

A benchmark study on psychosocial care-giving in Hemophilia

Richa Mohan

Consultant Clinical Psychologist, Delhi University, Delhi

The study explores the psychosocial care-givers knowledge and skills on medical and psychosocial issues in Hemophilia pre-and post participation in the training program conducted in four different North Indian States. The objectives of the study is 1) To approach a cross-section of psychosocial workers and ascertain their views on the psychosocial support in Hemophilia; 2) To critically examine the views/perceptions of the psychosocial workers pre and post training workshop .3) To analyze the responses of the psychosocial workers about medical and psychosocial implications of hemophilia. 4) To identify issues, emerging from empirical evidence, which could be utilized for preparing the guidelines for the psychosocial workers. The findings showed that overall the psychosocial care-givers awareness improved post training on different subsets on the psychosocial awareness questionnaire. This indicates that regular education and updating of knowledge of the care-givers is important. A close perusal of findings suggests that age and experience were closely related to the awareness on the psychosocial issues in Hemophilia. It was found that the young respondents' awareness significantly improved post training whereas there were moderate changes in the responses of the older participants. On the whole, the change in awareness level witnessed after training illustrates that by providing adequate education and information, good results can be achieved, that will benefit PWH and their families, as well as those responsible for giving care to patients suffering from hemophilia.

Keywords: hemophilia, psychosocial support, carrier, care-givers, quality of life, psychosocial professionals

Hemophilia is a life-long condition affecting not only the person with Hemophilia but also as the immediate family members, friends and relatives. It affects them socially, physically and most important psychologically. As it is not a very common condition, several people are inadequately aware about it. Specifically, Hemophilia population's need of a psychosocial support is underestimated due to myths, stigma and lack of knowledge. This lack of awareness always compounded by myth and misconceptions which becomes a hindrance generating psychosocial support for hemophilia afflicted population.

Hemophilia is a genetic disorder, leading to loss of normal lifestyle. This loss leads to various restrictions, frustration, emotional stress and strains, distress and even depression. Some individuals may also develop low self-esteem and inferiority complex. This underlines the importance support services to persons with hemophilia (PWH). The importance of working on the psychosocial aspects of hemophilia is highlighted by the work of Rodriguez et al. (2004) in Philippines, and Torres Ortuno et al. (2004) in Spain. They report that majority of PWH give negative responses to anxiety, depression, suicidal ideation, denial and anger; whereas positive responses for attitude towards life, empathy, self-esteem, faith and sexuality.

Indeed, comprehensive hemophilia care requires not only medical treatment, but also psychological support and counselling. While the importance of psychosocial support within the paradigm of comprehensive hemophilia care is increasingly recognized in developed countries, it is somewhat lacking in the developing countries. The psychosocial support becomes all the more important when the resources are limited (in the form of medicine) and the needs are high.

Comprehensive care for people with hemophilia in India has evolved and developed over the last 15 years. Although hemophilia

was recognized and treated in a few institutions in the country from the 1950s, expertise was limited and there was hardly any network to help and guide patients. 1983 saw formation of National Foundation. Although initial progress was slow, it had picked up during the late 1980s. With the continued efforts of the lay and medical volunteers, the care of people with hemophilia (PWH) in India has improved. This progress was limited to the medical care. In 1998, Danish Government Aid Agency DANIDA has provided support to expand its infrastructure and activities. These efforts contributed to greater awareness in the community, training for medical volunteers, identification of new PWH, youth camps, etc. However, psychosocial support could not wholly take off in the project due to several reasons like lack of awareness of hemophilia and related issues, shortage of trained professionals, attitude and mental blocks of professionals and patient's organization, etc.

In the absence of information, awareness, training and skills, person with hemophilia and their family members mostly remain deprived of those facilities which unburden them. To the best of knowledge of this researcher, there is at present no facility available for providing training or updating knowledge and skills of the psychosocial professionals or volunteers who are working in the field. It is therefore, important to understand the readiness and the level of awareness available to the psychosocial workers (psychologists, social workers, volunteers and also the first contact the nurses) on psychosocial issues in hemophilia and how to deal with them. This is possible to achieve through providing training to the group of psychosocial workers at various places.

The new century has brought along considerable breakthroughs in the treatment of hemophilia, and as a result person with hemophilia can now enjoy a better quality of life. Moreover, there is now a consensus on the need for additional support for hemophiliacs, a 'Comprehensive Care Treatment' that includes the well-being of the body and the mind of patients, their nuclear family and other relatives.

A great number of knowledge-enhancing experiences on how to deal with the psychosocial aspects of hemophilia have been developed. A review of literature on the psychosocial aspects of hemophilia covers the topics of psychosocial support for children and teenagers, education modules for hemophilia, family and sibling support, quality of life and support for the carrier.

Psychosocial aspects for children and teenagers with Hemophilia

As is well-known, hemophilia results in important physical, psychological and social changes in the lifestyle of the patient. Evidence of the psychosocial effects of hemophilia on young patients is shown in several of the works. Studies on anxiety symptoms on patients aged 7-16, carried out by Grana, (2004), Abali, Zulfikar, Kircelli, Karakoc, Gokturk, and Duman (2008) shows quality of life (QoL) is negatively affected by psychiatric symptoms (e.g., anxiety, depression, interfamilial stress) in children with hemophilia (CWH).

The work of St-Louis and Rivard (2008) in Canada shows that parents' transmission of knowledge of the disorder to their children is erroneous. They suggest teaching and assessing knowledge should be part of pediatric hemophilia treatments given by the professional psychosocial worker to adolescents before transferring them to adult programs, especially considering they should be aware on personal management and coping with their bleeding disorder.

Impacts of bodily changes are very important among young Hemophilics. Balcells and Grases (2006) found that arms and ankles are the important body parts that young hemophilics are more sensitive, as a deformity in such parts affects the self image of the child.

On the treatment side, social interaction in camps with children has been tested with positive outcomes in the studies of Diaz et al (2008) in El Salvador and Sholten and De Bruin (2008) in The Netherlands. Bottos et al. (2006) showed that teachers knowledge and positive approach to the disorder helped to promote and protect autonomy of children, without inhibiting their cognitive, affective and corporal evolution. Kaufman (2004) highlights the importance of an appropriate transition to adult care; as the chronic aspect of hemophilia has an impact on the changes in adolescents which many a time creates barriers to independence. Kaufman states these barriers can be overcome by addressing all areas of the young adult's life in treatment: education, sexuality, and understanding of hemophilia, friends and family.

Family support

Hemophilia affects patients and their families, the latter especially due to psychological, emotional, and financial burden that is involved in caring a person with hemophilia. Ortun et al. (2008) in a study on 31 families with CWH aged 3-7 corroborate these hardships and found significant percentage of surveyed families showed a low cohesion degree; and only few showed favourable adaptability to their condition.

Mohan (2006) highlighted the importance of family support in the treatment of Hemophilia. She analyzed strategies and their psychosocial implications, for providing support to families; concluding that family support as part of a "total care" program can significantly decrease stress and anxieties of families with hemophilia.

Beeton et al. (2004) found that parental commitment and efforts help in coping with hemophilia in early years. Grana(2006) states

that meeting other parents facilitates communication and reduce anxiety, thus positively modifying family dynamics and fostering healthy environment. Cancio Lopez (2006) concludes that degree of coping is significantly influenced by the acceptance of disease by the family and the way they promote autonomy and confidence.

Review of studies of Kermode (2008), Chuansumrit et al. (2004), and Huber et al. (2006) shows importance of multidisciplinary approach that has allowed families to form supportive relationships and empowered them to cope with the psychosocial needs. The importance of empowering parents is also highlighted in the programs of Cantini et al. (2008) and Merritt and Kuebler, (2008). They stressed the usefulness of training parents of CWH on issues like child development, dealing with feelings, behaviour management, parenting styles and parent/family communication to build their skills and confidence.

Education modules on hemophilia undertaken both in developing and developed countries range from the traditional to the innovative, yet all of them show valuable lessons to share when seeking for a comprehensive care of hemophilia. Traditional approaches like ROCK- a reach out centre for Kids in South Africa, educates and empowers Hemophilia community in the management of their condition. A similar program seeking to maximize QoL in the context of limited resources was developed by Beheshtipoor and Karimi (2006) in Iran.

To teach care on hemophilia and do emotional prophylaxis in families with poor or no school instruction Cassis et al (2004) developed a set of cards with different drawings, for low-educated parents of CWH in Brazil. These cards help parents memorize basic information like blood clotting, first cares, improving self-confidence and parents' participation in treatment. Aublin (2008) presents the use of booklets as a source of information.

Guillion (2006) and Sek et al. (2006) suggested summer camps for education on self-treatment for patients. Alternative modules of Education include the education of PWH but more importantly of professionals and university students from the health sector Puche et al (2008). Kuebler (2008), found the leadership-developing program with a group of twenty hemophilic patients aged 18-30 years has been successful in raising the confidence of patients and helping them achieve a normal quality of life. Music therapy as a means for younger hemophilia patients (aged 4 -15) has been explored by Grases (2006) in Spain.

The use of audio-visual mechanisms can provide great help for educating the hemophilic community, as shown by Dunn et al (2008) in Ireland, and Aubin et al. (2008) in Canada. The former presents the results of an educational DVD created to change the perception of hemophilia, by showing the treatment development of the last four decades. Similar projects include the work of Elander et al (2006), who designed a DVD at the London Metropolitan University, UK, which featured five PWH describing life with joint pain.

Finders-Binje (2006) presented an educational CD game developed in Belgium to teach and share information of hemophilia with patients aged 8-14. The CD game is an entertaining mechanism that uses funny ways to tackle major themes. Trelless et al (2006), Beardsley et al. (2006) present a software platform for synchronous distance learning that allows hemophilia students to be virtually present in the classroom with their peers and teacher, via the Internet.

Quality of Life (QoL)

Review of literature on QoL presents different approaches to assess the effects of hemophilia on the QoL. MacKensen and Federici (2006) found focus group discussions to be an important approach to assess patients' QoL and concluded that patients with different congenital bleeding disorders showed similar concerns and worries. Perez et al. (2006) assessed QoL using SF-36 in PWH in Argentina and found lower QoL in hemophilic population than in normal population.

Beeton et al. (2006) explore the QoL in the UK using a qualitative methodology and found patients had incorporated strategies to positively construct their lives around haemophilia. Hence, perceived results on QoL were good, despite physical limitations and psychosocial effects, as patients had changed their aspirations according to their condition. Finally, Hoorfar and Mobaraky (2006) use the standardize SF-36 questionnaire to evaluate the QoL of severe hemophilics and compare it to results for 50 healthy subjects, in Iran. They found patients have a self-perceived physical handicap but their emotional QoL is less affected.

Lopez (2006) focuses on the issue of depression, and shares the experience of psychological treatment carried out in Mexico with 271 patients, which found high degree of stress and anxiety due to the fear of frequent bleeding, lack of knowledge of parents to adapt to the illness, low scholar results, and functional limitations. Smajli (2004) shows a grim picture for PWH in developing countries, especially in times of conflict or post-conflict.

Mackensen and Bullinger (2004) developed a tool for assessing QoL for CWH (Haemo-QoL questionnaire) which was tested on 339 children in six EU countries for psychometric properties. The results showed younger children were more affected in the dimensions of family and treatment whereas older children had higher impairment in social dimensions like perceived support and friends. The Haemo-QoL questionnaire ratifies that QoL is dependent not only on clinical, but also on psychosocial characteristics. The exercise proved the validity of the Haemo-QoL for assessing QoL and it is ready for clinical research. Mercan et al. (2008) survey found QoL in physical health, feeling, sports-school and family was more impaired in Turkish patients than in the above mentioned multi-center European study.

Physical activity, as a way to enhance the QoL of Hemophilia patients was explored by Verones et al. (2008) in US and Nakadate et al. (2008) in Japan. It was found sport activities jointly with prophylaxis resulted in less bleeding episodes and higher self-esteem. They concluded sports activities can improve the emotional and social well-being of children, and therefore should become part of the global approach to hemophilia management. An additional study including social and sport activities, and FGDs on psychosocial impact of the disorder; was evaluated by Bos (2006). It was found that activities give good results in increasing self-esteem, physical performance and QoL in general.

Anderson et al. (2008) analyzed a rarely discussed topic, albeit being of the utmost importance: sexual intimacy in persons with bleeding disorders. Their work explored practical methods to assist persons with bleeding disorders to develop satisfying sexual intimacy and thus QoL. It concludes on the importance of honest communication between partners and the possibility of achieving a pleasurable sexual activity by making some medications in one's sexual practice. Additionally, authors state that a satisfying intimacy may help patients

feel more "normal" and in control of their life and disease.

Self treatment as a means to improve the QoL is presented by Lopatina et al. (2004). A study carried out by the Russian Hemophilia Centre analyzed subjective changes in the QoL in a group of 42 patients subject to home care for a 3-year period.

Psychosocial effects on the carrier

To be a carrier of hemophilia gene implies impaired self-esteem, psychological distress and problems regarding reproductive choices. This can be worsened in countries where socio-cultural constraints limit the role of women in society, as is the case especially in some developing countries. Al Sayyede (2006) found 60% of the carriers affirmed that the subject is considered taboo by their families and information is hidden to outsiders. The study concludes that being a Carrier in a developing country significantly impacts the QoL, therefore psychological and social support must be provided to cope with family pressures and social problems. Sohail (2004) presents a picture of the socio-cultural issues affecting carriers in Pakistan. She states that in a country with low awareness of hemophilia, the psycho-social effects on carriers are tremendous due to the impact of strong ethnic and religious influences and preconceived notions about the disorder. The situation is grim in the developing countries because the gender-based discrimination tends to be higher than in developed countries (Mohan, 2002).

Tedgard, and Mackensen (2008) explored how being a carrier influence the QoL. The researchers state that there is a need for considering a wider array of aspects than those currently analyzed, to adequately assess the situation of hemophilia carriers. Dunn et al (2008) survey in UK on 66 adult carriers and their couples showed the carrier perceives much greater prejudicial effects than the couple in terms of emotional well-being, family planning, lifestyle and carrier choices.

Cecchini et al. (2008), assessed the needs and concerns of carriers in Canada and came up with a booklet "All About Carriers - a Guide for Carriers of Hemophilia A or B"; addressing topics like inheritance of hemophilia, bleeding symptoms, treatment options, comprehensive care, carrier testing, diagnosis, and reproductive options.

Information gap in the existing literature

The preceding review of literature indicates that psychosocial support in hemophilia has many facets. Conceived as an important aspect of hemophilia care, psychosocial support has been treated as independent variable or as a mediating variable. Programs centring the person with hemophilia and their family are conceived and carried out in both developed and developing countries. Studies done on family support, educational models for parents and person with hemophilia, quality of life issues, and strategies on family dynamics etc are patient centric. No study has been undertaken on the other aspect of the psychosocial program which throws light on building the capacity of the psychosocial professionals, social workers, lay volunteers and nurses (being the first contact points) who provide the services to the patients.

Relevance of the study

Against the backdrop of current research on psychosocial support in hemophilia the present study is formulated to have an insight in to the existing knowledge of the psychosocial professional on the psychosocial care aspects.

There are two different foci of psychosocial support strategies. One is the importance of educating the patient and the family on the symptoms, proper care, family and community support and emotional effects, and other is building the capacity of the psychosocial care-givers. The strategy of supporting PWH and their family are influenced by a helping, nurturing and well being rationale Kinoshita (2008).

Capacity building and training of the care givers has rationale for equipping and updating the knowledge of health care provider (e.g. Psychologists, social workers and counselors) under the 'Comprehensive Care' Model. This seeks to develop and educate health care professionals (not only students but educators as well) who with a limited economic resources can provide counselling and therapeutic support to the PWHs, Cantini et al. (2004) and Aublin (2008). Efficiency and availability is often the guiding principle in providing, centring on a desire to use care-givers potential to the advantage of providing best supportive services.

No data is available on the effectiveness of the Psychosocial training programme which measured pre and post training responses of the psychosocial professional and volunteers, who are providing their services to PWH and their family.

The present researcher feels that this study is important for developing countries, because it hopes to establish the catalytic effects of trained psychosocial professionals and volunteers in 'Comprehensive Care' team and PWH and their family's transformation, especially, in controlling bleeds triggered by stress, which also can unburden the hemophilia families of emotional and negative feeling and may contribute towards better coping skills and life adjustments. It may provide indirect economic benefits in the form of spending on the anti-hemophilic factors due to lesser bleeds.

The effectiveness of the training program is a significant factor to study and see whether providing awareness on the information, knowledge and skills on the psychosocial support in hemophilia makes a difference in enhancing the knowledge of the psychosocial caregivers and thereby establishing effective provision of supportive services in the hemophilia care.

The present study is on the psychosocial care givers (psychologist, social workers, nurses and volunteers) with a specific focus in making them aware and train about the medical aspects, psychosocial issues in hemophilia and counseling skills in order to make them effective care providers. This will be the first study of its kind, to the best of the knowledge of this researcher, which will scientifically measure the pre and post awareness level of the psychologist, social workers and volunteers on the psychosocial issues in the hemophilia care.

The foregoing in view, the present study explores the care-givers knowledge and skills on medical and psychosocial issues in hemophilia pre and post participation in the training program conducted in four different north Indian States. The participants were assessed pre and post training on information, knowledge and skills, involved in the psychosocial problems and its management. The training program was also devised to cover various components which the psychosocial caregivers should understand before providing any psychosocial services to PWH and their families.

The study

As is known, that hemophilia affects the person both physically and mentally. Somehow, the mental aspect is given less importance in providing comprehensive care to person with hemophilia. This is

because of partly un-availability of the psychosocial workers in hemophilia and partly due to the little awareness among the existing psychosocial workers. The present study examines the pre and post changes in the awareness level of the psychosocial workers in Delhi, Uttar Pradesh, Bihar and Rajasthan.

Objectives of the study

The objectives of the study are as follows:

- To approach a cross-section of psychosocial workers and ascertain their views on the psychosocial support in hemophilia;
- To critically examine the views/perceptions of the psychosocial workers pre and post training workshop.
- To analyze the responses of the psychosocial workers about medical and psychosocial implications of hemophilia.
- To identify issues, emerging from empirical evidence, which could be utilized for preparing the guidelines for the psychosocial workers.

Method

This study assesses awareness of psychosocial issues in hemophilia among the care-givers/volunteers who are actively involved in providing counseling and supportive services.

Overall goal

The overall goal of the study is to administer the training programme to the psychosocial care-givers and assess their awareness on psychosocial issues in hemophilia and its management pre and post training.

Research design

The research design for the present study has been evolved in a way that it would facilitate the fulfillment of the objectives of the study. The overall plan of research has been prepared with a view to have a clear direction for the process of data collection and its analysis, in accordance with the objectives of the study.

In line with the above, methods of data collection have been selected and appropriate tools have been constructed, field-tested and finalized. The overall emphasis has been on developing an insight into the level of awareness among the psychosocial professionals/care-givers about hemophilia and mental problems emanating from it.

An extensive review of the psychosocial aspects, mental health and Hemophilia literature was conducted to identify instruments previously used to measure awareness level on psychosocial support aspect among the caregivers. The search was conducted on International psychosocial Abstracts, Medline (PubMed), PsycINFO, and Social Sciences Index databases. The investigator sought information from editorials, commentaries, abstract books of World Hemophilia Conferences and review articles in addition to reports of empirical studies to identify additional factors that might contribute to impact the mental health of person with Hemophilia.

The above procedures were instructive in generating an initial list of 100 item statements in six domains related to psychological, emotional and social support, supportive techniques and counselling and fact on Hemophilia. After the pre test a final questionnaire containing 70 items were finalised. The questionnaire was based upon the Guttman procedure of summated rating scale. The main domains of the final questionnaire on which the participants were assessed are as follows:

Hemophilia as an affliction

Chronic Illnesses such as hemophilia requires the psychosocial care giver possesses knowledge on the general medical aspect and its implications on the lives of the person with hemophilia. The study explores the respondents (psychologists, social workers, nurses and lay volunteers) information on the medical aspects of hemophilia.

Psychosocial support and its implication

The term Psycho Social Support, means a person is provided with emotional, behavioral and/or social support. This can be best understood in the context of providing comprehensive care to all persons with hemophilia. 'Comprehensive Care' implies the care for the body as well as the mind. Mind is a term related to the psychological aspects of a person that primarily include the feelings (emotions), thoughts, and behaviour. These are experienced and expressed in the context of a social setting, i.e. in relation to other people.

Role of psychosocial care-giver

There is diversity in the scope of psychosocial support services across the world through which help is offered to the persons with hemophilia and their families. In small number of countries, psychosocial support is seen as a priority in work with people in the hemophilia community. These are the countries which are more developed, where government supports the funding for psychosocial staff to work with the patients in a variety of capacities. In some other places the hemophilia foundations employ the professional psychologists, counselors or social workers provide and organize psychosocial support for the hemophilia community. They work within the 'comprehensive care' team as an important member of the team. In the developed world, the psychosocial workers may also be attached even to general hospital systems, hemophilia treatment centres or hematology wards.

According to Spillsbury (2006), the psychosocial workers in these countries provide interventions in many areas. These may be cognitive functioning, self esteem, loss and grief, anger management and communication skills. At times they may support connections to leisure and recreational activities, which contribute to a person's quality of life. They may provide advocacy in situation of discrimination, facilitate a person's involvement in the life of local community, and support the person through the transition of life. They may provide skilled genetic counseling, supporting individuals and couples through the process of family planning. Yet other may deal with areas of sexuality and relationship counseling, Peer relationships, women's issues and the impact of the disorder on the family. The boundaries of support are limited only by the mandate of the service and the worker's own personality, skills and the level of experience.

The psychosocial services can be provided by a professional counselor, social worker, psychologist or psychiatrist, whether voluntary or in paid capacity, while acknowledging the fact that other allied professionals might also provide valuable psychosocial support to families within the hemophilia community. Of all the members of the health care team, it is typically the psychosocial worker who is trained to break through this discomfort for the benefit of the person they are working within. The present research investigates the psychosocial care-givers awareness about their role in providing the supportive services to the PWH and their families.

The relevance of counselling

The lack of psychosocial staff with dedicated time to support families with inherited bleeding disorders means that issues of psychosocial concern are not addressed or fully explored. In a significant number of crisis situations in busy medical facilities, psychosocial support may not be provided at all. The focus of psychosocial work may include individual, couple, family or group support, counseling that aims to facilitate either change in the individual or change at the community level. The term is used to cover all forms of 'helping relationship' and ranges from individual counseling and psychotherapy, to community-based group work and research.

Coping mechanism

Depending upon the stages of child development and process of diagnosis and subsequent care, the person with hemophilia and their parents may experience a combination or mix of emotions. Coping with the emotions are very important for acceptance of the disorder. The study also finds out the respondent's awareness on skills involved in coping mechanisms used for dealing with the emotional aspects.

Social support

No family member escapes the impact of hemophilia; it is a pervasive factor within the family life. Holidays, special events, and vacations as well as daily life, are subject to descriptions because of the bleeding episodes. This causes certain conflicting feelings among the family members. The psychosocial support offered to the family as a unit and to individual family members as well as the PWH himself.

The present study is based on the pre and post test research design. The participants were first assessed about their knowledge, attitude and skills on psychosocial problems in hemophilia and treatment issues. They were then trained on the subject and after the training they were again administered the post test questionnaire to assess the retention of the knowledge.

Coverage

Universe and Sample: The universe of the study comprises of nurses, psychologists, social workers, and active hemophilia volunteers from various hemophilia societies, hospitals and universities who had previous experience in providing psychosocial care.

The sampling design has been so planned as to maximize the accuracy of the findings and to facilitate generalization. The study covered four north Indian states and six cities namely, Delhi, Patna in Bihar, Varanasi, Allahabad and Gorakhpur in Uttar Pradesh and Jaipur in Rajasthan.

This sample design provides for testing four groups of psychosocial professionals and their awareness level about the psychosocial problems occurring in person with hemophilia due to the chronic disorder. Keeping in view the probable background of participants, structured interview technique has been the choice for the collection of first-hand data. Towards this, a brief and focused interview schedule, having both close-ended and open-ended items, has been drafted, pre-tested, rendered into vernacular and canvassed.

Further, as per sampling design, information has been gathered from 352 participants (see Table 2.01).

Table 2.01: District-wise distribution of Participants.

Participants	District						Total
	Delhi	Patna	Allahabad	Varanasi	Jaipur	Gorakhpur	
Psychologist	5	34	8	38	16	20	121
Social Workers	22	-	2	50	-	-	74
Nursing	-	124	-	-	-	-	124
Lay Volunteers	6	-	9	-	10	8	33
Total	33	158	19	88	26	28	352

*Note: Out of 365, thirteen cases could not be classified.

First-hand data thus collected have been edited and entered into a computer-file, using the software SPSS. Subsequently, one-way and two-way statistical tables, with relevant statistical tests, have been prepared. A few diagrams have also been developed, so as to highlight underlying trends.

The profile of participants that emerges from the analyzed data is as interesting as it is revealing. Among them, 78 percent were females; their average age was 34 years; their educational level were quite high (Senior secondary, 23 percent; and graduation, 41 and post graduation is 36 percent); the participants professional were psychologists (35 percent), social workers (21 percent), Nursing (35 percent), and lay volunteers (9 percent); and their median income was Rs. 17,000 per month.

Instruments

Both quantitative and qualitative methods were used in the study. Following tools were used in the study. They were:

Questionnaire for Care-givers: For the purpose of eliciting the responses on the psychosocial care giving a questionnaire schedule was developed on the basis of Guttman summated rating scale. The questionnaire comprises of 70 items with 7 subsets.

Focus Group Discussions: Focus group discussions were carried out with the medical professionals, person with Hemophilia, parents groups, siblings, women group etc and established psychosocial workers. In all 10 FGDs were carried out in various cities.

Clinical Practice: Years of clinical practice and the range of emotional and social needs of person with Hemophilia and their family members also provided an insight to the researcher in construction of the questionnaire for the care-givers.

Data analysis and report

Prior to analysis, screening of each forms were done carefully. Both the pre test and post test forms were attached together for the easy data entry. Any forms which had missing 50% information were not entered in to the data-file.

Statistical package for Social Scientists (SPSS version 14.0) for windows was used to analyse the data. The purpose of the analysis was to describe the group participants and investigate the pre training and post training change in the participants following participation in the training Programme. Descriptive statistics were generated for demographic variables (including age, gender, socio-economic status, experience in care-giving and marital status) and for the dependent variables. Paired percentages were used to evaluate the impact of the training on the participant's knowledge from pre to post testing.

Findings

In order to have a better knowledge of the capacities and awareness of those responsible for the care of person with hemophilia (PWH) in India, and seeking to support those working for improving the quality

of life of patients coping with hemophilia, a assessment was carried out with 352 of psychosocial care-givers in India.

A training intervention was also imparted on these same topics, as-well-as a assessmentpre and post-training, to measure the effect of the training on raising awareness, and also to help determine how similar interventions should be carried out in the future.

The main findings drawn from examination of the responses provided both preand post training intervention are presented in accordance with the division of topics covered in the hemophilia psychosocial awareness questionnaire.

Awareness on role of care-givers

Respondents interviewed showed in general good awareness and knowledge on the role of care-givers to provide a comprehensive care to PWH. Majority of topics mentioned in this spectrum were defined as either "Important" or "Very Important", both pre and post training intervention. However, in some topics there were some significant changes after training: relatively high percentage of respondents went from considering these topics only as "important" to consider them as "Very Important"; as shown in the below table.

Table 3.01: Respondents Awareness on Role of Psychosocial Care-Givers in Hemophilia

When dealing with PWH*, how important is / what importance do you give to:	Important/ Some Importance		Very Important/ High Importance	
	Pre (%)	Post (%)	Pre (%)	Post (%)
Being attentive and respectful	25	13	65	82
Talk according to his/her age	43	19	48	74
Promote harmonious relations between PWH and his/her family	38	25	55	71
Summarize measures (at end of session) necessary to improve his/her situation	30	17	66	81
Assuage their condition has little to do with his/her thinking/behavior	41	22	55	73

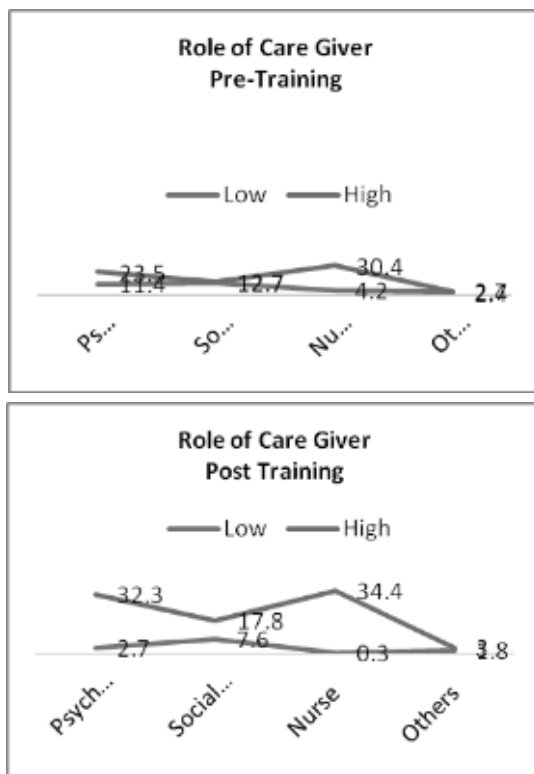
*PWH: Person with Hemophilia

Most considerable changes (percentage of people choosing "Very Important/High Importance" as their answer, pre and post training, are included between bracket) were in the topics of "treating PWH according to their age" (pre 48%, post 74%), "assuaging the patient that their condition has little to do with his/her thinking or behavior" (pre 55%, post 73%), and "being attentive and respectful towards a PWH" (pre 65 %, post 82 %). Other aspects that received a "High Importance" score pre-intervention, and therefore did not present significant change after training were those of "listening to feelings of PWH" (pre 83% - post 88%), "understanding/perceiving medical problems" (76% pre, 84% post), and "maintaining medical and psychosocial confidentiality" (74% pre, 78% post).

The findings suggests that, psychosocial professionals in India present good levels of awareness and knowledge on the role of care-givers (Pre training mean 26.42, SD 2.82 whereas post training mean 22.97 and SD 1.73). Notwithstanding this, their information and levels of awareness can be further strengthened with educational activities, such as the training intervention used in the present initiative. Apparently, the participants' views on the role of psychosocial care giver in the management of the disorder tend to be stronger with maturity and experience. This is reflected in both pre training and post training data quite clearly (pre training $X^2 = 9.247$; $df = 3$; $C = .17$; $p < .005$) and post training ($X^2 = 14.987$; $df = 3$; $C = .24$ $p < .001$).

Have the perceptions about caregiver' role in providing the psychosocial care has any linkage with the educational Background?

Diagram 3.01: Respondents Educational Background and Awareness on Role of Care Giver



A perusal of Diagram 3.01 would show that the opinion of the participants about caregivers' role significantly differs with their educational background. The relationship between the two is found to be weak pre training (rank correlation, $\tau = 0.133$; $p > .0001$) and post training (rank correlation, $\tau = .21$; $p < .0001$). Another interesting relationship is seen between the experience and the respondents' awareness and the role of psychosocial care-giving (pre training $X^2 = 9.000$; $df = 2$; $C = 0.447$; $p < .05$) as shown in table 3.02

Table 3.02: Respondents Experience and Awareness on the Role of Care-Giving in Hemophilia

Experience (in yrs)	Awareness on Role of Care-Giving		Total
	Low (15-22)	High (22-30)	
Small (1-5)	16.7	16.7	33.4
Medium (6-16)	5.6	27.7	33.3
Large (18-38)	0	33.3	33.3
	22.3	77.7	100

Awareness on social support

In regard to the subset, awareness on social support, findings from the pre training showed an incomplete clarity on this aspect (Pre training mean 13.37, SD 1.27 whereas post training mean 13.73 and SD 1.41), as majority of respondents did not take a definite stand, but instead went for the answer that was “in the middle” (i.e. “Some”). Examples of questions where the answer given was “Some” include : “PWH carry on schooling without difficulty” (69% pre, 65% post); “parents avoid discussing with each other/accepting they have a CWH” (73% pre, 68% post); “over-protection of parents leads to the CWH becoming increasingly dependent on them” (64% pre, 59% post); and “employers at workplace understand and help PWH overcome their occupational problems” (68% pre, 63% post).

Table 3.03: Respondents views on Social Support in Hemophilia

Persons with Hemophilia	Some		All	
	Pre (%)	Post (%)	Pre (%)	Post (%)
Are normal persons that can handle daily life activities at their own	72	50	26	47

As the table 3.03 suggests, the only topic under this subset that presented a significant change after training was that of PWH being able to handle daily life activities on their own; whose percentage of people responding “All” went from 26% pre-training to 47% post training. Interestingly enough, educational status of the respondents has a close linkage with their response on the issue of social support during pre training ($X^2 = 7.951$; $df = 3$; $C = 0.159$; $p < .05$) which was not significant in the case of post training.

Though these are issues on which it is difficult to have complete certainty on the situations that affect individuals with hemophilia; as there are many subjective elements that cannot be controlled and are difficult to define/determine; the high percentage of respondents choosing the answer “Some” in this topic, can lead to conclude that this is a matter on which an important degree of awareness and knowledge is required to be imparted on those responsible for the care of PWH, so that they can do a better job in improving the quality of life of the PWH in India.

Awareness on psychological implications

The topic of Psychosocial implications of Hemophilia was one where the training imparted was more fruitful, as a significant percentage of those surveyed went from manifesting no awareness on the topics at hand during pre-training (i.e. their answer was “Can't Say”), to taking a more definitive position (i.e. “Agree”, or “Disagree”) after training intervention; as shown in the table below:

Table 3.04: Respondents views on Awareness on Psychological Implications in Hemophilia

Can you agree on the following psychosocial implications of Hemophilia	Can't Say		Agree	
	Pre (%)	Post (%)	Pre (%)	Post (%)
Parents blame themselves for the affliction of their CWH*	37	9	34	79
CWH find it difficult to follow school routine and activities	24	5	53	81
For PWH it is difficult to move around, go to school or workplace	18	4	47	80
CWH often remain absent from School	24	7	56	80
PWH prefer to remain single throughout their life	40	17	29	49
PWH lack biological ability to have sexual relations or produce children	41	12	22	28

*CWH: Child with Hemophilia

All the items in this subset of questionnaire showed a remarkable change in the responses in before training and after training with the mean and SD for pre training was 21.63 and 3.61 respectively; whereas after training the mean and SD was 24.83 and 4.72. The linkage between the respondents views on the psychological Implications of hemophilia were closely related to the age and were found to be highly significant (pre training $X^2 = 29.040$; $df = 3$; $C = 0.293$; $p < .0001$) and post training (post training $X^2 = 20.816$; $df = 3$; $C = 0.254$; $p < .0001$).

Clearly the results of the survey show very low awareness on this topic, one of the most important in order to achieve a comprehensive care of PWH; yet the change in awareness witnessed after training illustrates that by providing adequate education and information, good results can be achieved, that will benefit PWH and their families, as well as those responsible for giving care to patients suffering from hemophilia.

Relevance of counselling

The respondents' awareness on Relevance of Counselling in providing psychosocial care in Hemophilia showed lower awareness before training than expected for professionals who are qualified to provide psychosocial services to the person with hemophilia, though not as low as compared to the subset psychological implications. Respondents presented high awareness on the relevance of counseling for particular issues but not for others for example "PWH would remain with feelings of hopelessness even when receiving counseling", where 48% of the respondents agreed to this statement (52% after training). Similarly, 30% of respondents agreed that contact and discussion would not help PWH if they are restless and suffer from anxiety in small matters (41% after training).

Table 3.05: Respondents views on Relevance of Counselling in Hemophilia

Can you agree on the following topics of the relevance of counseling a PWH?	Can't Say		Agree	
	Pre (%)	Post (%)	Pre (%)	Post (%)
Counselling or not, PWH remain with feelings of hopelessness	22	8	48	52
PWH keep away from others and become lonely	28	9	32	57
Recounting medical/ psychosocial conditions of other PWHs is important for counselling	23	8	73	88
Parents of CWH remain doubtful about effectiveness of treatment	26	13	64	78

However, counseling was also considered as relevant, as seen by answers provided to the questions: "If a patient suffering from hemophilia get irritable and angry, counseling would help" (66% answered "A great deal", 77% after training); "recounting medical/psychosocial conditions of other PWH is important for counselling" (73% answered "A great deal", 88% after training); "counselling helps PWH, if they do not have restful and adequate sleep" (54% answered "A great deal", 69% after training).

Apart from the above, other subjects in which training intervention considerably increased the awareness of the respondents were "PWH keep themselves away from others and become lonely" (32% responded "Agree" before training, 57% after

training); and "parents of a CWH remain doubtful about effectiveness of treatment" (64% responded "Agree" before training, 78% after training).

The contradictory answers and incomplete knowledge strengthen the need of updating the knowledge, and making professionals more aware on the need of counseling and its importance as well as the training on the skills involved in providing counseling to the PWHs and their families. The respondents age and the awareness on relevance of counseling is found to be significant during the pre training (pre training $X^2 = 8.493$; $df = 3$; $C = 0.164$; $p < .05$)

Awareness on coping mechanisms

The participants responses on the various coping mechanisms to deal with the stress related to hemophilia presented medium level of awareness, before training intervention. However, lower awareness was present especially in the matter of undertaking physical activities as a mechanism to cope with hemophilia, as shown in the three first rows in the table 3.06, where significant percentage of respondents answered "Can't Say" when asked about the benefits or hurdles of different physical activities as a coping mechanism for PWH. This is reflected in the pre training mean 18.83 and SD 2.82 and post training mean 20.46 and SD 2.39. After training intervention the awareness level of the people interviewed was significantly improved, as shown in the table 3.06.

Table 3.06: Respondents views on Coping Mechanisms in Hemophilia

Can you agree on the following Statements on coping mechanisms for a PWH?	Can't Say		Agree	
	Pre (%)	Post (%)	Pre (%)	Post (%)
For improving fitness of PWH, daily exercise is waste of time	18	4	27	28
For PWH, swimming is Injurious and risky.	35	7	44	49
They must keep away from outdoor games (cricket, foot-ball, etc.)	24	6	55	78
It is good for PWH to or limit their day-to-day activities.	21	8	45	65

Another important point arising from the survey is the incomplete knowledge on the importance of PWH to be informed about their disorder, as a mechanism to cope with the effects of hemophilia. In the pre-training, 22% of respondents agreed on this not being important, and similarly 32% agreed on this matter after training. This is a point that must raise concern, since for an improved quality of life and better coping with hemophilia, it is important for patients to be aware about their condition and its implications. The linkage between the respondents awareness on the coping mechanism employed by the person with hemophilia in managing the disorder were closely related to the age and were found to be highly significant during pre training ($X^2 = 40.212$; $df = 3$; $C = 0.338$; $p < .0001$), which shows that understanding on certain psychosocial concepts clears with increasing age, as shown in diagram 3.06.

Apart from the points raised above, other questions in which the training produced relative change after training were "PWH always require professional help, as they cannot develop skills for managing their medical/psychosocial problems" (pre 61%, post 75%); and "circumstances of PWH do not allow setting of goals for their daily life, and improve their condition" (pre 47%, post 65%).

The above findings suggests, that psychosocial professionals in India, present medium levels of awareness on the coping mechanism to be adopted by the patients to deal with their condition. However, two points that are both useful and important; such as physical activities (due to its capacity to improve the quality of life , yet also having a risk factor involved due to the physical effects of hemophilia on the person) and information, must be emphasized in future activities of sharing information and capacity building of psychosocial care-givers in India.

Awareness of Hemophilia as an affliction

Hemophilia is a bleeding disorder and not many physicians are aware about its implications and more so in the case of allied health professionals. The findings were mixed in regard to the awareness of the participants who were allied health professionals imparting psychosocial care to person with hemophilia, as can be seen in pre training mean 27.66 and SD 2.79 and post training mean 30.21 and SD 2.61.

The respondents presented good awareness that was further enhanced with training in the topics of percentage of respondents that answered “Yes” before and after training “PWH have excessive bleeding as they lack clotting factor in their blood” (pre% 78, post 94%); and “when anti-biotic does not work, patients need blood clotting drugs” (pre% 63, post 85%).

Table 3.07: Respondents Awareness on Hemophilia as an Affliction

State your knowledge on the following statements on Hemophilia as an affliction	Can't Say		Yes	
	Pre (%)	Post (%)	Pre (%)	Post (%)
The disease is passed from parents to children	21	3	46	95
PWH have excessive bleeding as they lack clotting factor in their blood.	18	3	78	94
Blood clotting deficiency in PWH is uniform from patient to patient	43	12	30	28
When anti-biotic does not work, patients need blood clotting drugs	31	8	63	85
PWH can be trained to do home therapy, like self-infusion	30	5	54	90
For small bleeds, cold fomentation (ice-packs) helps	33	4	8	93

Very low awareness was found in other important topics regarding hemophilia; and subsequently after training intervention some of these questions presented the most significant and positive changes in the awareness of respondents for the entire survey. These topics were, “The disease is passed from parents to children” (pre 46%, post 95%); “PWH can be trained to do home therapy, like self-infusion” (pre 54%, post 90%); and “for small bleeds, a measure like cold fomentation (ice-packs) helps” (pre 8%, post 93%).

Low awareness was also found in the questions “In human blood, how many factors are there that help in clotting it”, which was answered correctly (i.e. “ten by only 40% of respondents before training and 85% after training; and “for the treatment of PWH, what are the safe blood products”, to which the correct answer (i.e. “Recombinant”) was given by only 26% of people before raining and 61% after training.

Although there were mixed results in the level of awareness found in this topic, it is important to highlight the low awareness on basic facts of hemophilia (i.e. it is passed from parents to children); and in measures of treatment to improve the condition of PWH and their quality of life (i.e. home therapy, use of ice-packs). However, the training imparted allowed for increasing awareness on these topics to very high levels, therefore showing that these topics should not be taken for granted when carrying out activities of education and capacity building of the psychosocial or allied health professionals.

Discussion

Hemophilia is a chronic bleeding disorder that imposes lot of limitations on the individual suffering from it, but at the same time it provides an opportunity to bring about positive change in their personality through learning and self-awareness. This is represented in the form of psychosocial support which is also an integral part of the overall management of hemophilia.

Psychosocial support is based on a number of theories about people and the way in which they function. One such theory, which has been further developed in modern psychological circles, is Maslow's humanistic theory, hierarchy of needs that throws light on range of individual psychosocial needs. The hierarchy starts from the basic needs of food, shelter and clothing. Additional levels of needs that outlined by this well-accepted theory includes safety, social needs, self-esteem and self-actualization (Kiel, 1999). The goal of meeting these needs fits neatly with the role of psychosocial support.

People living with hemophilia also expect to develop autonomy and independence, a healthy personality and lead a better life. The issues of concern that affect healthy functioning includes, pain and immobility, financial constraints, employment problems, relationship difficulties etc. Some of the community related problems that occur are stress, depression, poverty, housing and transport, ageing etc. This gap between the person and his environment is filled by the services of the psychosocial care-givers. Therefore, the role of psychosocial care-givers plays an important role in the management of hemophilia. This is also supported by the findings of the study as all the respondents significantly acknowledged the role of psychosocial care-givers in hemophilia.

The psychosocial care-givers primarily provides supportive services through addressing person's emotional and social needs in their situation, as opposed to medical and nursing needs. However, since nurses are the first contact in the hospital settings they are sometimes expected to provide the psychosocial support. Therefore, the present finding on the awareness of psychosocial care-giving all groups of respondents (psychologists, social workers, nurses and lay volunteers) were found to be significant, that is they were moderately aware on the psychosocial issues.

The findings showed that overall the psychosocial care-givers awareness improved post training on different subsets on the psychosocial awareness questionnaire. This indicates that regular education and updating of knowledge of the care-givers is important. The findings are supported by the studies of Bottos et al. (2006).

A close perusal of findings suggests that age and experience were closely related to the awareness on the psychosocial issues in Hemophilia. It was found that the young respondents' awareness significantly improved post training whereas there were moderate changes in the responses of the older participants.

The care-givers awareness significantly improved on the components like psychological implications of Hemophilia, coping mechanisms employed by the person with Hemophilia, awareness on relevance of counselling and awareness on Hemophilia as an affliction. There was a significant shift in the respondents' perceptions from the pre- training responses to the post- training responses. This emphatically points out that psychosocial worker skill in the area of management supports interdisciplinary collaboration within the local health settings.

The study was limited in many ways. Further research may profit if the study is extended across India and investigated in relation to different context along with dimensions. In fact, although being an important component in the hemophilia care, psychosocial support has only recently being recognized in India. The present awareness scale can be further studied and tested in more centres in order to establish it as a Hemophilia Psychosocial Awareness Scale.

Acknowledgments

Ms. Richa Mohan is the recipient of a Caregiver's Education Award from Bayer Healthcare Pharmaceuticals and the Hemophilia Awards Program. The author acknowledges Prof. M. Z. Khan for valuable discussions and reviewing the manuscript.

References

- Abali, O., Zulfikar, B., Kircelli, F., Karakoc, S., Gokurk, U., & Duman, M., (2008) The assessment of anxiety symptoms and parent attitude in children with hemophilia. *Haemophilia* 14(2), 166
- Al Sayyedah, A., (2006) Social issues for carriers in developing countries case of Jordan. *Haemophilia* 12 (2), 145
- Anderson, A., Kuebler, E., & Zappa, S., (2008) Promoting sexual intimacy in person's with bleeding disorders. *Haemophilia* 14(2), 38
- Antunes, S.V., Marquez de Aquino, B., & Lupinacci, F.L., (2004) Evaluation of Haemophiliacs' QoL perception through the WHOQOL BREF. *Haemophilia*. 10 (3), 120.
- Aubin, N., Amesse, C., Meilleur, C., Baillargeon, L., Derome, F., & Godbout, J., (2008) New innovative patient information booklets on rare bleeding disorders. *Haemophilia* 14(2), 46
- Bacher & Lysgaard, D., (2004) Improved quality of life documented by two identical surveys at 10-year intervals in persons with haemophilia in Denmark. *Haemophilia* 10 (3), 94.
- Beeton, K., Neal, D., Brown, S., & Lee, C., (2004) An evaluation of quality of life for parents of children with severe haemophilia. *Haemophilia*. 10 (3), 117.
- Beeton, K., Neal, D., Watson, T., & Lee, C., (2006) So what's the problem? Constructing life positively around Haemophilia. *Haemophilia* 12 (2), 121
- Beheshtipour, N., & Karimi, M., (2006) Home treatment in Iranian patients with hemophilia. *Haemophilia* 12 (2), 38
- Bos, R., (2006) Good Haemophilia QoL results: the real life! objective facts subjective experiences. *Haemophilia* 12 (2), 122
- Cancio, L., (2006) Family dynamics hemophilia at home. *Haemophilia* 12 (2), 114
- Cantini, M., Zappa, S., Kuebler, E., & Desrosiers, M., (2004) Educating rural health care professionals in Central America about bleeding disorders. *Haemophilia*. 10 (3), 34.
- Cantini, M., Ramirez, E., Murillo, A., & Kuebler, E., (2008) Parents empowering parents in El Salvador. *Haemophilia* 14(2), 71
- Cassis, F., Santos, V., Damico, A.E., Villaca, P.R., & Chamone, D.A.F., (2004) In families with poor or no school instruction: how to teach hemophilia and do emotional prophylaxis? *Haemophilia*. 10 (3), 121.
- Cassis, F.Y., Villaca, P., Damico, E., & Santos, V., (2006) Flash cards: an interactive and educational tool for people with hemophilia, family and care agents. *Haemophilia* 12 (2), 38
- Cecchini, C., Stewart, P., & Page, D., (2008) All about carriers: a Guide for carriers of factor VIII and factor IX hemophilia. *Haemophilia* 14(2), 217
- Chuanumrit, A., Kuhathong, K., Suebsangad, A., Chantarukha, R., Wongwerawattanakoon, P., & Isarangkura, P., (2004) Education for patients and families with haemophilia and family members in developing countries. *Haemophilia*. 10 (3), 94.
- Dunn, N., (2008) How does being a carrier affect women and their partners: experience in the UK. *Haemophilia* 14(2), 68
- Dunn, N., Miller, R., & Griffioen, A., (2008) Changing perception of haemophilia using a DVD. *Haemophilia* 14(2), 45
- Elander, J., Robinson, G., & Morris, J., (2006) Coping with hemophilia joint pain: Evaluation of a theory-based, patient-centered DVD intervention. *Haemophilia* 12 (2), 37
- Finders-Binje, P. (2006) The educational CD briefly. *Haemophilia* 12 (2), 38-39
- Fondanesche, C. & Schved, J.F., (2004) Evaluation of the benefits of physical training in haemophiliac patients in a wide spectrum of sports activities. *Haemophilia* 10 (3), 95.
- Gagliano, F., Accomando, S., & Mancuso, G. (2004) Home care and auto infusion in pediatric haemophiliac patients. *Haemophilia* 10 (3), 35.
- Gonzalez, R., & Fung, E., (2006) Siblings of children with bleeding disorders speak up. *Haemophilia* 12 (2), 116.
- Grana, S., (2004) Workshops with adolescents. *Haemophilia*. 10 (3), 95.
- Grana, S., (2004) Haemophilia and its impact in family dynamics and quality of life. *Haemophilia*. 10 (3), 122.
- Grases, S., (2006) Haemophilia & music therapy. *Haemophilia* 12 (2), 37-38
- Guillion, P., (2006) Summer camps for educational program of self-treatment in Caen haemophilia centre. *Haemophilia* 12 (2), 37
- Hoorfar, H., & Mobaraky, G., (2006) Quality of life in severe Haemophilia in Esfahan. *Haemophilia* 12 (2), 121
- Huber, H., Partin-Welch, P., Van Loon, R., Guuppo, R., & Robinson, N., (2006) Families and providers leading the way: a model for meeting the psychosocial needs for families. *Haemophilia* 12 (2), 117
- Javier, B., Helena, G., Eduardo, R., & Carola, D., (2008) Haemophilia carriers: analysis of psychological variables. *Haemophilia* 14(2), 256.
- Kaufman, M., (2004) Transition to adult care: barriers to independence for young men with hemophilia. *Haemophilia*. 10 (3), 118.
- Kinoshita, M., (2008) The importance of various educational materials that support total care for hemophiliacs. *Haemophilia* 14(2), 48
- Keubler, E., (2008) Peru leadership program: rising up and taking charge. *Haemophilia* 14(2), 41
- Kuhathong, K., Wongwerattanakoon, P. & Chunansumrit, A., (2006) A package for teaching home care treatment for Thai hemophiliacs. *Haemophilia* 12 (2), 39
- Lopatina, E.G., Plyushch, O.P., & Kopylov, K.G., (2004) Change of quality of life in patients with hemophilia on home treatment. *Haemophilia* 10 (3), 117.
- Lopez, R. (2006) The depression in the haemophilia. *Haemophilia* 12 (2), 121
- MacKensen, S.V., & Federici, A., (2006) Quality of Life in patients with haemophilia and von willebrand disease. *Haemophilia* 12 (2), 121
- Mercan, A., Sarper, N., Mercan, H., Zengin, E., Etiler, N., & Goumlkalp, A., (2008) Hemophilia specific quality of life index (haemo-qol questionnaire) of children and adults: results of a single center from Turkey. *Haemophilia* 14(2), 200
- Merritt, D. & Kuebler, E., (2008) Mentoring the parents empowering parents (PEP) program to success: developing a mentoring component to parents empowering parents program. *Haemophilia* 14(2), 40
- Mackensen, S.V. & Bullinger, M., (2004) The Haemo-QoL assessment measure for children and adolescents. *Haemophilia*. 10 (3), 117.
- Mohan, R., (2002) Analysis of Carrier Situation in India, Hemophilia (2002), 8 240-242
- Mohan, R., (2006) Towards care & support to the families with hemophilia-An Indian perspective. *Haemophilia*, 12 (2), 111
- Nakadate, H., Ishii, M., Furukawa, S., Kaida, M., Ishii, S. & Ohnuki, T., (2008) Enhancing QOL for the hemophilic children through the sports activities with prophylaxis. *Haemophilia* 14(2), 793.
- Ortuno, A.A., Puche, J., Sabatel, R., Alvarez, M., Moreno, M. & Munuera, J., (2008) Perception of disease in young people affected by Haemophilia and its influence on quality of life. *Haemophilia* 14(2), 203
- Puche, J., Ortuno, A. A., Garcia, A., Galiano, I., Moreno, M. & Moreno, G., (2008) Training courses on haemophilia for professionals and university students. *Haemophilia* 14(2), 121
- Rayner, B. & Cruickshank, A-L., (2008) ROCK Reach out centre for kids: the South African hemophilia foundation intervention. *Haemophilia* 14(2), 38
- Rotinov, M., (2008) Psychoeducation and quality of life in hemophilic patients and their relatives. *Haemophilia* 14(2), 200
- Satti, M., (2008) Limited resources, unlimited efforts: healthcare models in developing countries patient education. *Haemophilia* 14(2), 81
- Sched, J., (2006) The benefits of soccer for people with deficiency of coagulation. *Haemophilia* 12 (2), 130
- Sek, J., (2006) An evaluation of organized camp experience for children and youth with inherited bleeding disorders. *Haemophilia* 12 (2), 119
- Smajli, A., (2004) Global view of patient self-determination developing country perspective. *Haemophilia*. 10 (3), 29.
- Sohail, S. (2004) Sociocultural issues affecting a woman related to person with hemophilia in Pakistan. *Haemophilia* 10 (3), 119
- St-Louis & Rivard (2008) Adolescents with haemophilia need a better understanding of their disease. *Haemophilia* 14(2), 146
- Tedgard, U. & Von Mackensen, S. (2008) Being a carrier of haemophilia How does it influence quality of life? *Haemophilia* 14(2), 208