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PSYCHOSOCIAL CARE FOR PEOPLE WITH HEMOPHILIA

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PSYCHOSOCIAL CARE FOR PEOPLE WITH HEMOPHILIA

Introduction

Psychosocial support is an integral part of comprehensive care for people with hemophilia. Beyond the medical condition, individuals with hemophilia commonly face several psychosocial challenges. Social workers, psychologists, and counselors play a crucial role in helping people with hemophilia and their families adapt and learn to cope with their new reality, and to live with hemophilia day-to-day.

It is possible to have hemophilia and still live a full life, even for those who face many social and economic challenges. However, medical treatment does not automatically translate into a better quality of life. Beyond medical treatment, the responsibilities of the hemophilia treatment centre (HTC) include educating families about how to manage hemophilia and helping them find interventions for psychosocial issues.

This monograph aims to shed light on some of the psychosocial issues encountered by people living with hemophilia, and guide healthcare professionals in the interventions and support that can be provided. It is the author's wish to share her clinical experience and to describe how a psychologist can work in an HTC with caregivers and people living with hemophilia.

This monograph is intended for all healthcare professionals who may be involved in supporting patients from a psychosocial perspective. This may vary among treatment centres and countries.

Psychosocial aspect of comprehensive case

Psychologists, social workers, and counselors have different expertise and strengths. In HTCs with the resources for a multidisciplinary team, there are individual staff members who specialize in these areas. However, in centres with limited resources, other healthcare professionals may be the ones to provide psychosocial support. Regardless of the resources available, all HTC healthcare professionals should be aware of the psychosocial issues that may arise with hemophilia and other bleeding disorders.

Therefore, this monograph does not differentiate between psychologists, social workers, and psychotherapists in general but also considers the nursing staff and doctors who work in HTCs and often take on the task of providing psychosocial support.

To provide optimal care, healthcare professionals need to be able to identify issues and challenges related to having a bleeding disorder that may be affecting their patients' cognitive and emotional development, as well as their occupational state and social life.

A bleeding disorder is a chronic condition that imposes limitations, but it can also represent an opportunity to bring about positive change through learning and self-awareness.

There are different ways of experiencing and coping with pain and chronic illness. Some people with hemophilia may focus on the emotional challenges, while others find ways to better cope with their situation. Short-term psychotherapy, alternative therapies, and social services can help individuals with hemophilia cope with symptoms and limitations, and develop a healthy sense of self. Supporting and guiding families (parents, siblings, and spouses) is an important task for the psychosocial team to maximize the family's ability to help the person with the bleeding disorder, and to improve their own quality of life as they live with the person with hemophilia.

The role of psychosocial support

Psychosocial support in the medical setting helps individuals gain a personal understanding of hemophilia. Healthcare professionals provide psychosocial support by helping patients and their families develop strategies to cope with physical, mental, emotional, and social challenges related to having a bleeding disorder. This includes

providing education, individual and family counseling, resources, and community referral services.

In psychosocial care, it is as important for healthcare professionals to learn from their patients as it is for them to provide guidance. Cultural values and socioeconomic factors affect how psychosocial issues are experienced and addressed. Other important issues for people with bleeding disorders include the HTC's accessibility, availability of factor replacement products and prophylactic therapy, access to physiotherapy and corrective surgery, and support from hemophilia associations.

Support for different stages of psychosocial development

Psychosocial functioning and well-being are often specific to age and cognitive development. Issues and stressors arise at different stages. These stages can be classified as:

- Infant to toddler (newborn to age 5);
- Early childhood (6-9 years);
- Pre-adolescence (10-13 years);
- Adolescence (14-17 years); and
- Adulthood (18 years and over) with its periods: young adult, maturing adult, and aging adult.

These age groupings, similar to those in child development literature, are based on the author's decades of clinical experience in guiding families living with hemophilia through the various phases of their child's development.

Infants and toddlers (birth to age 5)

Helping families deal with diagnosis

Two key questions that often arise early on with hemophilia are how to cope with the diagnosis and how to balance vigilance and overprotectiveness.

Couples who know of hemophilia in their family history can make an informed decision about whether or not to have a child that may inherit the hemophilia genetic mutation. In some countries, when there is a family history of hemophilia, genetic counseling is available to evaluate family medical records, determine whether testing is advisable, and help prospective parents understand test results and their options. Psychosocial support is significant for parents deciding to proceed with reproduction. In about one-third of hemophilia cases, there is no family history of the bleeding disorder.

The diagnosis of hemophilia can be traumatic because the idea of a bleeding disorder raises anxieties about danger and death. Most of the diagnoses are in a very traumatic situation – severe bleeding immediately after circumcision or the first severe injury of the child. Usually, it includes hospitalization in the Intensive Care Unit, and very often involves a misdiagnosis. Thus, most parents are in a state of shock or post-traumatic stress. The initial reactions of denial, anger, and sadness following a hemophilia diagnosis are well documented. The typical reaction of parents trying to search the internet for information often makes the situation even worse when they see pictures of disabled people with hemophilia from many years ago, before the use of factor replacement therapy.

Therefore, it is important to help families put the new diagnosis into perspective. After all, parents, especially mothers, may sometimes feel guilt at having passed on hemophilia to their children. If addressed early, the feeling of guilt will pass by creating a safe space to talk about it. It is important to highlight that not all mothers experience this feeling.

Other feelings include anxiety over access to treatment or cost of treatment, concern about venous access for the delivery of factor replacement, anxiety about family disruption and sibling rivalry over the attention spent on the child with hemophilia, and fears about treatment and care. However, it is important to remember, that these feelings are likely accompanied by positive emotions, such as the joy of having a new baby and the unique experience of being part of that child's emotional and physical development.

It is essential to watch for signs of difficult adjustments such as a parental rejection or distancing oneself from the child, blaming the father or mother, shame, or intense conflict in the family. With time and support from healthcare professionals, there can be acceptance.

It is also important for healthcare professionals to look out for persistent anxiety or signs of depression that may affect day-to-day life and family relationships; providing appropriate psychosocial support is essential.

CASE STUDY: PSYCHOSOCIAL SUPPORT FOLLOWING DIAGNOSIS

A little boy, aged 3 years, was brought to see me in my small office at the HTC in Sao Paulo, Brazil. His mother confessed that whenever they brought their son to the HTC either to be evaluated or for treatment, they felt frustrated and defeated by the realities of their son's diagnosis. This was their first session with a psychologist.

Building trust

Diagnosis is often first made at a hospital. The interactions in this setting shape the parents' and the child's initial impressions of the healthcare system, and the treatment and care available for hemophilia. The toddler's diagnosis of severe hemophilia B was a very traumatic experience for the family.

Doctors had taken a very long time to diagnose the bleeding disorder. With no known family history of hemophilia, the parents had to endure questions about domestic violence and child abuse. Not knowing what is wrong with one's child can be terribly difficult for parents.

Following diagnosis, it is important to help patients and their caregivers understand the services available at HTCs. The role of HTC professionals is to provide information and support, and sometimes to help restore a sense of balance to family dynamics affected by hemophilia. This includes building awareness of the range of medical and psychosocial services and support available early on, and cultivating trust in the HTC.

Counseling parents

Although the child was the primary patient, in the early sessions, I focused on the parents' emotional welfare and coping abilities. The mother needed to express her disappointment and frustration and learn to accept her son's chronic disease. The father showed great interest in learning about hemophilia. His need was to gain control by understanding the disorder and taking an active role, while the mother's need was to work through the emotions that made her feel helpless. It is important to help parents gradually accept that the diagnosis of hemophilia represents the beginning of a new and different awareness. Being a parent is always an adventure where we must be courageous to face whatever happens.

Counseling children

After addressing the parents' anxieties, I began to work with my young patient. The focus was his fear of treatment, especially of getting injections. This involved helping him understand, through play therapy and psychoeducation, basic facts about hemophilia and addressing his fear of pain. With time, someone with hemophilia learns when a bleed starts, how to treat it, and when it begins to heal.

After a year of weekly sessions, my young patient was at ease coming to the HTC. He came to understand that infusions may hurt a little but will help him heal better and faster. The child's mother learned how to administer clotting factor to her son and now does so at home. Eventually, the child will be able to enroll in a program on self-infusion for 4- and 5-year-old children.

Family dynamics

Hemophilia affects not just the individual but also the whole family. Siblings should be included in counseling sessions and given a basic understanding of hemophilia, and they should be able to express their feelings about their role and importance in the family. Their questions should be answered honestly and parents should be encouraged to do the same.

It is sometimes easier for parents to deal with the diagnosis in families with a known history of hemophilia. However, there can be challenges, such as generational differences and new developments in understanding hemophilia and its management. Past generations of children with hemophilia who did not have access to factor therapy were discouraged or prevented from participating in sports or supportive activities, and were often overprotected and somewhat isolated. Medical advances such as prophylaxis, and the availability of high-quality factor concentrates, have allowed people with hemophilia to be more active and live fuller and healthier lives, with physical activity and full insertion into society.

Support networks

Because hemophilia is a rare disease, parents often do not have the chance to find or meet other parents of a child with hemophilia. Parent should be encouraged to join support groups or hemophilia organizations where they can talk with other parents or caregivers affected by hemophilia about their concerns, and where children can meet others who have bleeding disorders. This way, they can exchange experiences, learn how to deal with their worries, and attend events (such as meetings and camps) where their children can meet other children with the same inherited bleeding disorder.

Vigilance vs. overprotection

Caution and injury prevention is important for people with hemophilia. However, it is important to distinguish between prevention and overprotection.

Parents should be counselled to encourage normal activities—certain risks must be taken for healthy development to take place. If toddlers are not allowed to crawl, walk, or run normally, they will become insecure and fearful, and possibly even more prone to injury because of lack of experience and muscle strength. Healthcare professionals can help parents and children learn the difference between normal and unnecessary risks.

Inactivity and overprotection can often bring on issues such as isolation due to poor social interaction and weight problems due to lack of exercise. The healthcare professional can guide parents on how to balance giving

CASE STUDY: OVERPROTECTION

Not long ago, I met a single mother in her early twenties, whose first child had been diagnosed with severe hemophilia A. The nurse at the centre had detected the mother's lack of knowledge about hemophilia and considerable anxiety about how to keep her son safe. The young mother's difficulty in learning was not because of cognitive limitations but due to high levels of anxiety and fear.

At our first session, she held her one-year-old baby tightly. Every time he tried to move around, touch an object, or venture even slightly beyond his range, his mother automatically held him closer. She was afraid of any new movements that he made. The child would usually stop moving at his mother's reaction but would then resume the behaviour of typically curious children.

Body language

The mother's reaction to try to protect her son from bumping his head, falling, or injuring himself was instinctive and natural. However, such constantly restrictive behaviour can be harmful.

Through body language, parents can unknowingly convey to the child a sense of what he can or cannot do. However, it is essential to remember that learning occurs in stages. For example: when learning to climb down from a sofa, the baby's feet and buttocks feel the contact with the floor. By sliding backwards, the little body's weight moves toward the firm floor. Parents should let the child discover and feel its body, while still helping the child feel safe.

When the child begins to walk, they can hold on to their parents' hands or the banister until they have mastered the movement on their own. If a parent routinely forbids activity, the child will have difficulty learning these skills and understanding the restrictions on their impulses and curiosity. Or if movement is always prohibited, the child can become very dependent on their caregiver or overly worried about being cautious.

The health professional can help parents assess when they are being overprotective of their child and correct the behaviour.

The goal is to help parents:

- Recognize their fears and discuss them;
- Be aware that parental influence on their children eventually diminishes and that the parents' role is to guide their child toward independence; and,
- Understand that overprotection may hinder the child's emotional, social, and physical development.

In this case, I counseled the mother for six months and worked on various everyday situations. Through roleplaying, she could express her feelings and anxieties, and realize how she was expressing them. By putting herself in other people's shoes, she could also see how others perceived her.

This gave her a better understanding of herself. My empathy for the challenges of hemophilia also helped her strengthen her self-esteem and confidence as a mother.

Different approaches will work for other individuals. Psychosocial staff can help parents develop an appropriate balance between giving their children autonomy and putting some limits on their impulses. Identifying issues and goals in advance, and encouraging parents to practice being firm, caring, and patient, is critical. For example, explaining: "Today you have played a lot and exercised your joints and muscles. Now your body needs to rest and recover. You can watch some TV, read, or paint, or we can do something together like cooking or gardening."

their child room to discover minor risk while also setting limitations.

Nowadays, many countries, including Brazil, offer prophylaxis treatment, which gives parents more peace of mind about letting their little ones play and run freely. Prophylaxis also helps protect the joints from future bleeding, leading to excellent psychomotor development.

Guiding parents toward sensible protection

In the early years, the use of protective measures and devices (such as elbow or knee padding) help protect joints from injury and bleeds. At the same time, a child must be able to feel their body, learn to trust their sensations, and learn how to best manage their movements.

Balance is key: in some situations, it can be a good idea to protect the joints to allow for further play while protecting against bleeding risks. For example, a family living in a home with concrete floors may be advised to protect their toddler's knees with padding when they crawl, or to install carpeting. Parents will have to make their own decisions about whether environments need to be adapted and whether to use padding, by weighing protection against the child's developmental and learning processes. In the author's centre, the social worker pays a visit to the parent's house to better understand the local conditions and guide parents adequately.

It is important to keep in mind that a child needs to be protected, but at the same time, they need to gradually learn how to become independent.

Strategies for the first years

- Help parents accept the diagnosis and understand that hemophilia is just one aspect of an individual's life.
- Counsel parents to react calmly. This will set a healthy response pattern, and will calm the child's fears and those of other family members. Overreaction to a bleed can cause the child to feel guilt and distress, which is harmful to developing a healthy self-image.
- Help parents move beyond emotional reactions to a practical mindset; invite them to explain in their words what hemophilia is, define prophylaxis treatment, etc.
- Encourage parents to develop confidence and coping strategies by learning as much as possible about their child's bleeding disorder, and about various treatments, and new techniques like gene therapy. Facilitate access to the multiple professionals who are available to families.
- Use colorful, fun pictures to teach various topics related to hemophilia.
- Introduce parents to the various online games and educational decks that national and international organizations, such as the World Federation of Hemophilia, have available for health professionals and people with bleeding disorders. (See the IN-HEMOACTION flashcards and memory game at www.wfh.org)
- Use dramatization, drawing, and roleplay techniques to bring out the child's feelings. By acting out and mixing various types of emotions, the patient can deal with their concerns and find solutions to overcome problems. Activities and stories should be tailored to suit each child's interests.
- Play make-believe to help the child lose their fear of being touched during a factor infusion in a peripheral vein or catheter, or even during a simple doctor's appointment, by playing the role of the patient who faces the situation and is brave while receiving medication.
- Use gentle pinching play to compare different types of pain, such as an infusion versus an insect bite, always keeping the mood playful and light.
- Use group psychotherapy for the children: encourage the toddlers to talk about infusions and factors, and invite every child to infuse their stuffed toy.

Goals for the first years

In the first years, it is very important for health professionals to:

- Provide the family with basic information about hemophilia, familiarize them with the services at the HTC, and ensure they know first-aid measures for treating a bleed;
- Help the family adapt to the fact that hemophilia is a lifelong chronic condition; and,
- Guide the development of the child's confidence in basic activities, such as crawling, walking, running, dancing, playing, etc.

Early childhood (ages 6 to 9)

The early childhood years are important for developing cognitive skills, social competence, and emotional health. At around the age of six years old, children begin to read and write, and are eager to learn and master new information. They begin to gain an understanding of themselves within the social context. Gradually, patient education and counseling can be directed more toward the child. The key focuses during early childhood are cognitive development and socialization.

Cognitive development

Social interactions are important to children's learning and cognitive development. At this stage, they develop important social skills through relationships with peers and family. They also gain a sense of mastery and self-awareness (understanding who they are). It is important to provide a supportive environment as they begin to develop self-confidence and self-esteem.

Guiding parents in teaching children

Psychosocial staff can help parents develop techniques to answer their child's difficult questions. Dialogue, the search for answers and good communication are very important to encourage children to remain optimistic and develop basic skills such as empathy, communication, self-discipline and the ability to listen.

Showing your child that you appreciate their efforts while they are receiving their treatments (such as prophylaxis, immunotolerance, or physical therapy) can also encourage them to take care of themselves. This is another aspect of their life, like participating in recreational activities or studying to one day become the professional they want to be.

Helping children accept hemophilia

Children with hemophilia do not want to be seen as different and want to be treated the same as their peers. At the same time, they need to understand that sometimes they will be patients, such as when there is a bleed and they need treatment, or when they need to rest to allow injuries to heal. We can teach them that they are not different, but rather that they are unique. It is important that, as patients, children continue to learn about their hemophilia and their bodies, and come to accept that they have a chronic condition for life.

It is important for healthcare professionals to continually re-evaluate the extent of the child's knowledge and ask them to review what they have already learned about hemophilia. This method, called "teach-back", helps assess the effectiveness of their teaching techniques and ensure that the material is well understood. It is worth emphasizing that the use of playful educational techniques with images facilitates learning.

Storytelling and imagery

Images and visual aids are very effective tools for teaching children about how blood functions and the clotting process. Storytelling, imagery, and comparisons to familiar concepts are also used to facilitate learning. For example, the clotting process can be explained as cells plugging a hole in a blood vessel, similar to plugging a sink to stop water from draining.

Another effective way to explain the coagulation process to children is to use a turtle to represent very slow healing. In the IN-HEMOACTION educational cards, the turtle also appears to be turbocharged, speeding up when it takes the replacement factor to complete good clotting.

Hemophilia involves an ongoing developmental process for parents and families. Ultimately, it is important that parents understand that children with hemophilia go through the same normal emotional and cognitive development as other children.

Socialization

Early socialization is important for children with chronic diseases. This will enable both the parents and the child to adjust more quickly to the challenges of school and social life.

Some children with hemophilia face integration problems at schools that have a lack of knowledge about chronic diseases. Other difficulties may also occur, such as missing school for health reasons, or feeling different when playing sports. However, social interactions that take place in early childhood help children develop self-confidence and a sense of belonging to a peer group. At the same time, they learn to interact with others, and their peers learn to help and care for their classmates with hemophilia.

Parents should be encouraged to take advantage of early opportunities for socialization, such as playing or sleeping

over with friends and participating in community events for children. All special activities, like school trips and camps, would also be encouraged.

Nonetheless, parents of a child with hemophilia can have some apprehensions as the school years begin. At the treatment centre in Sao Paulo, the pediatrician and nurse provide parents with an information manual about hemophilia, and a letter for the child's teacher and school director outlining key points such as:

- How the school can provide support to ensure that the child is able to engage in normal activities;
- Appropriate activities for children with hemophilia (this will depend on individual circumstances);
- What to do and who to contact when a bleed occurs; and,
- Risky activities and vulnerable areas of the body (e.g., head, abdomen).

Other interventions can include family members or HTC staff meeting with school staff and teachers, bringing important information to everyone. Group therapy involving others with hemophilia is an effective approach for counseling children in this age group.

Parents should also be encouraged to create opportunities for family and social interactions, which are important for building the child's self-confidence and sense of belonging to a circle of caring people, thereby feeling like he or she is living a normal life.

Psychosocial support for parents

It is important to help parents deal with their various emotions, reactions, and thoughts about hemophilia. One of the goals during the preadolescent phase is to teach children to deal with their hemophilia by gradually delegating more tasks to them. During this phase, children gain confidence as they take more and more part in their treatment, get to know their bodies better, and begin to trust their own ability to manage their hemophilia.

Informing schools about hemophilia

Whether, when and how much to disclose about a bleeding disorder is something that the family will have to manage. For some families, it is very important to keep the fact that the child has hemophilia private. Other families prefer to share the diagnosis with the broader family, friends, colleagues, and neighbors. The psychosocial HTC member/representative should determine the parents' views regarding sharing the diagnosis, and help the parents be aware of the source of their feelings and the consequences. After the parents makes the decision, they should communicate it to the child with hemophilia and their siblings. In early childhood, the child's exposure to new physical activities and potential risks at school makes it prudent to advise the school about hemophilia and bleeding tendencies. However, if the child is on prophylaxis treatment, he should be allowed to participate in sports class normally. If the child gets hurt (such as from falling), he should first receive first aid and then be observed to see whether he is healing normally (on prophylaxis, this should occur). When the child agrees or if he wants to share the private matter of having hemophilia with his classmates, the author's advice is to help him in the best way to explain to others what hemophilia is, including demonstrating the infusion in a way that they will see the child with hemophilia as a superhero.

As the years go by, children may make the decision to keep the information about hemophilia to themselves. Children entering puberty around the age of 10 usually don't like to talk about it with any of their classmates. However, the author always emphasizes that it is their right not to mention it, but that they should be able to clearly explain what hemophilia is, if needed. As they grow up, they will know more about hemophilia, and should be able to accept it.

The approach and degree of information conveyed can be reconsidered each year. It is not necessary for children with hemophilia or their teachers to make a special point of telling the class about their condition every year. However, it is certainly important for children with hemophilia to be able to explain their bruises or health issues that may cause them to miss school occasionally.

Families and school officials need to work out simple and practical solutions for schoolchildren with hemophilia. A "buddy system" with a classmate who lives nearby helps those who must miss school get the lessons needed and keep up by doing assignments at home. It is important that the children remain in contact with their school so that they feel that they belong and are members of their class even when if they are away for any reason. Flexibility helps—it is important to understand that children who miss school due to bleeding episodes may not be able to

CASE STUDY: BUILDING SOCIAL CONFIDENCE

The idea of starting school and learning how to read and write was very exciting for one of my patients with moderate hemophilia A, aged seven. His parents were also very happy, but at the same time his mother worried about leaving him alone with all the other big kids. My patient was overweight at the time, due to lack of exercise and the fact that his parents allowed him to overeat to compensate for his lack of freedom to run.

When I asked him for a self-portrait, he drew a whale. He was the butt of jokes by some of his peers and had difficulty interacting with them, oscillating between mistreating others and being teased because of his weight. He had two target joints and already had some complications. At the time, there was still no access to prophylaxis.

Each child has their own challenges. The psychosocial worker aims to promote self-confidence by discovering each patient's potential. My patient had a unique sense of humour and was also talented with games, computers, and drawing. I determined that working on these qualities would help him cope better with his body image and reduce his anxiety. At the same time, he needed to be encouraged to exercise and to be more physically fit. I also introduced him to other kids at the hospital who were all his age and who attended the same treatment centre.

The interaction and learning about other experiences with hemophilia helped him gain confidence in his capacities while also recognizing his limitations.

complete all the assignments covered during school days when they are absent.

Nowadays, if the family has access and learns how to do prophylaxis at home, the child has a good chance of not having bleedings or complications that prevent them from attending school.

Goals for early childhood: Basic information

- Encourage parents to provide children with basic information about hemophilia but not overwhelm them with too much at a time;
- Encourage parents to be guided by their child's questions and use learning opportunities that arise naturally;
- Provide parents with information and educational materials, and put them in touch with reliable resources and support groups within associations;
- Remind parents that gaining knowledge about the medical, technical, and emotional aspects of hemophilia is a very gradual learning process;
- Give parents phone numbers of HTCs and some treating professionals. Ensure that parents have a list of emergency phone numbers, as well as family members and friends who can offer support; and,
- Facilitate discussions with school officials about the child's hemophilia.

Childhood or pre-adolescence (ages 10 to 13)

One of the goals during the pre-adolescence stage is to teach children how to manage their hemophilia. During this stage, children gradually gain confidence in their treatment, their bodies, and their own ability to manage their condition.

Self-infusion

It is important to encourage children to take an active role in the treatment and management of their health. Doctors or nurses will not always know when patients are ready for self-infusion. A cognitive and psychological evaluation helps determine if the child is ready to take control of the situation.

A "semi-directed" interview (alternating basic questions with questions that pick up on interesting comments by the patient) can detect problems and difficulties the child might be having that would hinder their ability to take responsibility. Each age group has its own characteristics and goals to achieve, but there are always cases that will need our individualized attention to help them overcome the difficulties.

Peer identity

With or without hemophilia, pre-adolescence is a complex phase when the identification of the individual within the group becomes very significant. Fitting into a group and not looking different from the others becomes very

important, since at this age children want to feel equal and accepted.

Body image

Body image gains importance during pre-adolescence. Aside from changes in voice, weight, and height as puberty approaches, pre-adolescence is also when children grow most rapidly, and these growth spurts include changes in joints and muscles.

Physical (for example, a knee bigger than the other) or functional limitations (limping or using a walking device) experienced by those who did not have access to prophylaxis early on, can make children feel shy or embarrassed, and they may be teased by their peers. It is fundamental to maintain consultations with the physiotherapist who will provide adequate treatments to improve the child's musculoskeletal system.

The role of the psychosocial worker during this stage is to help patients deal with their feelings about their physical changes and learn to start taking responsibility for their own health. Children should be reminded that despite their hemophilia and the associated physical health problems, they are full human beings who just happen to have a bleeding disorder that can be very well managed.

Bullying

Pre-adolescence is a stage when boys and girls can come up with highly creative but sometimes hurtful nicknames, and children with hemophilia, like any others, may be called hurtful names. Psychosocial professionals can help children learn to view their condition with some levity and be better prepared to handle teasing.

Children cannot always avoid meeting people who tease or bully, but they can be taught how to respond to provocation and not to be afraid or intimidated by the bully. At the same time, it is important that they learn how to be firm about not getting into physical fights. It is critical that children with hemophilia learn how to take care of themselves and not put themselves at risk for bleeds.

Psychotherapeutic support groups for pre-adolescents and adolescents are usually very effective. It is very rare to find a child with hemophilia that has another child with hemophilia in the same school, which means they don't have an opportunity to talk, know, or share emotions and experiences with someone who has the same situation. During the support group meetings, they have an opportunity to share their experience and emotions (anxiety, embarrassment, shame, etc.). They also have a chance to learn from others' experiences and evaluate their reactions, so they will be better prepared to cope with having hemophilia.

Setting boundaries

During pre-adolescence, children begin to be less inclined to listen to their parents about their care and start to test their limits. The parents, the child, and the healthcare professional must work together to identify activities, and the degree of liberties and limitations the child can handle, taking into consideration their level of maturity, psychological readiness, and the benefits obtained.

Just as in the general population, some children with hemophilia will be more outgoing than others. For these children, it is harder to deal with physical limitations. However, during this phase, parents must be able to set limits for their children because pre-adolescents have not yet learned how to maturely handle their impulses and desires. There will be rebellion and disagreements with parents as children seek to gain independence and their parents' trust. Encourage parents to give their children space to grow, while being firm about boundaries.

It is important for parents to know that children may try to hide information to avoid getting in trouble. The child must be made to understand that going to the hospital is not a punishment, even if it sometimes provokes stress.

When parents show stress or fear, it is important that they make it clear that these emotions are not the child's fault. Such conflicts happen and must be addressed to foster the necessary changes and ensure good family development.

Goals for pre-adolescence: Self-confidence and responsibility

- Encourage children to take an active role in the management of their bleeding disorder;
- Encourage children to take responsibility for their health and avoid dangerous situations and risks;
- Help children deal with their feelings about physical changes and health issues; and,
- Identify degree of liberties and limitations for children, taking into consideration level of maturity and psychological disposition.

CASE STUDY: HIDING INJURIES TO AVOID STRESS

One of my patients with severe hemophilia A, aged 12, is the eldest of three brothers. The middle brother also has hemophilia but the youngest does not.

Recent years were very difficult for the family due to financial challenges. The father was unemployed, and the mother earned a very low salary. Living space had become very cramped with the birth of the third child and the arrival of an aunt from another province to help take care of the children.

I had worked with the eldest child since he was seven years old. He had always shown great interest in learning about hemophilia, and in activities such as playing, drawing, and painting. However, after two years of coming to the walk-in clinic, the family stopped because of financial problems.

This kind of interruption occurs frequently—distance, money, time, and transportation are all issues that can limit interactions with the psychotherapist. One year later, I received a call from the HTC nurse, who told me that the child and his mother had had a heated argument because he had not told anyone about a serious elbow injury for days. The bleeding into the joint of his left elbow resulted in severe joint limitation, and the right elbow was headed in the same direction.

As the eldest brother, he felt very guilty about having a bleed and did not feel comfortable telling his parents, who were already so distressed about the financial situation. It became necessary to intervene with the parents as well.

I went back to weekly sessions with the child and gradually he told me about his frustration over not having a quiet place to study or rest, away from the shouting and teasing of his little brothers. It was possible to work on his self-esteem, recalling his positive experiences with his little brothers, and to value his way of being intelligent and sensitive.

We also worked on the feeling of guilt, and it was possible for him to understand that it was not a justified or healthy emotion, since it hindered his health even more and could cause more worries for his parents.

Furthermore, he had a high pain tolerance, allowing him to endure pain for days without anyone taking notice of his discomfort. His reactions were clearly related to the day-to-day difficulties his family was experiencing. It was important to empathize with the parents, yet also convey that their feelings of powerlessness were affecting their son's attitude toward his hemophilia care.

Adolescence (ages 14 to 17)

Perceptions of age and what is normal at each stage can vary in different cultures. In some societies, children reach adulthood quickly, marrying early or working from a young age to help support their families. Adolescence quickly gives way to adulthood, which can result in limited educational opportunities. In other societies, there are very distinct pre-teen and teenage stages, marked by rites of passage that vary greatly from culture to culture.

Maturity and independence

Depending on the societal, economic, or cultural context, adolescents will mature in different ways and at different rates. For example, adolescent boys who have to be the main breadwinner due to cultural or socio-economic circumstances may not have the time or resources to properly treat their bleeds. In addition, they may not want employers to know about their hemophilia for fear of being seen as problematic, or losing their jobs.

Psychosocial support guides young people so that they know more and more about their hemophilia: knowing how to define the dysfunction and how to clearly and confidently explain how to treat themselves is very effective in the context of a job interview. In any case, the most important thing is to provide guidance on the importance of receiving the prophylaxis treatment as soon as possible, including other treatments such as physiotherapeutic rehabilitation, if necessary.

Obedience and adherence: The role of the multidisciplinary team

Adolescents may have a tendency to ignore or even deny bleeding episodes. At this stage, they are usually more focused on the present moment and may not consider future consequences of their actions. Adhering to a treatment, such as prophylaxis or physical therapy, may interfere with their routine and make them feel that they are not free to choose. To avoid this, it is very important that the multidisciplinary team reaches an agreement with the young adolescent so that they commit to adhering

to the treatment, taking into consideration their routine and favourite activities. By showing that the benefits of doing their part in the treatment include the guarantee of greater autonomy and freedom of action, the adolescent usually ends up happily collaborating.

If some adolescents have difficulties at home, the psychosocial service can intervene by helping the family understand the communication problems that arise. Psychosocial professionals usually meet with families to address issues related to the adolescence phase, which is a difficult phase for the parents themselves, as they realise that their children are no longer children. The gradual gaining of rights is accompanied by a growing assumption of responsibility and awareness of one's duties as a young person.

Transition of care

During adolescence, young people gradually learn that they will move from the pediatrician to the adult hematologist. At this stage, it is important to encourage autonomy and independence.

Education and career decisions

In the mid- to late-adolescent years, youth begin facing decisions about schooling and preparation for the job market. During this stage, they will need guidance to make choices about academic programs and vocational pursuits that will satisfy their goals, make good use of their talents, and, most importantly, not involve high risk situations that may lead to injuries or bleeds. It is important to explore various career opportunities with adolescents and realistically assess the possible physical risks that accompany each one.

Dating and sexuality

Dating begins during the adolescent years. Adolescents with hemophilia and other bleeding disorders may have concerns or may be hesitant about dating because of how they feel about themselves. Self-esteem issues, fears, and doubts can arise such as "Will disclosing that I have hemophilia be a reason to no longer be accepted as a partner?" Cultural and religious aspects can also interfere in being able to experience the body, mind, and sexuality more freely and with growing responsibility. These aspects must be considered when listening to adolescents. During the dating phase, the issue and the secret of having hemophilia is raised again. Some adolescents with hemophilia talk about and share what it is like living with hemophilia with their dating partner on the first meeting. Others keep it a secret for a long period, usually until they feel confident enough that the partner will not reject them due to having hemophilia.

An adolescent with hemophilia may be concerned that a partner not understand some limitations of having hemophilia. For example, the partner may resent it if some plans must be canceled at the last minute due to a medical emergency, or if the person with hemophilia is in pain and/or recovering from a bleeding episode for a few days. Topics related to human communication and relationships are addressed when psychosocial workers meet their young patients and parents.

Today, those who take prophylaxis enjoy much more peace of mind, since spontaneous bleeding no longer occurs, and it is possible to plan a very normal daily life. Even so, the role of psychosocial workers is to help these adolescents develop strategies to help them and their partners understand what hemophilia is. A good idea is, for example, to bring the partner to the HTC for a visit and a conversation.

HIV or HCV disclosure

Before the advent of viral inactivation techniques for blood products, it was very common for HIV/AIDS or hepatitis C (HCV) infections to occur through blood transfusions, or with the use of a blood derivative, such as cryoprecipitate or plasma clotting factors. In countries where viral inactivation is not available, transfusion infection remains a substantial risk. Nowadays, many countries have treatments that are safe with both plasma and recombinant factors.

People with hemophilia who have HIV and/or HCV often benefit from psychosocial support to help deal with the social stigma. Psychosocial staff can also provide important support and coping skills for both the physical and mental challenges of having HIV and/or HCV. This includes sexual education, family planning, preventive safety measures, and genetic counseling, all taking into consideration the individual's cultural and/or religious background. The psychosocial work involves encouraging communication techniques that favour interpersonal relationships and conflict management, as well as promoting self-knowledge.

CASE STUDY: DISCLOSURE WHEN DATING

A patient of mine in his twenties, with hemophilia A and HIV, had many fears about forming romantic relationships. He felt that he did not have the right to fall in love or encourage love and affection from women. He was bitter, pessimistic, and sarcastic most of the time—attitudes, in fact, that would make it difficult for anybody to meet people and make friends.

Counseling provided a non-judgmental venue where he learned to accept his condition in a more constructive way. A major issue was his fear of rejection. We talked about how it is important to get to know the person that one is dating before opening up about having HIV. Gradually, he learned that intimacy is something built slowly through effort and communication.

Our sessions helped him talk about sensitive health issues and practice sharing the information with others. He also learned that he does not have to embark on a serious relationship right away—other kinds and levels of intimacy in relationships are still valuable.

Goals for adolescence: Self-management and growing autonomy

- Emphasize to adolescents the importance of taking responsibility for their health;
- Encourage gradual autonomy, self-management in treatment and care, and independence;
- Guide adolescents toward academic and vocational pursuits that do not involve significant physical risk; and,
- Help patients through common adolescent challenges such as self-esteem issues and dating.

Adulthood (ages 18+)

Today, due to medical advances and the kind of comprehensive care available for people with hemophilia, the period of adult life is fortunately long. It is for this reason that the author will divide adulthood into subphases including, young adulthood (from ages 18 to 40), middle adulthood (from 40 to 60), and the aging adult (from 60 years onwards, or the "golden years").

Challenges for young adults (18–40)

As people with hemophilia move into adulthood, they find that their life often becomes more complex. Challenges appear on different fronts: work, interpersonal relationships, starting a family, separations, and financial stability.

In many countries, treatment costs are one of the main issues that patients face as they enter adulthood and lose coverage from family or government health insurance. In Brazil, treatment is offered free of charge at any age, which is a great advantage. The challenge in the country is to raise awareness and educate the population about hemophilia and its various treatments, in order to ensure optimal adherence to the proposed treatment.

Another issue that can interfere with a productive adult life is social isolation and depression, which can arise when one has a chronic condition accompanied by pain and limited mobility. Other risks include alcohol and drug use. Specific therapeutic interventions may then become necessary.

Job interviews and hemophilia disclosure

Everyone knows how important it is to convey a positive self-image at a job interview. Individuals with chronic medical conditions often face additional issues, including disclosure. Different countries have different rules about disclosure, and it is important that individuals be made aware of their civil rights and liberties. Some regions and countries have programs or legislation that give workplace protection to people with physical disabilities and/or chronic illnesses, which includes people with hemophilia.

The issue of whether to disclose hemophilia or another bleeding disorder at a job interview raises several considerations. Hemophilia is not contagious and puts no colleagues at risk. An individual who has moderate or mild hemophilia and almost never has to go to a centre for treatment, may choose not to disclose their condition. In any case, the most important thing a person can do is be prepared to clearly and safely explain what hemophilia is, if asked. They should be able to assure the interviewer that with proper treatment, such as prophylaxis, they can work normally without being absent or experiencing pain.

Therefore, preparing young people from an early age to clearly formulate what hemophilia is brings a tangible

result in adulthood: an individual who is self-assured and aware of their real potential and limitations.

Disclosure may be necessary if:

- There is a potential for absence from work due to a severe hemorrhagic episode;
- A person is not on home prophylaxis and must go to the hospital frequently for treatment; and/or,
- The job involves activities that could be risky for people with severe bleeding disorders.

In such cases, the job candidate can propose solutions such as working from home on days when there are bleeding episodes, sharing duties with co-workers, etc.

The working life phase and its challenges

Adults in various stages of life may face several challenges at work: medical certificates, health insurance coverage, as well as possible limitations in reconciling treatment (prophylaxis, return visits to the HTC, surgery, etc.) with their work routine. This varies from country to country.

A multidisciplinary approach is ideal to help adults with hemophilia deal with such issues and help them adhere to their treatments without impairing their productivity.

For example:

- A social worker can help prepare young adults for the job market by steering them toward training courses and scholarships.
- A psychologist can help individuals explore different career paths by discussing feasible job options and potential difficulties that may arise.
- A guidance counsellor can perform vocational tests and interviews. When patients accept their real potential and limitations, it helps them choose and live fulfilled lives as productive citizens.

Marriage and family planning

Couples may have serious concerns about having children if a family history of hemophilia is known. An international study on communication between couples, with the woman having hemophilia (whether she has symptoms or not) and prior knowledge of hemophilia, revealed that there are still major challenges in improving communication in relation to becoming pregnant with the first child. For the man who has hemophilia, revealing to his partner that he has a bleeding disorder is more natural than for a woman who has one. The fear of being rejected, of not being able to fully enjoy generating a life, falls more heavily on a woman's shoulders. Socio-cultural issues also have a great influence.

Even though genetic counseling and prenatal diagnostic tests are available today, they are not accessible to all, whether for financial or other reasons. The decision on whether to have children who may have hemophilia is a family decision. The role of the HTC is to provide a range of information and the necessary support to help all members of a family living with hemophilia to make informed decisions.

Social networks

The importance of personal support networks in adulthood cannot be overstated. Adulthood brings more and more responsibilities, including new challenges in the workplace, within the family or the family to be, and mobility problems if joints are seriously affected.

Support from family, friends, and psychosocial professionals are crucial to helping individuals face such challenges. HTC professionals can refer young adults to groups for adults with hemophilia or encourage the development of a new group.

It is important that patients with HIV and/or HCV are not trapped in victim stigma (even though thoughts of being victims and injustice may occur). The focus of therapy should be on psychosocial well-being and on helping people with hemophilia seek appropriate and interesting activities.

Goals for transition to adulthood: Independence

- Guide adults as they make the transition into adulthood and the workplace;
- Provide couples with information on the genetics of hemophilia and support to help them make informed decisions; and,
- Encourage patients to participate in social or support groups for people with hemophilia.

The golden years: Growing old with hemophilia

Nowadays, medical advances, prophylaxis, and a comprehensive approach to hemophilia make growing old with

CASE STUDY: MANAGING CHRONIC ILLNESS AND WORK

One of my adult patients is a 40-year-old man with severe hemophilia A. When he was 17 years old, he was also diagnosed with HIV.

At the time, he thought he was going to die. Since then, he survived many phases of the epidemic and underwent various treatments. This patient originally came to me for psychotherapy because he had also acquired HCV and felt he no longer had the strength to endure any more cycles of treatment for hepatitis.

The diagnosis of hepatitis a year earlier had been a big shock and he had already gone through six months of treatment with very painful side effects. Discovering that he could not cope with the side effects of the treatment was a second unpleasant surprise. The patient was taking antidepressants, but the medication alone was proving insufficient. He wanted to reassess other aspects of his life, such as relationships with people at work and at home. He also wanted to better understand his perception of life and death, spiritually.

Our therapy sessions were a safe and comfortable space where he could explore all these issues and develop the means to find solutions to his challenges. When working with people living with HIV/AIDS, psychosocial professionals must also be prepared to talk about very difficult and sometimes taboo subjects, such as sexuality, death, faith, and feelings like rejection, jealousy, and anger.

hemophilia possible. Ageing well now means also taking care of other aspects of health. Other diseases such as cardiovascular disease, diabetes, arthropathies, and depressive conditions may appear, and should be treated.

The ageing person may face fears including loss of independence, isolation, being a burden, and of losing financial independence. Psychotherapists and social workers help the person deal with issues such as death and illness, relational and sexual life, and how to fill their free time.

Depending on the culture and ethical values of each society, old age is experienced differently. It is also a phase of life in which one should enjoy calm and quiet, time with family, and a social life that brings the feeling of knowing one is loved and valued.

Although in certain countries, like Brazil, elderly patients are offered prophylaxis, some prefer to keep their treamtent dose at home and only use it in case there is suspected bleeding. It is always important to leave the dialogue open to reach an ideal situation.

A situation that occurs frequently starting from middle adult life, is the possibility of having a joint prosthesis fitted. Generally, orthopaedic surgeons and physiotherapists offer psychosocial support in researching the best approach with the patient. In addition, their collaboration in the pre- and post-operative phases is important for a successful surgery.

Socio-economic issues in some regions of the world

Proper diagnosis and registration challenges

In many countries, there are still no reliable tests that provide a secure diagnosis or mechanisms to identify and register people with hemophilia. The absence of tools and information makes the treatment of hemophilia a challenge, where even if diagnosis is available, resources are limited.

Lack of knowledge and information

Basic patient education is a major challenge in some parts of the world. In areas where education is not a universal commodity and where illiteracy rates are high, knowledge and understanding of hemophilia may be greatly reduced.

Not all doctors may be trained in how to treat hemophilia. In some countries, study materials may be scarce or outdated or treatment centres may be too far away for patients to make regular visits for treatment. Through psychoeducation, HCPs can deliver knowledge about hemophilia and treatments in an efficient way.

Access to the treatment centre

Some people and families living with hemophilia are forced to travel long distances to get medical treatment. Sometimes, it becomes almost impossible to offer help, except by pressuring authorities to provide ambulances. And often, there is not even access to factor replacement. Differences in treatment availability are still enormous.

Therefore, it so important to have a psychosocial worker onsite to provide support, and to empower families and children through psychoeducation.

Social stigmatization

In some cultures, people with inherited bleeding disorders may be stigmatized or even face difficulties in being accepted as capable and important members of the community. Social isolation may then be detrimental to their participation in society, to their psychological well-being and their quality of life.

Early entry into the labour market and violation of children's rights

In some societies and families, children already begin to work from pre-adolescence onwards. These children may be forced to engage in heavy manual labour and hazardous working conditions where the chances of serious bleeding or injury are high. Problems arising from this early entry into the labour market include increased danger of work-related accidents, lack of time to treat bleeding during work hours, and dropping out of the education system due to absenteeism.

The social worker can guide families so that they can protect their child in the best possible way. The social worker also has the right to intervene legally if the family willfully exposes the child to danger and moral abandonment. Guaranteeing the rights of the child is one of the main duties of the professionals in a hemophilia treatment centre.

Conclusion

People living with bleeding disorders live all over the world. The treatment of hemophilia A and B, as in all chronic disorders, requires an approach that considers the characteristics and available resources of each society.

Professionals dealing with psychosocial aspects in HTCs play a very important, and sometimes critical, role in the lives of their patients. Hemophilia can affect a person far beyond the physical challenges, and therefore, HTCs should have a multidisciplinary and holistic approach. Psychosocial professionals offer key tools to help patients better accept their hemophilia, actively participate in treatment and live a productive life with improved quality of life and dignity.

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