ADULT CONGENITAL HEART DISEASES
NURSING CARE: PRESENT AND FUTURE
CHALLENGES

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Objectives

At the end of the presentation the audience will be able to identify:
1. the definition of Adult Congenital Heart Diseases
2. Classification of ACHD
3. Diagnostic procedures for patient with congenital heart diseases
4. Complication of Congenital heart diseases
5. Required knowledge/attitudes/skills for nurses and APN working with CHD patients populations
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Congenital Cardiovascular Defects: Statistics

• 3,531 people in the United States died from congenital cardiovascular defects in 2005.
• About 650,000 to 1,300,000 people in the United States with cardiovascular defects are alive today.
• From 1996 to 2006 death rates for congenital cardiovascular defects declined 26.7 percent.
Adult Congenital Heart Disease

- Advances in Diagnostic procedures, surgery, Non-surgical procedures and medication have allowed more children born with heart defects to survive.
- In addition, minor congenital heart defects that don't cause symptoms may not be diagnosed until a person is an adult or reaches middle age.
- It is estimated that 20,000 people with congenital heart disease reach adulthood every year in the United States.
Definition of Congenital heart disease:

- **Congenital heart disease** refers to a problem with the heart's structure and function due to abnormal heart development before birth. Congenital means present at birth.

- **Congenital heart disease**: A malformation of the heart or the large blood vessels near the heart. The term "congenital means "born with" or "present at birth."
Adult Congenital Heart Disease

ACHD related issues:

• Transition period
• Exercises
• Education
• Marriage
• Employment (Physical Activity)
• Pregnancy and control of birth
Classification of ACHD according to complexity

1. Great Complexity
   (Double-outlet ventricle, Eisenmenger syndrome, Fontan procedure, Mitral atresia, Single ventricle, Pulmonary atresia, Transposition of the great arteries, Tricuspid atresia, and Other abnormalities)

2. Moderate Complexity
   (Atrioventricular septal defects, Coarctation of the aorta, Ebstein’s anomaly, Patent ductus arteriosus, Pulmonary valve regurgitation (moderate to severe), Pulmonary valve stenosis (moderate to severe), Tetralogy of Fallot, and others)
Classification of ACHD according to complexity

Simple Congenital Heart Disease

- (Isolated congenital aortic valve disease, Isolated congenital mitral valve disease, Small atrial septal defect, Isolated small ventricular septal defect, Mild pulmonary stenosis, Small patent ductus arteriosus)
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Nurse specialists in adult congenital heart disease: The current status in Europe

• The Euro Heart Survey on Adult Congenital Heart Disease has previously showed that 20 out of 48 specialist centers (42%) have nurse specialists affiliated with their programme.

• Specialist centers had a median number of 2 nurse specialists on staff, corresponding with 1 full-time equivalent. In most centers, the nurse specialists were also affiliated with other cardiac care programme, in addition to congenital heart disease.
Personnel and Services Recommended for Regional ACHD Centers

- Cardiologist specializing in ACHD
- Congenital cardiac surgeon
- Nurse/physician assistant/nurse Practitioner
- Cardiac anesthesiologist
- Echocardiography (By physicians with expertise and training in CHD)
- Diagnostic catheterization (By physicians with expertise and training in CHD)
- Noncoronary interventional catheterization (By physicians with expertise and training in CHD)
- Electrophysiology/pacing/AICD implantation (By physicians with expertise and training in CHD)
- Exercise testing (By physicians with expertise and training in CHD)
- Cardiac imaging/radiology (By physicians with expertise and training in CHD)
Personnel and Services Recommended for Regional ACHD Centers

- Multidisciplinary teams
- High-risk obstetrics
- Pulmonary hypertension
- Heart failure/transplant
- Genetics
- Neurology
- Nephrology
- Cardiac pathology
- Rehabilitation services
- Social services
- Vocational services
- Financial counselors

- Information technology
Cardiology Explained 2004
Adult congenital heart disease

- Congenital abnormalities of the heart and cardiovascular system are reported in almost 1% of live births (see Figure 1) and about half of these children need medical or surgical help during infancy. In the first decade, a further 25% require surgery to maintain or improve their life. Only 10% survive to adolescence without surgery. Of these 10%, however, many live a normal life for years before their abnormality is discovered.
Planning the specialized care of adult congenital heart disease patients: from numbers to guidelines; an epidemiologic approach

- Guidelines published in 2001 recommended 1 regional adult congenital heart disease (ACHD) center per 3 to 10 million population. Our objective was to determine if published guidelines on the numbers of regional ACHD centers are sufficient to meet the needs of adults with congenital heart disease in the general population.

- In conclusion, we demonstrate that 1 regional ACHD center for a population of 2.0 million adults appears to be closer to what is required for improving access to specialized care for patients with ACHD in the United States and Canada.
Diagnostic Services for Adults with Congenital Heart Disease

- Echocardiography
- Electrocardiography (ECG or EKG)
- Coronary Angiography
- Nuclear Imaging Tests
- Electrophysiology Tests are used to evaluate the heart for arrhythmias.
- Testing for Inherited Cardiovascular Diseases (Genetics) Some congenital heart defects are caused by gene mutations that may present a risk to other relatives, including children.
Possible complications

- Arrhythmias
- Clots (MI, PE, DVT)
- Endocarditis
- Impaired lung function
- Fluid overload
- Drug side effects
Challenges

- Lack of specialist facilities (ACHD centers, ACHD Clinics, ACHD specialized persons)
- Large variety of conditions
- All staff need an understanding of their unique physiology and needs
ACHD Nurse Specialist

List of skills and knowledge areas for nurse specialists

As services expand to meet the needs of a growing adult population, the demand for training and development of nurses will increase for both nurses on cardiac wards and nurse specialists in congenital heart disease.
Cardiac Ward based staff knowledge/skills/attitude

- Understand altered anatomy of the heart and great vessels and their effects on cardiovascular system
- Knowledge of common congenital heart defects, interventions, procedures and treatment of CHD
- Basic assessment of the cardiovascular system
- Knowledge of effects of cardiopulmonary bypass
- Ability to teach patients and their family about their condition, Investigations, treatment, lifestyle related issues
Cardiac Ward based staff knowledge/skills/attitude

- Understand monitoring and basic ECG interpretation
- Ability to teach colleagues
- Understand the psychological effects of congenital heart disease
- Understand the effects of the transition process
- Communication skills including communicating with young people
- Knowledge of relevant pharmacology
Experienced cardiac ward manager knowledge/skills/attitude

Including all of the above plus:

- Understanding of the implications of pregnancy in women with congenital heart disease
- Understanding contraceptive therapy for women with a congenital heart disease
- Understanding of specific complications or problems which this group of patients might develop (Arrhythmias/Sudden Cardiac Death, Heart failure)
Experienced cardiac ward manager knowledge/skills/attitude

- Understanding of the numbers of adult patients with congenital heart disease in their Trust and the potential demands on the service
- Knowledge of specific health promotion issues e.g. family planning, diet/weight school/work life/exercise/insurance issues/benefits/driving/traveling
- Understanding of palliative care support
Adult Congenital Heart Disease nurse specialist knowledge/skills/attitude

All of the above (previous two categories) plus:

● Lead the development of clinical nursing practice for ACH patients.
● Plan own caseload management within clinical areas and clinics
● Develop in-house teaching programs for staff caring for ACH patients
● Establish links with local higher education establishments and academic colleagues to explore formal education provision opportunities for staff wishing to develop their knowledge and expertise further
● Provide clinical expertise to relevant managers to ensure an efficient, effective, quality service
Adult Congenital Heart Disease nurse specialist knowledge/skills/attitude

- Provide individualized information and support to patients and their families
- Provide information and support to staff in clinical areas caring for adults with congenital heart disease and their families
- Counseling skills
- Develop skills in utilizing and undertaking research to enhance evidence-based practice. This could include publishing and presenting at conferences
Roles and Responsibilities of Advanced practitioner Nurse

- Receive the telephone calls from patients, physicians, and hospitals
- Hospital admissions and discharges
- Arrangements for transfer of patients from other hospitals
- Scheduling diagnostic studies
- Monitoring patient compliance
- Providing comprehensive patient education including preventive health screening and counseling
- Providing counseling or referral for a number of psychosocial issues
- Assume responsibility for informing patients about nonpharmacologic and pharmacologic prophylaxis for infective endocarditis
- Provide education for patients and their families regarding medical and surgical expectations, and detailed postoperative instructions encompassing physical and sexual activity, dietary restrictions, breathing exercises, medications, and follow-up plans
- Nursing research, investigation, and collaboration are important roles of APN
Roles and responsibilities of staff Nurses

- Conduct comprehensive assessment (physical, psychosocial, spiritual)
- Review the medications
- Check the labs
- Prepare the patients for the procedures
Future steps for ACHD Specialized Nurses

• Development of formalized and widely available specialized course in ACHD
• Research within cardiac nursing needs to be expanded, to provide results for evidenced-based clinical practice related to ACHD patient population.
• Awareness about ACHD among nurses should begin in the university and graduates nurse should encouraged to undertake their master’s theses in this field.
• Establishment of national societies for ACHD nurses.
References


• American Heart Journal Volume 157, Issue 1, January 2009, Pages 1-8 Planning the specialized care of adult congenital heart disease patients: from numbers to guidelines; an epidemiologic approach
References

• http://www.uchospitals.edu/specialties/heart/services/adult-congenital-heart/
  Center for Adults with Congenital Heart Disease

• The Medical News
  8. November 2008 04:12
  These days most children born with congenital heart disease live well into adulthood, thanks to innovative surgical, interventional and medical treatments.

• March 20, 2010
  Congenital Cardiovascular Defects: Statistics
References

• The Nurse Practitioner, September 2005
  Better Treatments Improve Survival of CHD Patients
  Loretta Ninivaggi, MSN,RN, CDE

• ACC/AHA 2008 Guidelines for the Management of Adults With Congenital Heart Disease: Executive Summary. A Report of the American College of Cardiology/American Heart Association Task Force on Practice Guidelines (Writing Committee to Develop Guidelines for the Management of Adults With Congenital Heart Disease)
Thank you