






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

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Abstract

Introduction: Minimal research has been conducted examining the relationship of positive psychology variables with quality of life (QOL) for individuals with bleeding disorders. While many individuals manage their bleeding disorders well, some are at higher risk of developing psychosocial complications due to the daily stressors of managing illness-related symptoms.

Aim: The purpose of this study is to better understand the relationships between two positive psychology variables, self-compassion and hope and QOL (overall, psychosocial and physical) among individuals diagnosed with bleeding disorders.

Methods: Participants completed a survey identifying demographic information as well as rating scales of self-compassion, hope and quality of life. We conducted Pearson correlational and standard multiple regression analyses to explore the bivariate and linear relationships between the aforementioned variables in a sample of 86 patients with bleeding disorders between the ages of 15 and 65.

Results: Self-compassion and hope were significantly related to QOL. Together, self-compassion and hope were predictive of overall QOL, psychosocial QOL and physical QOL. However, hope was the only individual predictor of all three QOL dimensions.

Conclusion: Due to the significant relationships found between self-compassion, hope and QOL in this sample, it may be beneficial to incorporate positive psychology factors into the treatment of those diagnosed with bleeding disorders, especially those at higher risk for decreased QOL.

KEYWORDS

bleeding disorder, haemophilia, positive psychology, quality of life, von Willebrand disease

1 | INTRODUCTION

Bleeding disorders, such as haemophilia and von Willebrand disease (VWD), are inherited conditions characterized by insufficient production of factor or clotting agent in the blood.^{1,2} Both haemophilia and VWD have the potential to affect many aspects of quality of life (QOL), including physiological, psychological, social and educational/occupational functioning.^{1,3-5} While many individuals with bleeding disorders cope well with their illness, some experience

elevated stress and impaired QOL.¹ This subset of patients may be at increased risk for emotional difficulties associated with managing illness-related symptoms.^{1,6} Stressors, such as activity restrictions, social stigmatization, common public misunderstanding about their disease, discrimination in academic and occupational situations or feelings of rejection by their peers,^{5,7,8} can contribute to emotional concerns and may affect overall well-being and QOL. Strong social relationships provide a protective function and can reduce stigma, improve coping and facilitate overall adjustment.^{5,9} Two constructs

that warrant consideration as protective factors for adjustment are self-compassion and hope. These variables are hypothesized to facilitate healthy adaptation and coping with bleeding disorders, based on similar research findings with other chronic illness populations.

1.1 | 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.¹⁰ It also refers to the capacity to demonstrate understanding and express kindness and caring towards oneself, and avoid judgemental attitudes towards one's potential failures.¹⁰ Neff identified three main positive features of self-compassion, including self-kindness, common humanity and mindfulness, and three negative components (ie counterparts) of self-compassion that are self-judgement, isolation and over-identification.¹¹ These components of self-compassion are hypothesized to contribute to the ability to cope with stressful life events. Self-compassion has been associated with self-esteem, but researchers have established theoretical and statistical differences between the two constructs.¹¹

Self-compassion has been associated with positive psychological well-being.¹²⁻¹⁴ For patients with chronic illness, self-compassion was associated with numerous positive outcomes, including decreased depression, anxiety, self-pity and shame,^{15,17} improved coping with pain,¹⁶ greater utilization of adaptive coping behaviours, improved coping efficacy and lower stress levels.¹⁸ In addition, self-compassion was associated with more effective self-care and greater optimism.¹⁷

1.2 | Hope

Hope is a psychological construct that may promote resilience and increase QOL among individuals with chronic illness, such as bleeding disorders.¹⁹⁻²¹ Snyder's hope theory²² conceptualizes hope as, '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)' (p. 287). Hope theory has been compared with optimism, self-efficacy, self-esteem²⁵ and self-worth²⁶ and is defined as a discrete from these constructs. Individuals with chronic illnesses may report lower levels of hope compared with healthy peers.²³ Hope has been identified as an essential component of preventative psychological interventions,²⁴ which may be essential for individuals managing the increased stressors of living with chronic illness.^{1,6}

According to Snyder and colleagues,³⁵ implementation of the hope principles allows an individual to cope in the midst of challenging or difficult situations. For example, the pathways component of hope allows individuals to identify areas in need of change for improved health outcomes, such as identifying goals of decreased pain and fewer bleeding episodes. Agentic thinking in response to such goals may include establishing new routines to consistently

administer infusions or prompt treatment of injuries when they occur.

Hope has been evaluated in many contexts and has demonstrated a strong impact on emotional well-being and QOL. For example, high ratings of hope have been related to success in academics, athletics, physical health, psychological adjustment and psychotherapy.^{25,26} Griggs and Walker found that hope was positively related to QOL among adolescents with chronic illness.¹⁹ Further, multiple studies have found that hope is related to decreased levels of depression and anxiety in individuals with chronic illnesses.²⁷⁻²⁹ Interventions involving hope have also been found to be effective in disease management planning.³⁰ Hope is a powerful factor that influences multiple aspects of well-being and promoting hope in individuals who experience many stressors may very well enhance their QOL.

1.3 | Purpose of this study

The purpose of this study is to explore the bivariate and linear relationships between and among ratings of self-compassion, hope and QOL among individuals with bleeding disorders. While self-compassion, hope and QOL all potentially contribute to an individual's broader well-being, these variables are uniquely defined in the literature. For the purpose of this study, quality of life will be defined as the patients' perception of their disease and the impact of treatment on their physical, mental and social functioning.³⁴ It is expected that these findings will guide the development of positive psychology interventions for this population. We hypothesized that (a) overall QOL would be positively correlated with the self-kindness, common humanity and mindfulness subscales as well as the overall self-compassion score; (b) overall QOL would be negatively correlated with the self-judgement, isolation and over-identification subscales of the self-compassion scale; (c) hope would be positively correlated with overall QOL; (d) overall self-compassion and hope would predict overall QOL; and (e) overall self-compassion and hope would predict psychosocial and physical QOL.

2 | MATERIALS AND METHODS

Researchers recruited participants face-to-face ($n = 76$) and electronically ($n = 10$). Participants who completed the study in person were approached in their comprehensive clinic appointment at a haemophilia treatment centre (HTC). Three HTCs involved in this study were located in the Midwestern United States and one in the Northwestern United States. Potential participants were provided with information about the study and provided informed assent and consent prior to participation. Eligible participants were 15-65 years of age with a bleeding disorder diagnosis (eg haemophilia, VWD). Participants were informed that for every survey completed, \$5 would be donated to the National Hemophilia Foundation. Participants' identifiable information was kept separate from their survey data, and all materials were completed in a self-report

manner. This study was conducted in accordance with the affiliated Institutional Review Boards. Individuals who completed this study electronically were recruited via an HTC's email list. Participants followed a URL to a Qualtrics survey with two prescreener items (ie age and diagnosis) to assess eligibility to participate, followed by study materials. Online data collection was limited to individuals 18 years of age and older to ensure appropriate consent.

2.1 | Demographic questionnaire

Researchers developed a questionnaire to obtain demographic information such as age, gender, race/ethnicity, diagnosis, diagnosis severity, education level, gross family income, student/employment status and any co-morbid medical conditions.

2.2 | Self-compassion scale (SCS)

The SCS¹¹ was used to assess participants' level of self-compassion. The SCS is a 26-item self-report form that yields three positive (self-kindness, common humanity and mindfulness) and three negative (self-judgement, isolation and over-identification) subscales of self-compassion. Participants rated each item on a 5-point Likert-type scale ranging from 1—Almost Never to 5—Almost Always. Researchers obtained a total self-compassion score and six individual component subscale scores, each ranging from 0 to 5. Overall and subscale scores of 1-2.5 indicate a score in the low range, 2.5-3.5 indicate the moderate range and 3.5-5 indicate the high range.¹⁰ Higher scores indicated greater tendencies of thoughts, emotions and/or behaviours towards overall self-compassion or each subscale component. Neff found across multiple studies that the SCS exhibits acceptable psychometric standards.^{11,31} Cronbach's alpha for overall self-compassion was found to be excellent for the current sample ($\alpha = 0.92$) and ranged from acceptable to good for the six subscales of the SCS (self-kindness, $\alpha = 0.84$; self-judgement, $\alpha = 0.80$; common humanity, $\alpha = 0.76$; isolation, $\alpha = 0.78$; mindfulness, $\alpha = 0.76$; over-identification, $\alpha = 0.82$).

2.3 | Adult hope scale (AHS)

The AHS²² consists of 12 items rated on an 8-point Likert-type scale ranging from 1—Definitely False to 8—Definitely True. The scale was validated for individuals 15 years of age and older. It yields two subscale scores (Agency and Pathways) and a total hope score. The Agency subscale addresses determination to complete personal goals and the Pathway subscale assesses participants' ability to overcome challenges and meet their goals. Researchers calculated overall hope scores for each participant, which ranged from zero to 64. Higher scores indicate higher levels of hope. Subscale scores for Agency and Pathways were not utilized in the analyses of the current study. The AHS has been shown to be valid and reliable.^{22,32,33}

Cronbach's alpha for the overall AHS score was found to be good for the current sample ($\alpha = 0.86$).

2.4 | PedsQL inventory-core generic form (PedsQL)

The PedsQL is a 23-item inventory that includes assessment of physical, emotional, social and academic/occupational domains.³⁴ For this study, three versions of the self-report form were used: adolescent (15-18 years old), young adult (19-25 years old) and adult (>26 years old). Participants rated each item on a 5-point Likert-type scale, ranging from 0—Never to 4—Almost Always. The PedsQL is reverse-scored, with higher scores indicating higher levels of QOL. Varni and colleagues found the PedsQL to be a reliable and valid instrument.³⁴ The current sample yielded a Cronbach's alpha score for overall QOL within the excellent range ($\alpha = 0.93$) with QOL subscales in the acceptable to excellent ranges (physical functioning, $\alpha = 0.91$; for emotional functioning, $\alpha = 0.82$; social functioning, $\alpha = 0.77$; school/work functioning, 0.85; and psychosocial functioning $\alpha = 0.90$).

3 | RESULTS

Ninety-one individuals with bleeding disorders were recruited. Five participants were omitted from the data analyses due to incomplete data responses or ineligibility. Seventy-six individuals participated in person and 10 participated electronically. An ANOVA indicated no group differences between face-to-face and online recruitment methods. The final sample included 86 participants (38.4% female, 61.6% male) ranging from 15 to 65 years of age ($M = 29.7$, $SD = 14.4$). Individuals were separated into three age groups based on the age breakdown for the PedsQL; teen ($n = 22$, age 15-18), young adult ($n = 25$, age 19-26) and adult ($n = 39$, age 26-65). The majority of participants identified as White/Caucasian (67%) and were diagnosed with haemophilia A (44%) or VWD (44%). Forty participants identified the severity of their bleeding disorder as mild (46.5%; based on physician's assessment at the time of diagnosis), 12 moderate (14%) and 32 severe (37.2%). Two participants did not report the severity of their condition. See Table 1 for full sample information. This sample's mean score for overall QOL was 75.9 ($SD = 16.6$), psychosocial QOL was 77.1 ($SD = 16.2$) and physical QOL was 72.4 ($SD = 23.3$). The mean score for overall self-compassion was 3.4 ($SD = 0.7$), and the mean score for overall hope was 53.3 ($SD = 7.0$). See Table 2 for summary.

Pearson correlational analyses revealed a significant positive relationship between total QOL and overall self-compassion ($r = .39$, $P < .001$). More specifically, QOL was significantly and positively related to self-kindness ($r = .37$, $P < .001$), but not common humanity ($r = .01$, $P = .92$) or mindfulness ($r = .20$, $P = .06$). Further, there were significant and inverse bivariate relationships between overall QOL and each of the negative self-compassion subscales, including self-judgement ($r = -.44$, $P < .001$), isolation ($r = -.35$, $P = .001$) and

TABLE 1 Demographic information (N = 86)

	n	Per cent (%)	Cumulative per cent (%)	M
	86	100	100	
Age group				29.65
Teen (15-18)	22	25.6	25.6	
Young adult (19-26)	25	29.1	54.7	
Adult (27-65)	39	45.3	100	
Race				
White/Caucasian	58	67.4	67.4	
Black/African American	4	4.7	72.1	
Hispanic/Latino	4	4.7	76.7	
Asian American	2	2.3	79.1	
Native American	5	5.8	84.9	
Bi-racial	11	12.8	97.7	
Asian Indian	1	1.2	98.8	
Multi-Racial	1	1.2	100	
Gender				
Male	53	61.6	61.6	
Female	33	38.4	100	
Diagnosis				
Haemophilia A	38	44.2	44.2	
Haemophilia B	5	5.8	50.0	
Von Willebrand	38	44.2	94.2	
Factor XIII deficiency	2	2.3	96.5	
Afibrinogenemia F1	1	1.2	97.7	
Immune thrombocytopenic purpura	1	1.2	98.8	
Platelet disorder	1	1.2	100	
Severity of diagnosis				
Mild	40	46.5	46.5	
Moderate	12	14.0	60.5	
Severe	32	37.2	97.7	
Unknown	2	2.3	100	
Student				
Yes	36	41.9	41.9	
No	50	58.1	100	
Employed				
Yes	51	59.3	59.3	
No	35	40.7	100	
Income				\$55 300
\$0-10,000	2	2.3	2.3	
\$10 000-20 000	5	5.8	8.1	
\$20 000-30 000	11	12.8	20.9	
\$30 000-40 000	8	9.3	30.2	
\$40 000-50 000	12	14.0	44.2	
\$50 000-60 000	6	7.0	51.2	
\$60 000-70 000	6	7.0	58.2	
\$70 000-80 000	8	9.3	67.5	

(Continues)

TABLE 1 (Continued)

	n	Per cent (%)	Cumulative per cent (%)	M
\$80 000-90 000	4	4.7	72.2	
\$90 000-100 000	4	4.7	76.9	
\$100 000+	17	19.8	96.5	
Unknown	3	3.5	100	
Survey modality				
In person	76	88.4	88.4	
Online	10	11.6	100	

over-identification ($r = -.45, P < .001$). Hope was significantly and positively related to QOL ($r = .44, P < .001$). See Table 3 for correlational matrix.

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 >0.333 and VIF <3).

Standard multiple regression analyses were completed to evaluate the proposed models of the linear relationships between self-compassion and hope with overall, physical and psychosocial QOL. After controlling for gender and diagnosis, self-compassion and hope were found to be significant predictors of overall QOL when these variables were considered together, $F(4, 81) = 5.70, P < .001$. Approximately 22% of the variance in QOL was accounted for by the linear combination of overall self-compassion and hope ($R^2 = .22$). Similarly, after controlling for gender and diagnosis type, self-compassion and hope were found to be significant predictors of physical QOL, $F(4, 81) = 4.58, P < .01$ and psychosocial QOL, $F(4, 81) = 5.13, P < .001$, when considered together. Self-compassion and hope accounted for approximately 18% of variance in physical QOL ($R^2 = .18$) and 19% variance in psychosocial QOL ($R^2 = .19$). Examination of the standardized beta weights revealed that hope was the only significant individual contributor to all three QOL scores (overall QOL, $\beta = 0.32, t = 2.55, P < .05$; physical $\beta = 0.37, t = 2.89, P < .01$; psychosocial $\beta = 0.26, t = 2.05, P < .05$). See Table 4 for a summary of regression analyses.

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	0.72	2.05-5.00	0-5
O-H	53.3	7.00	33.00-64.00	0-64

Abbreviations: O-H, overall hope; O-QOL, overall quality of life; O-SC, overall self-compassion; P-QOL, physical quality of life; PS-QOL, psychosocial quality of life.

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	0.97**	0.84**	0.39**	0.44**	0.37**	-0.44**	0.01	-0.35**	0.20	-0.45**
PS-QOL	—	1	0.67**	0.39**	0.41**	0.34**	-0.43**	-0.01	-0.40**	0.19	-0.46**
P-QOL	—	—	1	0.30**	0.40**	0.35**	-0.35**	0.04	-0.18	0.19	-0.31**
O-SC	—	—	—	1	0.61**	0.85**	-0.83**	0.59**	-0.81**	0.79**	-0.81**
O-H	—	—	—	—	1	0.59**	-0.41**	0.38**	-0.45**	0.57**	-0.46**
SK	—	—	—	—	—	1	-0.62**	0.59**	-0.52**	0.74**	-0.53**
SJ	—	—	—	—	—	—	1	-0.25*	0.76**	-0.50**	0.78**
CH	—	—	—	—	—	—	—	1	-0.20	0.62**	0.13
I	—	—	—	—	—	—	—	—	1	0.62**	0.84**
M	—	—	—	—	—	—	—	—	—	1	-0.49**
O-ID	—	—	—	—	—	—	—	—	—	—	1

Abbreviations: CH, common humanity; I, isolation; M, mindfulness; O-H, overall hope; O-ID, over-identification; O-QOL, overall quality of life; O-SC, overall self-compassion; P-QOL, physical quality of life; PS-QOL, psychosocial quality of life; SJ, self-judgement; SK, self-kindness.

* $P < .05$.

** $P < .01$.

TABLE 4 Regression findings for self-compassion and hope as potential predictors of overall, physical, psychosocial and overall quality of life (n = 86)

Variable	B	SE B	β	R ²	P
Overall QoL				.22	
Step 1					
Constant	76.03	9.00			<.001
Gender	0.843	4.02	0.03		.84
Diagnosis	-0.66	1.47	-0.06		.66
Step 2					
Constant	19.82	15.31			.20
Gender	-1.37	3.82	-0.40		.72
Diagnosis	0.38	1.34	0.03		.78
O-SC	4.92	2.87	0.22		.09
O-H	76*	0.30	0.32		.01
Physical QoL				.18	
Step 1					
Constant	65.04	12.63			<.001
Gender	3.04	5.89	0.06		.61
Diagnosis	1.09	2.06	0.07		.60
Step 2					
Constant	-11.70	21.95			.60
Gender	0.74	5.49	0.02		.89
Diagnosis	2.55	1.93	0.15		.19
O-SC	3.29	4.12	0.10		.43
O-H	1.23**	0.43	0.37		.005
Psychosocial QoL				.19	
Step 1					
Constant	79.70	8.73			<.001
Gender	0.11	4.07	0.003		.98
Diagnosis	-1.24	1.43	-0.11		.39
Step 2					
Constant	30.33	15.06			.047
Gender	-2.08	3.76	-0.06		.58
Diagnosis	-0.35	1.32	-0.03		.79
O-SC	5.46	2.83	0.25		.06
O-H	0.60*	0.29	0.26		.04

Abbreviations: B, unstandardized coefficient beta; O-H, overall hope; O-SC, overall self-compassion; P, significance; QoL, quality of life; R², variance; SE B, unstandardized coefficients standard error; β , standardized coefficients beta.

*P < .05.

**P < .01.

4 | DISCUSSION

Few researchers have explored the relationship between hope and self-compassion, especially within chronic illness populations, and this is the first study of its kind to explore these constructs among individuals with bleeding disorders. In this study, self-compassion

and hope were significantly related to QOL among this sample of individuals with bleeding disorders. This finding is consistent with previous research with chronic illness populations.^{16,19,20} As hypothesized, the combination of self-compassion and hope significantly predicted overall, physical and psychosocial QOL. Hope was the primary predictor of all three QOL scales, which in part, could be explained by the shared variance between self-compassion and hope. These findings indicate positive psychology constructs, such as hope and self-compassion can demonstrate meaningful influence on QOL.

Although the findings of this study did not support self-compassion as strongly as hypothesized, self-compassion has been found to be an effective tool for coping with health-related stressors.¹⁸ Self-kindness, a positive component of self-compassion, was significantly and positively correlated with overall QOL for individuals with bleeding disorders, such that as self-kindness increased, overall QOL also increased. Strategies to improve self-kindness may be supported based on this relationship.¹⁸

As expected, QOL for individuals with bleeding disorders was significantly and inversely related to the three negative components of self-compassion (self-judgement, isolation and over-identification). This finding is consistent with previous research emphasizing the relationship between self-compassion and well-being.¹¹ Yet, self-compassion may counteract the negative effects of these self-judgements.¹⁸ Research has shown that social support is one of the most important factors influencing QOL among individuals with chronic illnesses⁹; therefore, seeking relational support when needed and avoiding isolating behaviours may be essential for improving QOL.

Hope was also significantly and positively related to overall QOL and was the most robust variable in the proposed model. The hope construct delineates a type of problem-solving scenario, in which individuals identify a goal and determine the actionable steps to achieve that goal. In individuals with chronic illness, such actions could easily be interpreted as protective health behaviours. In fact, Barlow and Ellard posited that interventions to increase hope for individuals with chronic illnesses could effectively improve disease management planning, which can be vital given the unpredictable nature of some bleeding episodes.³⁰ Further, hope may improve the emotional functioning of individuals with bleeding disorders and has been related to lower levels of depression and anxiety for individuals with chronic illnesses.²⁷⁻²⁹ Thus, hope may facilitate improvements in both the emotional and behavioural QOL components. In differing ways, both self-compassion and hope appear to have contributions necessary to increase QOL for individuals with bleeding disorders.

4.1 | Implications for practice with individuals with bleeding disorders

Findings from this study are valuable to consider for those working with individuals with bleeding disorders and provide support for the protective factors of positive constructs. Research has shown that

there are numerous positive psychology variables that may be useful to consider when working with chronic illness populations, including gratitude, identifications of strengths, positivity, mindfulness, spirituality, forgiveness and acts of kindness.³⁶ This study adds further support for benefits of self-compassion and hope among these adaptive coping behaviours. In fact, Snyder and colleagues have posited numerous solution-focused, narrative and cognitive-behavioural interventions to promote hope in various healthy and chronic illness populations.^{35,37} These findings support the strengthening of positive psychology constructs to improve overall well-being.

There are numerous strategies that healthcare providers can implement in the interest of improving patient well-being. One of the primary roles of HTC providers is to assess and address physical and psychosocial risk factors, and these findings provide guidance for implementation of positive psychology interventions. Cognitive-behavioural strategies are an excellent way to strengthen personal self-compassion and overall hope. Snyder offers several specific cognitive-behavioural techniques to facilitate improvements in hope, including strategies to increase state hope, trait hope and agentic thinking.^{35,37} Bolstering these skills is one route to improved self-care and overall improvements in QOL. Collaboration with HTC psychosocial team members to facilitate such interventions is recommended to initiate these steps and establish more holistic approaches to improving health.

4.2 | Limitations and recommendations for future research

Limitations of the current study should be noted. The sample size was a primary limitation, and differences based on bleeding disorder diagnoses, gender, age or severity levels were not able to be examined in this sample due to insufficient power. Additionally, the research methodology only allows for correlational analyses. Further investigation in this area is warranted to examine outcomes of positive psychology interventions and establish further support for these associations.

5 | CONCLUSION

Healthcare providers who work within HTCs can further support the patient populations by considering positive psychology factors that may help to improve coping and influence their QOL. The results of this study indicate that self-compassion and hope have relational and predictive value for improved health outcomes among individuals with bleeding disorders. These findings provide support for providers to implement assessment, education and intervention to facilitate positive coping and to enhance QOL.

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AUTHOR CONTRIBUTIONS

Darci E. Klein, MS involved in research design, recruitment and consent, data collection and management, data analysis and manuscript preparation. Carrie L Winterowd, PhD involved in research design, data analysis, manuscript preparation. Meredith Ehrhardt, MA involved in manuscript preparation. J. Carrick Carter, Psy.D. involved in clinic implementation, recruitment and consent, data collection and manuscript preparation. Osman Khan, MD involved in clinic implementation and manuscript preparation. Sunnye Mayes, PhD, ABPP involved in research design, recruitment and consent, data collection, manuscript preparation and clinic implementation.

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REFERENCES

1. Barlow JH, Stapley J, Ellard DR. Living with haemophilia and Von Willebrand's: a descriptive qualitative study. *Patient Educ Couns*. 2007;68(3):235-242.
2. Sadler JE, Budde U, Eikenboom JCJ, et al. Update on the pathophysiology and classification of von Willebrand disease: a report of the Subcommittee on von Willebrand Factor. *J Thromb Haemost*. 2006;4(10):2103-2114.
3. McLaughlin JM, Munn JE, Anderson TL, Lambing A, Tortella B, Witkop ML. Predictors of quality of life among adolescents and young adults with a bleeding disorder. *Health Qual Life Outcomes*. 2017;15(1):67.
4. Poon J-L, Doctor JN, Nichol MB. Longitudinal changes in health-related quality of life for chronic diseases: an example in hemophilia A. *J Gen Intern Med*. 2014;29(Suppl 3):760-766.
5. Williams KA, Chapman MV. Social challenges for children with hemophilia: child and parent perspectives. *Soc Work Health Care*. 2011;50(3):199-214.
6. Poon J-L, Zhou Z-Y, Doctor JN, et al. Quality of life in haemophilia A: Hemophilia Utilization Group Study Va (HUGS-Va). *Haemophilia*. 2012;18(5):699-707.
7. Rolstad EB. Perceptions of men with moderate to severe hemophilia regarding the management of their chronic disorder and utilization of community-based support. *Am J Mens Health*. 2015;9(6):486-495.
8. Iorio A, Forsyth A, Cassis F, Querol F. psychosocial aspects of living with haemophilia: the hero project and a narrative review of the published literature: P-we-493. *J Thromb Haemost*. 2011;9:675.
9. Bullinger M, von Mackensen S. Psycho-social determinants of quality of life in children and adolescents with haemophilia-A cross-cultural approach. *Clin Psychol Psychother*. 2008;15(3):164-172.
10. Neff K. Self-compassion: an alternative conceptualization of a healthy attitude toward oneself. *Self Identity*. 2003;2(2):85-101.
11. Neff KD. The development and validation of a scale to measure self-compassion. *Self Identity*. 2003;2(3):223-250.



12. Bluth K, Blanton PW. The influence of self-compassion on emotional well-being among early and older adolescent males and females. *J Posit Psychol*. 2015;10(3):219-230.
13. Muris P, Meesters C, Pierik A, de Kock B. Good for the self: self-compassion and other self-related constructs in relation to symptoms of anxiety and depression in non-clinical youths. *J Child Fam Stud*. 2016;25(2):607-617.
14. Neff K. The role of self-compassion in development: a healthier way to relate to oneself. *Hum Dev*. 2009;52(4):211.
15. Pinto-Gouveia J, Duarte C, Matos M, Fráguas S. The protective role of self-compassion in relation to psychopathology symptoms and quality of life in chronic and in cancer patients. *Clin Psychol Psychother*. 2014;21(4):311-323.
16. Costa J, Pinto-Gouveia J. Acceptance of pain, self-compassion and psychopathology: using the chronic pain acceptance questionnaire to identify patients' subgroups. *Clin Psychol Psychother*. 2011;18(4):292-302.
17. Brion JM, Leary MR, Drabkin AS. Self-compassion and reactions to serious illness: the case of HIV. *J Health Psychol*. 2014;19(2):218-229.
18. Sirois FM, Molnar DS, Hirsch JK. Self-compassion, stress, and coping in the context of chronic illness. *Self Identity*. 2015;14(3):334-347.
19. Griggs S, Walker RK. The role of hope for adolescents with a chronic illness: an integrative review. *J Pediatr Nurs*. 2016;31(4):404-421.
20. Schiavon CC, Marchetti E, Gurgel LG, Busnello FM, Reppold CT. Optimism and hope in chronic disease: a systematic review. *Front Psychol*. 2017;7:2022.
21. Venning A, Elliott J, Wilson A, Kettler L. Understanding young peoples' experience of chronic illness: a systematic review. *Int J Evid Based Healthc*. 2008;6(3):321-336.
22. Snyder CR, Harris C, Anderson JR, et al. The will and the ways: development and validation of an individual-differences measure of hope. *J Pers Soc Psychol*. 1991;60(4):570-585.
23. Venning AJ, Elliott J, Whitford H, Honnor J. The impact of child's chronic illness on hopeful thinking in children and parents. *J Soc Clin Psychol*. 2007;26(6):708-727.
24. Kwon P, Birrueta M, Faust E, Brown ER. The role of hope in preventive interventions. *Soc Personal Psychol Compass*. 2015;9(12):696-704.
25. Snyder CR. Hope theory: rainbows in the mind. *Psychol Inq*. 2002;13(4):249-275.
26. Snyder CR, Hoza B, Pelham WE, et al. The development and validation of the Children's Hope Scale. *J Pediatr Psychol*. 1997;22(3):399-421.
27. Evangelista LS, Doering LV, Dracup K, Vassilakis ME, Kobashigawa J. Hope, mood states and quality of life in female heart transplant recipients. *J Heart Lung Transplant*. 2003;22(6):681-686.
28. Germann JN, Leonard D, Stuenzi TJ, Pop RB, Stewart SM, Leavey PJ. Hoping is coping: a guiding theoretical framework for promoting coping and adjustment following pediatric cancer diagnosis. *J Pediatr Psychol*. 2015;40(9):846-855.
29. Yuen ANY, Ho SMY, Chan CKY. The mediating roles of cancer-related rumination in the relationship between dispositional hope and psychological outcomes among childhood cancer survivors. *Psycho-Oncology*. 2014;23(4):412-419.
30. Barlow JH, Ellard DR. Psycho-educational interventions for children with chronic disease, parents and siblings: an overview of the research evidence base. *Child Care Health Dev*. 2004;30(6):637-645.
31. Neff K. The Self-Compassion Scale is a valid and theoretically coherent measure of self-compassion. *Mindfulness*. 2015;7(1):264-274.
32. Roth DL, Harris RN, Snyder CR. An individual differences measure of attributive and repudiative tactics of favorable self-presentation. *J Soc Clin Psychol*. 1988;6(2):159-170.
33. Roth DL, Snyder CR, Pace LM. Dimensions of favorable self-presentation. *J Personal Soc Psychol*. 1986;51(4):867-874.
34. Varni JW, Seid M, Rode CA. The PedsQLTM: measurement model for the pediatric quality of life inventory. *Med Care*. 1999;37(2):126-139.
35. Snyder CR, Feldman DB, Taylor JD, Schroeder LL, Adams VH III. The roles of hopeful thinking in preventing problems and enhancing strengths. *Appl Prev Psychol*. 2000;9(4):249-269.
36. Ghosh A, Deb A. Positive psychology interventions for chronic physical illnesses: a systematic review. *Psychol Stud*. 2017;62(3):213-232.
37. Lopez SJ, Floyd RK, Ulven JC, Snyder C. Hope therapy: helping clients build a house of hope. In CR Snyder & CR Snyder (Eds.), *Handbook of Hope*: San Diego, CA: Academic Press; 2000:123-150.

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