



Wellness in Persons with Bleeding Disorders

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OVERVIEW

This chapter is focused on wellness approaches that persons with bleeding disorders may adopt to promote their own health. In order to provide a framework for these issues, there are some constructs of wellness that will be highlighted. Western Culture is focused on illness and its presence or absence as a measure of health. Because health is difficult to measure, agencies that collect data or define health in the context of sickness or illness measure such things as infant mortality rates, risk of heart disease, and rate of AIDS and other communicable diseases. In the US, health measures and policy standards are set by The US Department of Health and Human Services' Healthy People, a program started in 1979 by the US Surgeon General (1) and released every decade to set objectives and provide science-based benchmarks to track and monitor progress in the health of the US population.

For the first time in the 3-decade history of Healthy People, the Healthy People 2020 objectives contain target measures for persons with bleeding disorders. These will help to encourage collaborations across sectors, guide individuals toward making informed health decisions, and measure the impact of prevention activities. For more information on these specific bleeding disorders objectives, please visit the website. (1) While the specific objectives for bleeding disorders are included for 2020, there are standard health-related topics that include nutrition and weight status, health-related quality of life, oral health, and physical activity objectives that affect all persons and are intended to promote the health of all individuals. These goals and objectives can help guide our approach to healthy living for our patients with bleeding disorders. The World Health Organization (WHO) defined health in its broader sense in 1946 as "health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity." (2,3) Although this definition has been subject to controversy, in particular as having a lack of operational value and the problem created by use of the word "complete," it remains the most enduring. Many persons feel that they should rely totally on their medical care providers to make decisions and that they are not part of their treatment plan. Thus the burden of responsibility for their health is shifted entirely to the medical profession. For more than 30 years, the goal of hemophilia treatment center (HTC) staff has been to help patients assume responsibility for their own health and to assist them in obtaining the tools to make this goal a reality.

This chapter attempts to define wellness as more than the absence of disease but rather as the whole constellation of human behaviors that contribute to the life of the individual. In helping patients work toward wellness, it is important to recognize the **multiple dimensions of wellness:** (4)

Social	Emotional
Occupational	Environmental
Spiritual	Financial

Physical
Intellectual

Mental
Medical

WELLNESS IN NURSING PRACTICE

Using the framework of wellness in nursing practice for the care of persons with bleeding disorders may be a difficult adjustment for some nurses who practice traditional nursing as the “expert.” However, helping patients make their own informed decisions will pay big dividends in the healthcare of these individuals. (5) At any given stage in life, health is determined by a combination of factors. To assist patients in maximizing their health, it is often beneficial for healthcare providers to look at the factors that influence their own personal health and help the patient identify issues that may impact the patient’s health. In addition to traditional Western medical therapies, many patients have pursued other methods of health promotion, health enhancement, and health treatment. These will be discussed in the final section of this chapter. To promote optimal wellness and health in our patients, it is helpful to understand the concepts associated with wellness.

DIMENSIONS OF WELLNESS

Assuming the premise that wellness is multidimensional along the constructs outlined above, the basic areas are described below, including specific issues related to persons with bleeding disorders.

1. Social Wellness -- this dimension of wellness relates to how an individual’s interdependence with others influences his/her well-being. Family functioning and support play a role in the health or wellness in this construct.

2. Occupational Wellness – this area relates to the life tasks or occupation in which an individual is engaged. For younger people, that may be school. This dimension relates to how one finds personal satisfaction and enrichment in work. While there are a significant number of patients with bleeding disorders who are not employed or under-employed (31.9%) compared to the US adult population, (6) personal gratification and contribution to the larger community can easily fit into an occupational wellness lifestyle.

3. Spiritual Wellness – this category include seeking meaning and purpose in one’s own existence and developing an appreciation of the life that exists. Some patients with bleeding disorders may identify how having hemophilia has led to an internal examination that may not always occur in persons that aren’t faced with barriers to a calm and peaceful existence. Spiritual feeling and experiences, not necessarily related to logic and critical thought but intuitive and subjective, can affect a person’s wellness. These may be religious in nature but can be a broader awareness of the larger world in multiple dimensions of time and space. The role of the nurse in exploring this area of a patient’s health and wellness is to assist him/her with identifying the spiritual factors in his/her life that are important and supportive to that individual. Referral to additional spiritual resources may be appropriate in some cases.

4. Physical Wellness – many people think of health and wellness within the dimension of physical existence. However, this construct is related to physical



activity, nutrition knowledge, and discouraging the use of tobacco, drugs and excessive alcohol consumption. In some adults with bleeding disorders who have arthritic joints and chronic pain, use of tobacco, drugs and alcohol may be a method of coping, but this could negatively impact other facets of this dimension of wellness.

5. Intellectual Wellness -- this dimension of wellness encourages creative, stimulating mental activities. If an individual is intellectually well, he or she will continue to expand his/her knowledge and utilize cultural and artistic endeavors to bring pleasure into his/her life.

6. Emotional Wellness – when one is emotionally well, that individual will be aware of and accept his/her internal feelings. The wellness state also allows acceptance of feelings of others and allows one to develop relationships based on trust and respect.

7. Environmental Wellness – Many people believe that it is important to lead a lifestyle that is respectful of our environment. This includes respecting nature and those species living in it. Many concerns Americans have about their health revolve around environmental health issues, such as air and water pollution, radiation, food additives/preservatives, and smoking. These can be divided into household, workplace, and community hazards. Households are the site of potential health dangers such as chemicals, lead, radon, cigarette smoke, and physical hazards. The nursing role is to realistically reinforce the public health messages on the dangers of these potential household problems.

8. Financial Wellness -- Financial wellness is having an understanding of one's financial situation and taking care of it in such a way that one is prepared for financial changes. Maintaining that balance consists of being comfortable with where money comes from and



where it is going. Specifically for persons with bleeding disorders when the treatment is very expensive, this dimension may present challenges. Often, the pursuit of a job with good insurance benefits can drive this dimension while creating imbalance in other dimensions of health and wellness.

9. Mental Wellness -- this dimension of wellness is hard to define but rather is defined by not having depression, anxiety, or other behaviors that prevent optimal functioning. In one study in persons with bleeding disorders, 32% experienced problems with anxiety and/or depression. (7) Although many adults do not fit snugly into descriptions of depression and anxiety, depressive symptoms and behaviors that identify anxiety are seen in many people. Depressive symptoms affect the quality of life. Individuals suffering with depression are not able to maintain other dimensions of wellness including social, physical, and emotional wellness. Some people use alcohol or drugs to cope with losses and pain. Because these substances can slow the central nervous system, their consumption can intensify depression and can be lethal in some treatments of depression and anxiety.

Mental wellness is promoted through physical activity; good nutrition; adequate rest and sleep; stress reduction; an optimistic attitude that can include humor, creativity and faith; optimal medication management; and emotionally enriched environments.

Many theorists feel that stress reduction is the major area of mental health and wellness. Stress can be viewed as a condition in which events or circumstances (stressors) are perceived as threatening or harmful. Another approach treats stress as a response to state of tension or strain. A third perspective describes stress as a process that includes stressors and strains but adds the interaction between a person and his or her environment. However stress is viewed, it is clear that it is an important part of mental health, and successfully managing stress is critical to the concept of wellness.

All of us can identify sources of stress in job or school, life events, family problems, and daily living. We also know that not all stress is negative. The goal for each individual is to identify that level of stress that is optimal for self-motivation but not overwhelming and harmful.

Many good resources exist to help people utilize stress constructively and to eliminate or deal with stress appropriately. The role of the nurse is to help each patient identify his or her own sources of stress and to refer each patient to appropriate resources if needed.

10. Medical Wellness -- Medical Wellness, as defined by the Medical Wellness Association, is “the practice of health and medical care relating to proven wellness outcomes.” (8) Another definition is that this construct includes the use of health care to appropriately assist in a person's health. Medical wellness is an approach for delivering health care that considers the multiple influences on a person's health. Accordingly, there are multiple choices for an individual when treating and preventing disease.

Occupational/Vocational Wellness is not personal in nature, but a person's working and physical environments are factors that influence personal wellness. Research is necessary to clearly establish the relationship among the sub-dimensions. The dimensions of wellness fall into two broader categories, mental and physical. The mental or emotional component is sometimes overlooked while focusing on physical fitness and chronic disease risk factors. The role of the comprehensive care team in health promotion includes social workers for mental wellness assessment and treatment, while physicians, nurses and physical therapists focus most often on the physical component of wellness.

PREVENTION ACTIVITIES

PHYSICAL ACTIVITY

The traditional view of fitness is focused on cardiovascular functioning. A broader perspective should be used when assisting a patient to optimize his or her health. These other areas are development and structural health and flexibility. Developmental assessment of a client will include the stage of development and the presence of developmental lags in physical activity for age. All of us know that physical exercise is an important part of health. This information is part of standard health education. In all persons with bleeding disorders, physical exercise has an important effect on overall functioning. It has been demonstrated that persons who are physically active have fewer health problems than those who are sedentary. Fitness beyond aerobic exercise extending to



stretching, strengthening and flexibility assumes an added importance in maintaining health and preventing problems for persons with hemophilia because of the reduction in morbidity of joint disease associated with bleeding.

Physical activity has psychosocial benefits as well. Engaging in regular exercise can reduce feelings of stress and anxiety, can improve sleep, can improve work and school performance and attitudes, and can enhance self-concept and self-esteem. The physical benefits people gain from regular exercise are reflected in their health. While many studies demonstrate that people who exercise regularly live longer and are healthier during their lives, the psychological benefits are less demonstrable but are equally as important.

Physical activity and exercise guidelines

The U.S. Preventive Services Task Force (USPSTF) was first convened by the U.S. Public Health Service to rigorously evaluate clinical research in order to assess the merits of preventive measures, including screening tests, counseling, immunizations, and preventive medications. Its recommendations are considered the "gold standard" for clinical preventive services. Public health recommendations for physical activity are related to scientific evidence that physical activity prevents premature early death, heart disease, stroke, type 2 diabetes, hypertension, adverse blood lipid profile, metabolic syndrome, colon and breast cancers, and weight gain and promotes weight loss when combined with diet. Physical activity also results in improved cardiovascular and muscular health and better cognitive function in older adults, as well as reducing depression. Below is an up-to-date list of all current recommendations for physical activity for children and adolescents, adults, and older adults from the CDC Center for Chronic Disease Prevention and Health Promotion. (9)

Exercise Guidelines for Children and Adolescents aged 6 – 17 years

- 60 minutes (1 hour) or more of physical activity daily. Aerobic: Most of the 60 or more minutes a day should be either moderate- or vigorous-intensity aerobic physical activity and should include vigorous-intensity physical activity at least 3 days a week.
- Muscle-strengthening: As part of their 60 or more minutes of daily physical activity, children and adolescents should include muscle-strengthening physical activity on at least 3 days of the week.
- Bone-strengthening: As part of their 60 or more minutes of daily physical activity, children and adolescents should include bone-strengthening physical activity on at least 3 days of the week.
- It is important to encourage young people to participate in physical activities that are appropriate for their age, that are enjoyable, and that offer variety.

Exercise Guidelines for Adults aged 18 – 64 years

- All adults should avoid inactivity. Some physical activity is better than none, and adults who participate in any amount of physical activity gain some health benefits.
- For substantial health benefits, adults should do at least 150 minutes (2 hours and 30 minutes) a week of moderate-intensity, or 75 minutes (1 hour and 15 minutes) a week of vigorous-intensity aerobic physical activity, or an equivalent combination of moderate-



and vigorous intensity aerobic activity. Aerobic activity should be performed in episodes of at least 10 minutes, and preferably, it should be spread throughout the week.

- For additional and more extensive health benefits, adults should increase their aerobic physical activity to 300 minutes (5 hours) a week of moderate intensity, or 150 minutes a week of vigorous intensity aerobic physical activity, or an equivalent combination of moderate- and vigorous-intensity activity. Additional health benefits are gained by engaging in physical activity beyond this amount.
- Adults should also do muscle-strengthening activities that are moderate or high intensity and involve all major muscle groups on 2 or more days a week, as these activities provide additional health benefits.

Activity Guidelines for Older Adults aged 65+ years

The Guidelines for Adults also apply to older adults. In addition, the following Guidelines are targeted exclusively to older adults, but for younger adults with significant joint arthropathy, these guidelines are also useful:

- When older adults cannot do 150 minutes of moderate-intensity aerobic activity a week because of chronic health conditions, they should be as physically active as their abilities and conditions allow.
- Older adults should do exercises that maintain or improve balance if they are at risk of falling.
- Older adults should determine their level of effort for physical activity relative to their level of fitness. Older adults with chronic conditions should understand whether and how their conditions affect their ability to do regular physical activity safely.

NUTRITION GUIDELINES

The process of nourishing the body with food depends on the quality and quantity of the nutrients ingested and the way in which the body processes them. The body needs a balance of carbohydrates, proteins, fats, water, vitamins and minerals to produce energy and meet the metabolic requirements for growth, body repair, and proper cell and organ function. The correct balance of these ingredients can have a major effect on the health and functioning of a person. In 2011, the U.S. Department of Agriculture (USDA), in conjunction with the U.S. Department of Health and Human Services (USDHHS), released a public health campaign to encourage more healthful eating by Americans which replaced the food pyramid taught to several generations of school children. It is called My Plate. (10, 11)

Because more than one-third of children and more than two-thirds of adults in the United States are overweight or obese, the 7th edition of Dietary Guidelines for Americans places stronger emphasis on reducing calorie consumption and increasing physical activity.

“The 2010 Dietary Guidelines are being released at a time when the majority of adults and one in three children are overweight or obese, and this is a crisis that we can no longer ignore,” said USDA Secretary Vilsack. “These new and improved dietary recommendations give individuals the information to make thoughtful choices of healthier foods in the right portions and to complement those choices with physical activity. The bottom line is that most Americans need to trim our waistlines to reduce the risk of developing diet-related chronic disease. Improving our

eating habits is not only good for every individual and family, but also for our country.” (11) The specific guidelines are below.

The new 2010 Dietary Guidelines for Americans focus on balancing calories with physical activity and encourage Americans to consume more healthy foods like vegetables, fruits, whole grains, fat-free and low-fat dairy products, and seafood, and to consume less sodium, saturated and trans fats, added sugars, and refined grains.



- Grains & Protein. Grains and protein each represent less than one quarter of the plate. While the protein group was once known as the meat group, over time it has transitioned to incorporate other protein-rich foods such as fish, shellfish, poultry, eggs, beans, peas, nuts, and seeds.
- Dairy. The dairy group has been moved to a circle next to the plate and defined as fat-free or low-fat milk or yogurt.

◦ Fruits & Vegetables. The biggest star of the MyPlate debut is fruits and vegetables, winning half the available real estate on the plate. The plate stresses the key concept of filling half one's plate with fruits and vegetables.

If a normal, healthy person eats a balanced diet with fresh fruits, vegetables, dairy products and whole grains, he or she should not require supplemental vitamins. However, when dealing with patients who require extra calories for repairing damaged tissue, to recover from surgery or combat HIV or liver disease, supplemental vitamins may be required. Use of nutritional supplements should always be part of the nursing assessment.

The nursing role in nutrition is to assess the patient's current nutrition history, teach good nutrition and eating habits, and assist in altering his or her diet to maximize health benefits. For persons with bleeding disorders, maintaining an optimal weight is important for general body functioning and also for optimization of joint function. People who are overweight place extra stress on their joints, particularly the lower extremity joints. These individuals may also tend to be less active and to have more problems with their weight-bearing joints. Conversely, patients who are underweight may have smaller muscle mass and be less physically active than those with normal weight.

Referral to a nutritionist is appropriate for persons with hemophilia who may be obese or consistently smaller than the lower tenth percentile on a growth chart. Persons with HIV or liver disease may also need a referral for dietary counseling to assure that their dietary intake is adequate to maintain their weight and provide nutrition for their metabolic needs, which may change if their health status fluctuates. More information on nutrition in persons with HIV can be found in the chapter of this Nursing Handbook on HIV/AIDS and Hemophilia (Chapter 11) or online at <http://fnic.nal.usda.gov/diet-and-disease/aidshiv>

There is good evidence that a connection exists between diet and risk of cancer and other diseases. Obesity and high fat intake are linked to cardiovascular disease and cancers of the stomach, colon, gallbladder, kidney and breast. In persons who developed Hepatitis C from

blood products prior to 1985, alcohol use in addition to Hepatitis C is a high risk factor for development of cirrhosis and colon cancer. Helping patients become proactive in choosing their diet and debunking nutritional myths are appropriate and valuable nursing functions.

OTHER PREVENTION ACTIVITIES

The USPSTF has developed guidelines for prevention of many chronic diseases. As the bleeding disorders population ages, these individuals will require counseling about the same illnesses and age-related issues that face the general population. (12) Specific guidelines can be found at the USPSTF website and include cancer; heart and vascular diseases; injury and violence; infectious disease; mental health and substance abuse; metabolic, nutritional and endocrine conditions; musculoskeletal disorders; obstetric and gynecologic conditions; and vision and hearing disorders. The recommendations are very explicit and can be found at the website listed in the references. (12)

A brochure developed in 2008 by the nurses from U.S. Hemophilia Treatment Centers in USDHHS Regions VIII and IX highlights issues that have special consideration for persons with bleeding disorders. (13) These are:

1. *Medications* — The HTC staff should be involved in writing prescriptions for any anti-platelet medication that are often prescribed for older patients for prevention of cardiovascular events. Herbal medications are often used by patients as well; these should also be approved by the HTC staff.
2. *Body Art* – the HTC should be involved in the risks and treatment recommendations. Specifically body piercing may have more related bleeding than other body art (tattoos).
3. *Dental Care* – In all persons, preventive dental care is important to preserve dentition, promote a healthy diet, and eliminate sources of infection. In persons with hemophilia, dental care assumes added importance because of the bleeding associated with poor dental hygiene and the potential cost in time, money and health when major restorations and gum disease treatment are required. (14) Patients with joint replacements who are having invasive procedures or who have other infections are at increased risk of hematogenous seeding of their prosthesis. Antibiotic prophylaxis may be considered. (15) Points to include in patient education are:
 - daily mouth hygiene, including brushing, and flossing
 - regular dental check-ups with a dentist familiar with bleeding disorders
 - sealants for children to prevent caries
 - fluoride for those people who do not have fluoridated water
 - counsel parents to avoid giving children bottles at nap or bedtime to prevent decay
 - proper diet
4. *Osteoporosis* – Beginning at age 60, women are at increased risk for osteoporotic fractures. Calcium and Vitamin D supplements are recommended. Data suggest that persons with hemophilia are at risk for osteopenia/osteoporosis if there is joint arthropathy or limitation on weight-bearing activity that can enhance the normal bone mineral loss associated with aging. (16)

In all persons, avoiding illness is a primary motivator for a number of behaviors. Immunizations, hand-washing, proper food preparation, and many other health behaviors are motivated by a person trying to avoid getting sick or hurt. In persons with bleeding disorders, certain behaviors, such as avoiding dangerous activities that may precipitate a bleeding episode, are part of wellness activities. In persons with compromised immune systems, avoiding persons with communicable diseases, certain foods and water in developing countries, and animals that transmit diseases are all wellness strategies, and the nurse should help each patient identify his or her optimal health behaviors.

AVOIDANCE OF HOUSEHOLD HAZARDS

In persons with bleeding disorders the issue of biologic waste disposal becomes an important part of household health practices. Many people with bleeding disorders treat their bleeding episodes at home with replacement factor products. These are often blood products that contain potential viral contamination. Needles, syringes and other supplies that may be contaminated with the blood of a person with hemophilia are all potentially infectious items. Each household where biologically contaminated waste is generated should be supplied with a sharps container that is puncture proof and can be sealed when full. These containers should be disposed of according to community hazardous waste disposal rules and regulations. Anyone who has contact with someone with any potentially contagious disease should wear gloves when handling items that contain blood or other bodily fluids.

WORKPLACE HAZARDS

The workplace also brings potential dangers from asbestos, benzene, and other toxic substances. Safety in the workplace is another area of preventive health, and assisting patients in being able to assess their workplace safety is another role of the nurse. Patients should be aware of federal guidelines for protection of employees that are written and enforced by the Occupational Safety and Health Administration (OSHA).



COMMUNITY HEALTH HAZARDS

In the community, air, water and soil have become polluted with harmful chemicals and wastes. Public health agencies are addressing these issues, and every citizen has the right to know about environmental dangers and has the responsibility to become involved in changing his/her community for the environmental health of all. Other issues of public safety and security are also the responsibility and right of every citizen. While these may not seem to directly impact each person's health, these issues are part of the overall picture of preventive healthcare.



IMMUNIZATIONS

Immunizations are an important way to prevent illness. An official group of experts, the Advisory Committee on Immunization Practices, under the auspices of the Centers for Disease Control and Prevention (CDC) and in conjunction with The American Academy of Pediatrics and the American Academy of Family Physicians, make regular recommendations on immunization schedules for both pediatric and adult US residents. These recommendations are updated based on new vaccines becoming available and can be found on the CDC website



(<http://www.cdc.gov/vaccines/default.htm>).

In persons with bleeding disorders, the risk for muscle bleeding following an intramuscular injection of an immunization may require treatment with clotting factor. Some HTC's pre-treat persons with a factor infusion prior to immunizations. However, all HTC's recommend decreasing the risk of bleeding with immunization by giving injections with a small gauge needle and putting direct pressure on the site of injection for seven to 10 minutes to allow for platelet clotting and to minimize the risk for muscular hemorrhage. The product insert for each vaccine gives the recommended route of administration. Efficacy data are not available when alternative routes of administration are used for some vaccinations.

COMPLEMENTARY AND ALTERNATIVE THERAPIES

In 2007, a National Health Interview Survey identified that 38% of adult Americans use complementary and alternative medicine (CAM). These are defined as a group of diverse medical and healthcare systems, practices, and products that are not presently considered to be part of conventional medicine. Complementary medicine is used together with conventional medicine, while alternative medicine is used in place of conventional medicine in pursuit of health and well-being. (17)

CAM practices are often grouped into broad categories, including natural products such as herbal medicines or botanicals, vitamins, minerals and other natural products; mind-body practices such as meditation and yoga that focus on the interactions among the brain, mind, body, and behavior, with the intent to use the mind to affect physical functioning and promote health; and manipulative and body-based practices such as massage, therapeutic touch, manipulation, acupressure, and acupuncture, among others .

In dealing with the cultural diversity of patients, many of them bring their traditional healing practices, folk medicine, and beliefs from their cultural backgrounds. To them, Western or conventional medicine is the “alternative.” This can present a challenge to the nurse to find a middle ground that takes into account his or her biases as well as the patient’s values.



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