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Research Article

A Precede - Proceed Model Approach in Establishing a HemophiliaCenter in a Tertiary Medical Institution: A Descriptive Study

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ABSTRACT

Hemophilia is an inherited bleeding disorder diagnosed by deficiency of proteins in the blood called "clotting factors".It is a lifelong disease that requires factor replacement in times of bleeding, hence, continued support by providing a holistic program to address their needs is warranted.

Aims: To provide a comprehensive framework of care that can be offered by evaluating the quality of life, knowing the epidemiology, beliefs, environmental factors, including medical, surgical, psycho-social aspects of hemophilia care.

Methods: The researcher used the PRECEDE-PROCEED framework to assess the current status of he-mophilia care in a tertiary medical institution that may be used to create programs based on the retrospective data evaluation in the PRECEDE phase. The Haemo-HQOL questionnaire was used to evaluate the current status of patients seen as part of the PROCEED phase.

Results: A total of 202 patients were seen in the institution over the past three years. Important factors identified were the ability to manage bleeding episodes at home, challenges due to limited supply of factor concentrate and cost of treatment. The availability of patient support groups and provision of donated factor concentrates provided improvement in the care of persons with hemophilia (PWH).The PROCEED phase reevaluated the current status of care with the use of a validated Haemo-HQOL which showed the different dimensions of interest according to age group.

Conclusions: The study provided a comprehensive framework of care and service that can be offered to PWH. Evidences regarding the importance of creating a specialized treatment center to cater hemophilia patients despite the difficult political, socio-economic, behavioral and environmental problems of PWH confirmed that interventions will improve the quality of life of this population. Moreover, continuous monitoring and reevaluation will provide a good system to guide our pediatrichematologists regarding the practice of treating hemophilia patients.

INTRODUCTION

The treatment of Hemophilia and related bleeding disorders has developed over the years aided with continuous global integration efforts devoted in the care of person with hemophilia (PWH). As part of the World Federation of Hemophilia's (WFH) mission to improve and maintain care, several specific programs were created such as coagulation workshops, hemophilia fellowship programs, WFH center twinning program which included the Philippines in partnership with Australia, and provision of access to treatment through the Humanitarian Aid (HA) Program, among others [1].

The structure of a Hemophilia Treatment Center should ideally include a multidisciplinary team, which is composed of a medical doctor, a nurse, an orthopedist, a physiotherapist, a laboratory specialist and a psychosocial expert. Moreover, a comprehensive team for more advanced needs may also be put in place, as hemophilia remains to be a complex disorder requiring a widerange of needs for both the patient and his family [2].

The World Federation of Hemophilia estimates that about 10,000 Filipinos have hemophilia. To date, only around 1,500 PWH have been identified and registered with the WFH national member organization, the Hemophilia Philippines (HAPLOS Community) Foundation, Inc. Hemophilia is a serious andlifelong condition that many people are not yet aware of. It is estimated that about 75% of sufferers receive inadequate to no treatment at all [3].

As early as childhood, PWH should be oriented about expectations regarding acute bleeding episodes and taught about treatment

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regimens. Understanding the nature of their condition, why bleeding occurs, the need for timely medical consult, and how to self-administer factor concentrates should be instilled at an early age. Knowing their condition well will likely make them more responsible for their own care [4]. They would also need regular medical review of care and, more conveniently, require regular therapy. In fact, other countries are already into prophylactic factor replacement as a standard of care[5].

Availability of WFH-trained healthcare provider, clotting factor concentrates from the WFH HA program and government agencies, and facility for the care of PWH, the idea of putting together a Hemophilia Treatment Center offering a holistic hemophilia care program at the University of Santo Tomas Hospital transpired. A PRECEDE-PROCEED framework was applied to assess thecurrent status of hemophilia care in our institution that served as the basis for creating the program.

The PRECEDE-PROCEED is a proven framework as a means of creating a program for a special group of patients. This model consists of nine phasesbased on the premise that health behaviors are complex, multidimensional, and influenced by a variety of factors. PRECEDE consists of five phases (phase one to five) whereas PROCEED consists of four (phase six to nine.) [6,7].

The objective of this study was to evaluate and design the University of Santo Tomas Hospital's hemophilia care program using the PRECEDE-PROCEEDPlanning Model.Specifically, the study aimed to gather data on the social, epidemiological, behavioral, environmental, educational and ecologicalconditions of PWH seen at the at University of Santo Tomas Hospital from January 2016 to December 2018.

PATIENTS AND METHODS

(Figures 1 and 2)

This is a descriptive study regarding hemophilia care at the University of Santo Tomas Hospital. After securing approval from the Research Ethics Committee, the researcher gathered epidemiological data from the records and census of the Ambulatory Care Service (ACS) and the Section of Pediatric Hema-tology/ Oncology. Records of 48 patients diagnosed with hemophilia seen in the ACS with 133 consultations over the past 3 years between 2016 and 2018 were reviewed. Hemophilia diagnosis was confirmed by plasma factor VIII or factor IX assay less than 40% for hemophilia A and B, respectively. Epidemiological data such as specific diagnosis with disease severity, number of admissions and out-patient consults were gathered. Those with unknown causes of bleeding disorders were excluded.

Twenty-three children with moderate to severe hemophilia without inhibitor, not on factor prophylaxis, who can read, with no co-morbid conditions and who were actively consulting at the Benavides Cancer Institute of the University of Santo Tomas Hospital were included for interview. Data such as age, type and severity of hemophilia, relationship to guardian, and socioeconomic status (SES) were obtained. The Filipino version of the Haemo-QoL questionnaire was administered to all children aged 4 to 17 years while interviews were conducted to their legally authorized representative/guardians after an informed assent and consent was given, respectively. Convenience sampling was employed in this study.

The principal investigator served only as researcher and was not directly involved in the care of PWH at the time of the study.

Counts with percentages and mean with standard deviations (SD) were used to summarize the data gathered from the respondents. Fisher's exact test was used to compare categorical data between groups, while Mann-Whitney U test and Kruskall-Wallis ANOVA were used to compare responses expressed in 3- and 5-point Likert scales. Kruskall-Wallis ANOVA was also used to compare the scores in the beliefs assessment. All the statistical tests were performed in SPSS ver 13.0, under 5% level of significance.

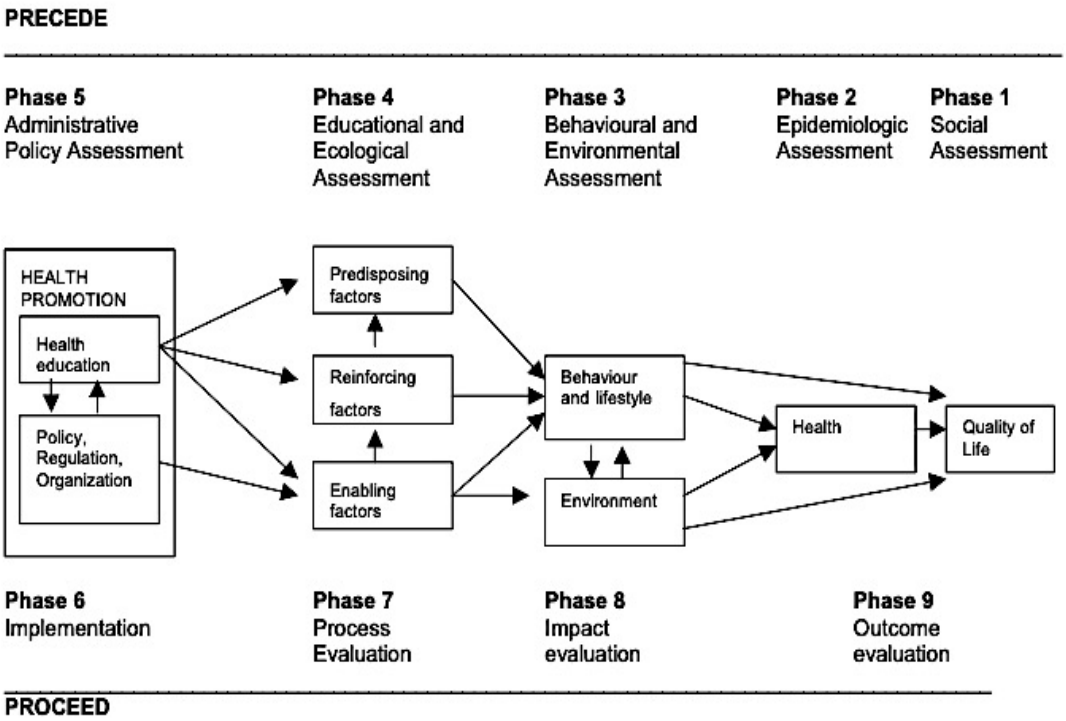

Figure 1. Precede – proceed framework.

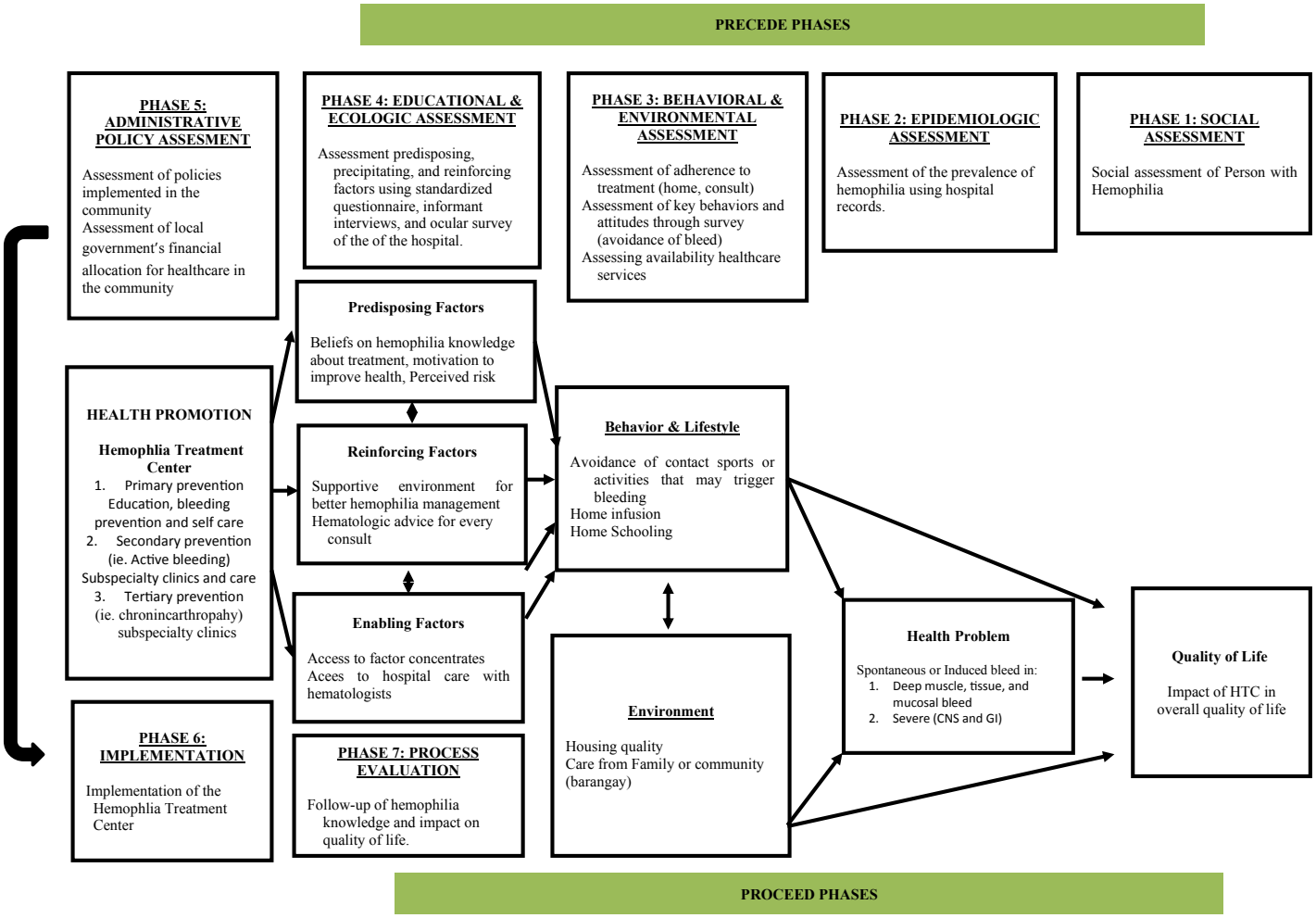

Figure 2. Application of the PRECEDE-PROCEED Model in the development of a Heamophilia Treatment Center.

Table 1: Demographic Profile of the Respondents (N = 23).

Demographic Profile of the Respondents (N = 23)				
Characteristics	Age Group			Total (n=23)
	Group I (n=2)	Group II (n=10)	Group III (n=11)	
Age (Years) (Mean, SD)	7.00 (0.00)	10.50 (1.35)	15.18 (1.25)	12.43 (3.10)
Severity (f, %)				
Moderate	2 (100.00%)	5 (50.00%)	4 (36.36%)	11 (47.81%)
Severe	0 (0.00%)	5 (50.00%)	7 (63.64%)	12 (52.17%)
Family Member with Hemophilia (f, %)				
None	0 (0.00%)	2 (20.00%)	6 (54.55%)	8 (34.78%)
Brother	1 (50.00%)	6 (60.00%)	3 (27.27%)	10 (43.48%)
Uncle	0 (0.00%)	0 (0.00%)	2 (18.18%)	2 (8.70%)
Brother and Uncle	1 (50.00%)	1 (10.00%)	0 (0.00%)	2 (8.70%)
Cousins	0 (0.00%)	1 (10.00%)	0 (0.00%)	1 (4.35%)
Monthly Household Income (f, %)				
Less than PHP 10,000	0 (0.00%)	3 (30.00%)	6 (54.55%)	9 (39.13%)
Between PHP 10,000 to PHP 20,000	2 (100.00%)	1 (10.00%)	3 (27.27%)	6 (26.09%)
Between PHP 20,000 to PHP 50,000	0 (0.00%)	6 (60.00%)	1 (9.09%)	7 (30.43%)
More than PHP 50,000	0 (0.00%)	0 (0.00%)	1 (9.09%)	1 (4.35%)

Note: Group 1 (4 – 7 Years Old); Group II (8 – 13 Years Old); Group III (14 – 17 Years Old)

RESULTS

Demographic Profile of the Respondents

Table 1 summarized the demographic profile of the 23 respondents. The mean age was 12.43 years (SD=3.10). Twelve respondents (52%) have severe while 11 have moderate hemophilia (48%). Eight PWH (35%) did not have a family member with the disease while the majority had relatives with hemophilia. The average monthly household income was less than PHP 10,000 for 39% of the respondents.

Phase 1: Socialassessment

In Phase 1 assessment, the results of the study conducted in 2013 on Health-Related Quality of Life As-sesment in Filipino Children with Hemophilia Aged 4 to 16 years in a Tertiary Hospital using the validated questionnaire provided the different social dimensions covered within the quality-of-life questionnaire. [8]. The scope included the individual's perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns.

The *Physical* scale included questions regarding pain, mobility and anxiety; *Feeling was* concerned with the children's mood, emotional consequence and actions in relation to hemophilia; *Attitude* scale dealt with relationships to others and to own person; the Family scale dealt with restrictions, the child's position in the family, problems at home, activities of the parents and own feelings in the family; Friends scale dealt with the child's relationship, feelings of anxiety and activities with his friends; *Perceived Support* scale had questions about how the children recognized social support or estrangement and isolation they received from others; *Sports and School* asked about sports participation and school activities and the *Coping* asked questions about the children's control and emotional acceptance of their hemophilia. Hemophilia care and treatment side effects were asked in *Treatment* scale; how they interact with others was asked in the *Other Persons*; and *Future* and *Relationships* asked about their views of the future and the possibility of having relationships with the opposite sex.

The study included 51 participants. Group I PWH aged 4-7 years showed the most impairment in the sub-scale of Family (43.75 ± 36.8), while Group II PWH aged 8-12 years and Group III PWH aged 13-16 years showed most impairment in Sports and School sub-scale (Group II: 58.2 ± 18.77; Group III: 59.27 ± 17.46). Group I showed least impairment in Attitude (6.25 ± 7.60) while Groups II and III had least impairment in Treatment sub-scale (TSS) (Group II: 12.5 ± 15.26; Group III: 23.99 ± 11.02). The total mean TSS in this study was 28.39 ± 4.76, reflecting a good QOL of included patients.

Phase 2: Epidemiologic assessment

Through the years, the UST Hospital Section of Pediatrics Hematology/Oncology provided care and treatment for hemophilia patients with the epidemiological profile presented in Table 2. A total of 202 patients were seen in the institution over the past 3 years. It admitted 69 PWH from 2016 to 2018, with an average 5-day hospital stay. Thirty-eight (55%), 24 (35%) and 7 (10%) had severe, moderate and mild hemophilia, respectively. Twenty-one (32%) of them were admitted due to muscle bleeding.A total of 133 consults were made in the out-patient department (Benavides Cancer Insitute) for the same period.

Among the 69 PWH, 23 PWH of different ages were recruited by convenience sampling for interview and Haemo-QoL assessment. Almost half of them (47%) experienced bleeding 1-2 times monthly, all 4- to 7-year-old and half of those 8- to 12-year-old. Majority (55%) of the 13- to 17-year-old PWH experienced less than one bleeding episode monthly.

Phase 3: Behavioral and environmental assessments

Table 3 summarized the behavioral and environmental data of the 23 respondents. Eighty-seven percent of them attended regular school while the rest preferred home schooling. More than half did not engage in exercise. Seventy-eight percent preferred to isolate themselves to prevent trauma while the rest preferred to infuse factor concentrate prior to any physical activity. All of the respondents used the Rest, Ice, Compress, Elevate (R.I.C.E.) approach as an initial management for bleeding.Most (91%) of them sought consult during episodes of bleeding. Of note, half of the respondents (n=12) rested for one week during days of bleeding.

Majority of PWH availed of clotting factor concentrates from patient support groups and the Philippine Charity Sweepstakes Office. Only about a quarterwas able to buy their own factor concentrate out-of-pocket.Sixty-five percent utilized a private vehicle for transportation going to the hospital while the rest used different forms of public transportation (Table 4).

Phase 4: Educational and ecological assessments

All PWH gained knowledge about hemophilia from their attending physicians.Other sources of information include the internet or books, lay fora and relatives.Majority believed that hemophilia is inherited from family members. Thirty-nine percent thought, especially those without family history, that it is secondary to genetic mutations.A little more than half of PWH were worried about bleeding episodes.But some worried about their inability to attend class and/or games, development of joint deformities and other sickness and the state of always being careful to avoid bleeding (Table 5).

Phase 5: Administrative policy assessment on hemophilia

Rare diseases make local, national and international efforts difficult especially in establishing general health care infrastructure.Financial instability together with differing views within a government system in a country result to mismanaged healthcare systems[9]. Substantial help coming from the WFH through their fellowship training program, Hemophilia Treatment Center twinning program, national member organization twinning program and humanitarian aid program improved access to hemophilia care in developing countries. Data from local hemophilia registry was one of the major strategies to inform the Government to take action in

Table 2: Epidemiological Assessment of Hemophilia in UST Hospital.

Epidemiological Assessment of Hemophilia among the Respondents (N = 23)				Total (N=23)
Characteristics	Age Group			
	Group I (n=2)	Group II (n=10)	Group III (n=11	
Frequency of Bleeding per Month (f, %)				
Less than 1 Time	0 (0.00%)	4 (40.00%)	6 (54.55%)	10 (43.48%)
1 – 2 Times	2 (100.00%)	5 (50.00%)	4 (36.36%)	11 (47.38%)
More than 3 Times	0 (0.00%)	1 (10.00%)	1 (9.09%)	2 (8.70%)
Note: Group 1 (4 – 7 Years Old); Group II (8 – 13 Years Old); Group III (14 – 17 Years Old)				

Table 3: Behavioral and Environmental Assessments of Hemophilia among the Respondents.

Behavioral and Environmental Assessments of Hemophilia among the Respondents (N = 23)				
Behavioral Characteristics	**Age Group**			**Total (N=23)**
	Group I (N=2)	**Group II (N=10)**	**Group III (N=11)**	
School Set-up (f, %)				
Home School	0 (0.00%)	1 (10.00%)	2 (18.18%)	3 (13.04%)
Regular School	2 (100.00%)	9 (90.00%)	9 (81.82%)	20 (86.96%)
Engaging in Exercise (f, %)				
Engages in Exercise	1 (50.00%)	4 (40.00%)	5 (45.45%)	10 (43.48%)
Does Not Engage in Exercise	1 (50.00%)	6 (60.00%)	6 (54.55%)	13 (56.52%)
Trauma Prevention Practices (f, %)				
Isolation	1 (50.00%)	9 (90.00%)	8 (72.7%)	18 (78.2%)
Infusion prior to Activities	1 (50.00%)	1 (10.00%)	3 (27.27%)	5 (21.8%)
Initial Management of Bleeding (f, %)				
Rest, Ice, Compress, and Elevate (R.I.C.E.)	2 (100.00%)	10 (100.00%)	11 (100.00%)	23 (100.00%)
Home Infusions	0 (0.00%)	0 (0.00%)	1 (9.09%)	1 (4.35%)
Consultation during Bleeding Episodes (f, %)				
Clinic/Hospital	2 (100.00%)	10 (81.00%)	10 (81%)	21 (91.3%)
Self-Infusions	0 (0.00%)	1 (9.00%)	1 (9%)	2 (8.7%)
Rest Days when with Bleeding Episodes (f, %)				
1 – 2 Days	0 (0.00%)	3 (30.00%)	3 (27.27%)	6 (26.09%)
More than 2 Days	0 (0.00%)	0 (0.00%)	3 (27.27%)	3 (13.04%)
More than 1 Week	2 (100.00%)	6 (60.00%)	4 (36.36%)	12 (52.17%)
Stops Going to School	0 (0.00%)	1 (10.00%)	1 (9.09%)	2 (8.70%)

Table 4: Environmental Characteristics of Hemophilia among the Respondents.

Environmental Characteristics	Age Group			Total (N=23)
	Group I (n=2)	**Group II (n=10)**	**Group III (n=11)**	
Availability of Factor VIII Concentrate (f, %)				
Patient Support Group	2 (100.00%)	6 (60.00%)	9 (81.82%)	17 (73.91%)
Out-of-Pocket	1 (50.00%)	2 (20.00%)	3 (27.27%)	6 (26.09%)
Charity (PCSO)	1 (50.00%)	7 (70.00%)	5 (45.45%)	13 (56.52%)
Support System				
Family	0 (0.00%)	5 (50.00%)	3 (27.27%)	8 (34.78%)
Friends	0 (0.00%)	0 (0.00%)	1 (9.09%)	1 (4.35%)
Community	0 (0.00%)	0 (0.00%)	0 (0.00%)	0 (0.00%)
Patient Support Group	2 (100.00%)	7 (70.00%)	9 (81.82%)	18 (78.26%)
Transportation Method (f, %)				
Commute	1 (50.00%)	4 (40.00%)	3 (27.27%)	8 (34.78%)
Private Care	1 (50.00%)	6 (60.00%)	8 (72.73%)	15 (65.22%)
Note: Group 1 (4 – 7 Years Old); Group II (8 – 13 Years Old); Group III (14 – 17 Years Old)				

the care of its own hemophilia patients [10].

In some developed countries like the United Kingdom, medical insurance is taken as an additional coverage through the National Health service whichmakes every disease treatable and free of cost under its umbrella. Due to unavailability of medical insurance facility in many developing countries, PWH themselves do not get insurance cover even when they approach insurance companies to take adequate health cover. [9]. In developing countries, the government is not unexpected to provide limited sources for financial support due to high cost of hemophilia care. This leads to substantial out of pocket expenses for individual families, having a PWH hard to manage [11].

In the Philippines, hemophilia patient groups are paving the way in putting health care regulations for hemophilia. The Hemophilia Philippines (HAPLOS Community) Foundation had been, for years, meeting up with the Departmentof Health, the Philippine Health Insurance Company, the National Institute of Health and several congressmen and senators advocating for the allocation of resources for the care of persons with hemophilia. Senator Grace Poe filed a Senate Bill 2343 or "An Act To Assist Persons With Hemophilia And Other Bleeding Disorders" that seeks to establish four treatments centers in Metro Manila, Luzon, Visayas and Mindanao, and provide P100 million for treatment of the rare disorder on August 5, 2014. [11,12] A similar bill "The Bleeding Disorders Standard of Care Bill or Senate Bill 1335" calling for

Table 5: Educational and Ecologic Assessments of Hemophilia among the Respondents.

Educational Assessment of Hemophilia among the Respondents (N = 23)				
Behavioral Characteristics	**Age Group**			**Total (N=23)**
	Group I (N=2)	**Group II (N=10)**	**Group III (N=11)**	
Sources of Knowledge on Hemophilia (f, %)				
Relatives	1 (50.00%)	1 (10.00%)	2 (18.18%)	4 (17.39%)
Hematologic Consults	2 (100.00%)	10 (100.00%)	11 (100.00%)	23 (100.00%)
Lay Forum	0 (0.00%)	2 (20.00%)	2 (18.18%)	4 (17.39%)
Internet or Books	1 (50.00%)	4 (40.00%)	3 (27.27%)	8 (34.78%)
Method of Inheriting Hemophilia (f, %)				
Familial	2 (100.00%)	8 (80.00%)	8 (72.73%)	18 (78.26%)
Acquired	0 (0.00%)	0 (0.00%)	0 (0.00%)	0 (0.00%)
Mutations from Genes	1 (50.00%)	3 (30.00%)	5 (45.45%)	9 (39.13%)
Degree of Worry with Hemophilia (Mean, SD)	3.50 (0.71)	3.00 (1.56)	3.18 (0.87)	3.18 (1.18)
Worries with Hemophilia (f, %)				
None	0 (0.00%)	2 (20.00%)	2 (18.18%)	4 (17.39%)
Bleeding	1 (50.00%)	4 (40.00%)	8 (72.72%)	13 (56.52%)
Joint Deformity	1 (50.00%)	0 (0.00%)	0 (0.00%)	1 (4.35%)
Sickness	0 (0.00%)	1 (10.00%)	0 (0.00%)	1 (4.35%)
Being Careful	0 (0.00%)	1 (10.00%)	1 (9.09%)	2 (8.70%)
Inability to Attend Classes	0 (0.00%)	1 (10.00%)	0 (0.00%)	1 (4.35%)
Inability to Play Games	0 (0.00%)	1 (10.00%)	0 (0.00%)	1 (4.35%)

Note: Group 1 (4 – 7 Years Old); Group II (8 – 13 Years Old); Group III (14 – 17 Years Old)

the establishment of Hemophilia Treatment Centers in different areasin the Philippines and allocation of funding for the purchase of factor concentrate was filed by Senator Joel Villanueva on February 17, 2017 [13].

Currently in the hospital, no administrative policies pertaining to the specific care of hemophilia patients are in writing. Majority of our patients acquire their medications through donated factor concentrates from the WFH and at the same time wait in long lines to be accommodated by the PCSO. PWH covered with health insurances have a limited amount that they can consume, providing treatment for only few of their bleeding episodes.

Usth administrative policy assessment on hemophilia

The USTH Section of Pediatric Hematology/Oncology has been catering for hemophilia patients for decades now. In 1990s, the Philippine Society of Hematology and Blood Transfusion tasked the UST Hospital as the "pilot hemophilia center" pioneering for the care of this special group of patients.The section gathered families with hemophilia and organized them as the core group of the first lay support arm of Filipino PWH in Manila, the "Hemophilia Association of the Philippines for Love and Service Inc." or "HAPLOS Inc." in March 1993.Now known as the "Hemophilia Philippines (HAPLOS Community) Foundation Inc, this lay support group was recognized internationally by and eventually became the national member organization of the World Federation of Hemophilia. In 1998, the UST Hospital Short Stay Service was established, pioneering efforts in hemophilia care by involving multidisciplinary departments to provide holistic care and better management strategies. The availability of donated factor concentrates paved the way in helping hemophilia patients promptly treat acute bleeding episodes and delay disease progression.

Implementationand Re-evaluation

For this last phase, the Haemo-QoL was again used to determine the quality of life of current patients that are being treated in the hospital to reevaluate the different dimensions as explained in phase 1 (social assessment). The descriptive statistics and comparative analysis of the dimensions of quality of life (QoL) are presented in Table 6. Among the 4- to 7-year-old PWH, the most impaired dimension of QoL was attitude or views ($\bar{x}$=37.50, SD=53.03), followed by *feelings* ($\bar{x}$=41.67, SD=35.36), and *treatment* ($\bar{x}$=50.00, SD=23.57). The least impaired, however, was the *family* dimension ($\bar{x}$=100.00, SD=0.00).

The 8- to 13-year-old had the most impaired *other persons* dimension ($\bar{x}$=3.50, SD=12.71), followed by *physical health* ($\bar{x}$=46.25, SD=27.81), and *attitude* or *views* ($\bar{x}$=46.88, SD=10.21), while the *perceived support* ($\bar{x}$=69.38, SD=20.51) was the least impaired.Results of the 14- to 17-year-old indicatedthat *relationship* ($\bar{x}$=31.82, SD=27.59) was the most impaired dimension of QoL, followed by *feelings* ($\bar{x}$=34.09, SD=18.58), and other people ($\bar{x}$=45.59, SD=22.42), while *future* ($\bar{x}$=69.32, SD=20.81) was the least impaired. Compara-tive analysis also showed that almost all dimensions of QoL were comparable among the three age groups, except the *family* dimension which was statistically higher (F=3.91, p=0.037) among those who were 4- to 7-year-old.

DISCUSSION

The objective of this study was to use the PRECEDE-PROCEED framework to assess the current status of hemophilia care in our institution that will be the basis for creating programs based on the preceding evaluation. Since there are still no formal programs for holistic treatment and care for PWH in the country hence, the idea of putting together a Hemophilia Treatment Center at the University of Santo Tomas Hospital emerged.

Table 6: Comparative Analysis of Quality of Life (QoL) according to Age Group.

Comparative Analysis of the Dimensions of Quality of Life among the Respondents according to Age Group (N = 23)					
Dimensions of Quality of Life	**Age Group**			**F-value**	**p-value (Two -Tailed)**
	Group Ia (N=2)	**Group Iia (N=10)**	**Group III (N=11)**		
Physical Health	66.67 (31.43)	46.25 (27.81)	46.96 (19.99)	0.62	0.55
Feelings	41.67 (35.36)	50.83 (27.97)	34.09 (18.58)	1.25	0.308
Attitude	37.50 (53.03)	46.88 (10.21)	52.27 (15.66)	0.68	0.516
Family	100.00 (0.00)	56.50 (24.50)	54.83 (19.58)	3.91*	0.037
Friends	75.00 (35.36)	63.13 (18.51)	67.61 (25.13)	0.25	0.778
Perceived Support	–	69.38 (20.51)	62.50 (17.23)	0.7	0.414
Other People	–	31.50 (12.71)	46.59 (22.42)	3.5	0.077
Sports and School	50.00 (23.57)	48.93 (19.05)	54.55 (14.41)	0.29	0.751
Coping	–	68.21 (13.41)	66.88 (19.83)	0.03	0.86
Treatment	75.00 (35.36)	51.88 (9.22)	50.00 (12.34)	3.05	0.07
Future	–	–	69.32 (20.81)	–	–
Relationship	–	–	31.82 (27.59)	–	–

Note: Group 1 (4 – 7 Years Old); Group II (8 – 13 Years Old); Group III (14 – 17 Years Old)

aThe domains of Perceived Support, Other Persons, Coping, Future, and Relationship were not included in Group I, while Future and Relationship domains were not included in the questionnaire for Group II respondents.

*Significant at 0.05.

†Significant at 0.01.

The increasing number of young people with chronic illnesses or disabilities originating in childhood survive to adulthood, and ultimately these young people need health care programs specialized for their problems. [4] The management should start at the time of diagnosis and continue throughout life. There are certain phases of child to adult development that we should takenote and understand in order for us to go about with each aspect of care. It is recommended to create a multidisciplinary team that can handle patients with hemophilia. The team should develop written guidelines on the holistic care for persons with hemophilia, including transition to adult care. Treating PWH is a team effort among the health care professionals, the patient, the family, and the patient support group

There are a lot of challenges living with hemophilia. As part of living with the disease, it is important to have people around you who understand and participate with the nature of hemophilia care. Peer acceptance is one issue these individuals tend focus on. If they are being understood and welcomed by their peers, then living with hemophilia becomes more manageable. The importance of support from family and friends improves the ability of these patients to cope with the disease, a way of empowering them to embrace and manage hemophilia. Increasing the amount of support will result to a more compliant and more self-sufficient patient. The readiness comes with expectations surrounding its challenges and benefits.

Medical issues could include managing any joint disease that developed as well as any other complications that may have resulted from years of bleeding episodes. Otherwise, the most important issue facing doctors is ensuring that young adults find a suitable primary care physician. Vocational counseling, as they cannot attempt certain careers, is very important. For example, jobs with a significant physical burden may lead to higher risk for bleeding, particularly if prophylaxis is not in place.Issue of disclosure, if not already dealt with, must be discussed now, as issues of disclosure to employers, roommates, friends and potential spouses take on added significance for independent adults

Based from the assessments gathered, among those who are 4- to 7-year old, attitude or views thatpertains towards self-acceptance with the challenges of having hemophilia was the most impaired while family dimension that pertains with the family members sharing their part in giving comfort and showing care with patient was the least. At this age range, family support is very valuable and greatly impacts these growing years. Having a good support system will better prepare an individual to accept challenges in their lives knowing that they are accepted and loved for who they are. In the clinics, programs suited for more exposures with people with similar condition are deemed to be created, such as hemophilia day celebration and lay forums with some physical activities. Furthermore, programs that promote bonding while not exposing them to possible injuries like swimming lessons and indoor game activities may also enhance camaraderie and sense of belongingness.

Among the 8- to 13-year-old, *other people* dimensionwhich is the aspect pertaining to how they feel accepted by people around them and if these people make them feel important was most impaired while *perceived support* which is the aspect that pertains to how they feel people react and respond to their disease was the least impaired. At this point, the impact and the interplay of having peers and acceptance from other people are notable. This stage shows the value of having relationships and perceived support which may affect their life and well- being.According to Lee et.al, a child transitioning to the adolescent stage is crucial with regards to peer acceptance and creating relationships. Identity development is part of the psychological change together with the body's maturation during puberty. The need to grow and feel autonomous to several decisions also develop during this transition. Hence, this is a challenging time for a child transitioning to the adolescent group especiallyfor this special population dealing with a lifelong disease. [4] The QoL findings in this age group were consistent with that of Lee et al. A transition clinic is a proposed program specifically dealing with the patients aged 8 to 13 years old who will then go on to complete the adolescent stages, providing regular assessments

with continued knowledge check and adequate care to address the difficulties that this age group may encounter.

Among those 14- to 17-year-old, results indicate that *relationship which* involves dealing with having intimate relationships with the opposite gender, was the most impaired while future that deals with un-certainties in the future regarding possible hardships in taking care of self as an adult or in the later years of life was the least impaired.The results showed a more concrete response looking at the future with utmost acceptance of the realities that comes with having to deal with hemophilia. The most impaired aspect wasabout relationships as this is not unexpected since living with a bleeding disorder would entail delicate care, much patience and possibly tolerance with dealing with other people who may not even care of the subtlety of this disease. An important realization in this aspect that we can achieve is to create clinics that will cater to the psychological and mental health while these patients are growing. A strong referral system and accessible programs regarding wellness, seminars regarding acceptance and more lay forums addressing issues to promote independent care of self at home and during social gatherings are necessary. Specifically, quarterly gatherings with expertsfor mental health and well-being and/or regular activities that will enhance their knowledge on hemophilia, creatinga venue as well to know more people with the same disease are suggested.

Limitations

This study was limited with the short-term evaluation of the clinic. This included only partly Phase 6 with having to implement yet the program proposals.The researchers also used self-reported questions which may lead to under or over estimation of results. Participation in the study was also limited to PWH who were able to follow-up in the clinic for consult, and to a single center only which may not depict the real situation of hemophilia care in the country.

CONCLUSIONS

This study provided the foundation for creating a specialized treatment center catering to persons with hemophilia. Specific programs and interventions may improve the quality of life of this special subset of the population despite the difficult political, socio-economic, behavioral and environmental challenges they face.

It is recommended to assess and reassess more PWH to better reflect health care needs. Moreover, con-tinuous monitoring and reevaluation will provide a good system to guide the multidisciplinary team flexibility to update and/or upgrade comprehensive hemophilia care provision.

REFERENCES

1. Giangrande PL, Black C. World Federation of Haemophilia programs in developing countries. InSeminars in thrombosis and hemostasis 2005(05)555-560.
2. World Federation of Hemophilia Fact Sheet 7: Structure and Functions of Comprehensive Hemophilia Treatment Centres 1996,
3. LeeCA, Textbook of Hemophilia, Third Edition, 2014Chapter 21 page 150-152. John Wiley & Sons, Ltd, USA
4. Maggs B, Paula H., Transition of care from pediatric to adult services in hematology, Arch Dis Child .2007;92:797-801.
5. Glanz K, Rimer BK, Health, Behavior and Health Education Theory, Research and practice 4th Edition Wiley Imprint, Part V Using Theory in Practice ;2008;405-431.
6. Louise I, Carolyn BL., Public Health Nursing, Leadership, Policy and Practice, Delmar Cengage Learning New York, Chapter 15; 2008;318.
7. Ivey BJ,, The future of the public's health in the 21st Century, Institute of Medicine (US) Committee on Assuring the Health of the Public in the 21st Century Washington (DC): National Academies Press (US); 2002
8. Ghosh K, Management of Haemophilia in Developing Countries Challenges and Options. Indian Journal Haematology Blood Transfusion 2016;32 (3): 347-355.
9. Bryson S. Lower-dose Preventive Therapy Reduced Bleeding Events in Thai Children with Hemophilia A, Study Shows, 2019
10. "Standard of Care for Patients with Bleeding Disorders Proposed. newsinfo.inquirer.net, 2017.
11. Young G, From boy to man: recommendations for the transition process in hemophilia, Haemophilia 2012;18;27–32.
12. Sterling LE. Growing Up with Hemophilia: Assessing Teens' Experiences and Needs During Transition to Adult Health Care. University of Toronto Medical Journal, 2013;90, 149.
13. Espaldon AM,Hern FG, Health – Related Quality of Life Assessment in Filipino Children with Hemophilia aged 4 to 16 years in a Tertiary Hospital. J Hematol Thromb Dis 2014 2:2