **almost always** a problem

There are no right or wrong answers.
If you do not understand a question, please ask for help.

*In the past **ONE month**, how much of a **problem** has this been for you …*

ABOUT MY HEALTH AND ACTIVITIES *(problems with…)*	Never	Almost Never	Some-times	Often	Almost Always
1. It is hard for me to walk more than one block	0	1	2	3	4
2. It is hard for me to run	0	1	2	3	4
3. It is hard for me to do sports activity or exercise	0	1	2	3	4
4. It is hard for me to lift something heavy	0	1	2	3	4
5. It is hard for me to take a bath or shower by myself	0	1	2	3	4
6. It is hard for me to do chores around the house	0	1	2	3	4
7. I hurt or ache	0	1	2	3	4
8. I have low energy	0	1	2	3	4

ABOUT MY FEELINGS (problems with…)	Never	Almost Never	Some-times	Often	Almost Always
1. I feel afraid or scared	0	1	2	3	4
2. I feel sad or blue	0	1	2	3	4
3. I feel angry	0	1	2	3	4
4. I have trouble sleeping	0	1	2	3	4
5. I worry about what will happen to me	0	1	2	3	4

HOW I GET ALONG WITH OTHERS (problems with…)	Never	Almost Never	Some-times	Often	Almost Always
1. I have trouble getting along with other teens	0	1	2	3	4
2. Other teens do not want to be my friend	0	1	2	3	4
3. Other teens tease me	0	1	2	3	4
4. I cannot do things that others teens my age can do	0	1	2	3	4
5. It is hard to keep up with my peers	0	1	2	3	4

ABOUT MY WORK/STUDIES (problems with…)	Never	Almost Never	Some-times	Often	Almost Always
1. It is hard to pay attention in class	0	1	2	3	4
2. I forget things	0	1	2	3	4
3. I have trouble keeping up with my schoolwork	0	1	2	3	4
4. I miss school because of not feeling well	0	1	2	3	4
5. I miss school to go to the doctor or hospital	0	1	2	3	4

(SELF-COMPASSION SCALE)

HOW I TYPICALLY ACT TOWARDS MYSELF IN DIFFICULT TIMES

Please read each statement carefully before answering. To the left of each item, indicate how often you behave in the stated manner, using the following scale:

Almost Never   **Almost Always**

1   **2**   **3**   **4**   **5**

_____ 1. I'm disapproving and judgmental about my own flaws and inadequacies.

_____ 2. When I'm feeling down I tend to obsess and fixate on everything that's wrong.

_____ 3. When things are going badly for me, I see the difficulties as part of life that everyone goes through.

_____ 4. When I think about my inadequacies, it tends to make me feel more separate and cut off from the rest of the world.

_____ 5. I try to be loving towards myself when I'm feeling emotional pain.

_____ 6. When I fail at something important to me I become consumed by feelings of inadequacy.

_____ 7. When I'm down and out, I remind myself that there are lots of other people in the world feeling like I am.

_____ 8. When times are really difficult, I tend to be tough on myself.

_____ 9. When something upsets me I try to keep my emotions in balance.

_____ 10. When I feel inadequate in some way, I try to remind myself that feelings of inadequacy are shared by most people.

_____ 11. I'm intolerant and impatient towards those aspects of my personality I don't like.

_____ 12. When I'm going through a very hard time, I give myself the caring and tenderness I need.

_____ 13. When I'm feeling down, I tend to feel like most other people are probably happier than I am.

_____ 14. When something painful happens I try to take a balanced view of the situation.

_____ 15. I try to see my failings as part of the human condition.

_____ 16. When I see aspects of myself that I don't like, I get down on myself.

_____ 17. When I fail at something important to me I try to keep things in perspective.

_____ 18. When I'm really struggling, I tend to feel like other people must be having an easier time of it.

_____ 19. I'm kind to myself when I'm experiencing suffering.

_____ 20. When something upsets me I get carried away with my feelings.

_____ 21. I can be a bit cold-hearted towards myself when I'm experiencing suffering.

_____ 22. When I'm feeling down I try to approach my feelings with curiosity and openness.

_____ 23. I'm tolerant of my own flaws and inadequacies.

_____ 24. When something painful happens I tend to blow the incident out of proportion.

_____ 25. When I fail at something that's important to me, I tend to feel alone in my failure.

_____ 26. I try to be understanding and patient towards those aspects of my personality I don't like.

(ADULT HOPE SCALE)

THE FUTURE SCALE

Directions: Read each item carefully. Using the scale shown below, please select the number that best describes YOU and put that number in the blank provided.

1. = Definitely False

2. = Mostly False

3. = Somewhat False

4. = Slightly False

5. = Slightly True

6. = Somewhat True

7. = Mostly True

8. = Definitely True

___ 1. I can think of many ways to get out of a jam.

___ 2. I energetically pursue my goals.

___ 3. I feel tired most of the time.

___ 4. There are lots of ways around any problem.

___ 5. I am easily downed in an argument.

___ 6. I can think of many ways to get the things in life that are important to me.

___ 7. I worry about my health.

___ 8. Even when others get discouraged, I know I can find a way to solve the problem.

___ 9. My past experiences have prepared me well for my future.

___ 10. I've been pretty successful in life.

___ 11. I usually find myself worrying about something.

___ 12. I meet the goals that I set for myself.

Vita

Darci Elizabeth Klein

Candidate for the Degree of

Doctor of Philosophy

Dissertation: THE RELATIONSHIP OF SELF-COMPASSION AND HOPE WITH
                QUALITY OF LIFE FOR INDIVIDUALS WITH BLEEDING DISORDERS

Major Field: Counseling Psychology

Education:
   Completed the requirements for the Doctor of Philosophy in Counseling Psychology at
   Oklahoma State University, Stillwater, Oklahoma in July, 2019.

   Completed the requirements for the Master of Science in Educational Psychology at
   Oklahoma State University (OSU), Stillwater, Oklahoma in July, 2015.

   Completed the requirements for the Bachelor of Science in Psychology at Missouri State
   University, Springfield, Missouri in December, 2013.

Clinical Experiences:
   University Counseling Services – Grief and Loss Counselor, OSU, 2017-2018
   University Health Services – Consultation Counselor, OSU, 2017
   Wings of Hope Family Crisis Services and Shelter – Practicum Counselor, 2016-2017
   Child Study Center - A Better Chance Clinic – Assessment Counselor, 2016-2017
   Child Study Center – Parent Child Interaction Therapy – Practicum Counselor, 2016-2017
   OUHSC Pediatric Hematology/Oncology – Practicum Counselor, 2015-2016
   OUHSC Sooner Pediatrics Primary Care – Practicum Counselor, 2015-2016
   Counseling & Counseling Psychology Clinic – Practicum Counselor, OSU, 2014-2015

Awards/Honors:
   Graduate College Robberson Summer Dissertation Fellowship, OSU, 2017
   OSU for Women's Philanthropy Scholarship, 2017-2018
   L. Mignon Albers Scholarship, OSU, 2017-2018
   Colleen & George McMullen Endowed Scholarship, OSU, 2016-2017
   J. Anderw Holley Memorial Endowed Scholarship, OSU, 2015-2016
   Top Tier Fellowship, 2014-2015