Sexual Health and Pregnancy

Living the best life with a Single Ventricle Heart Circulation

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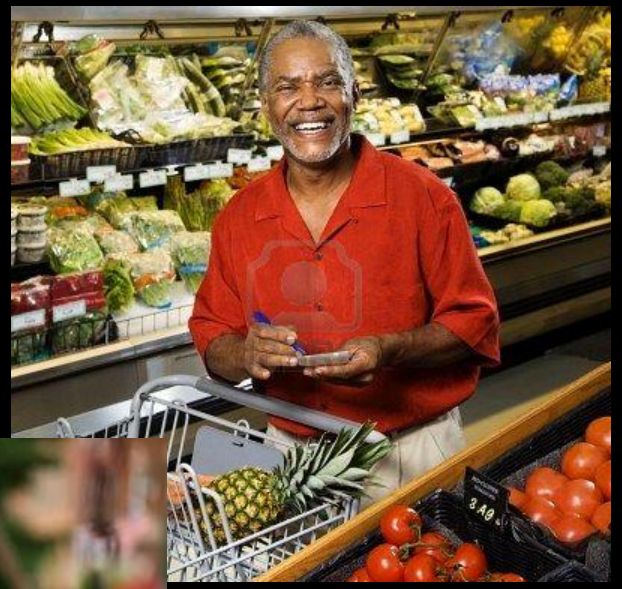
Honorary lecture at Imperial College London

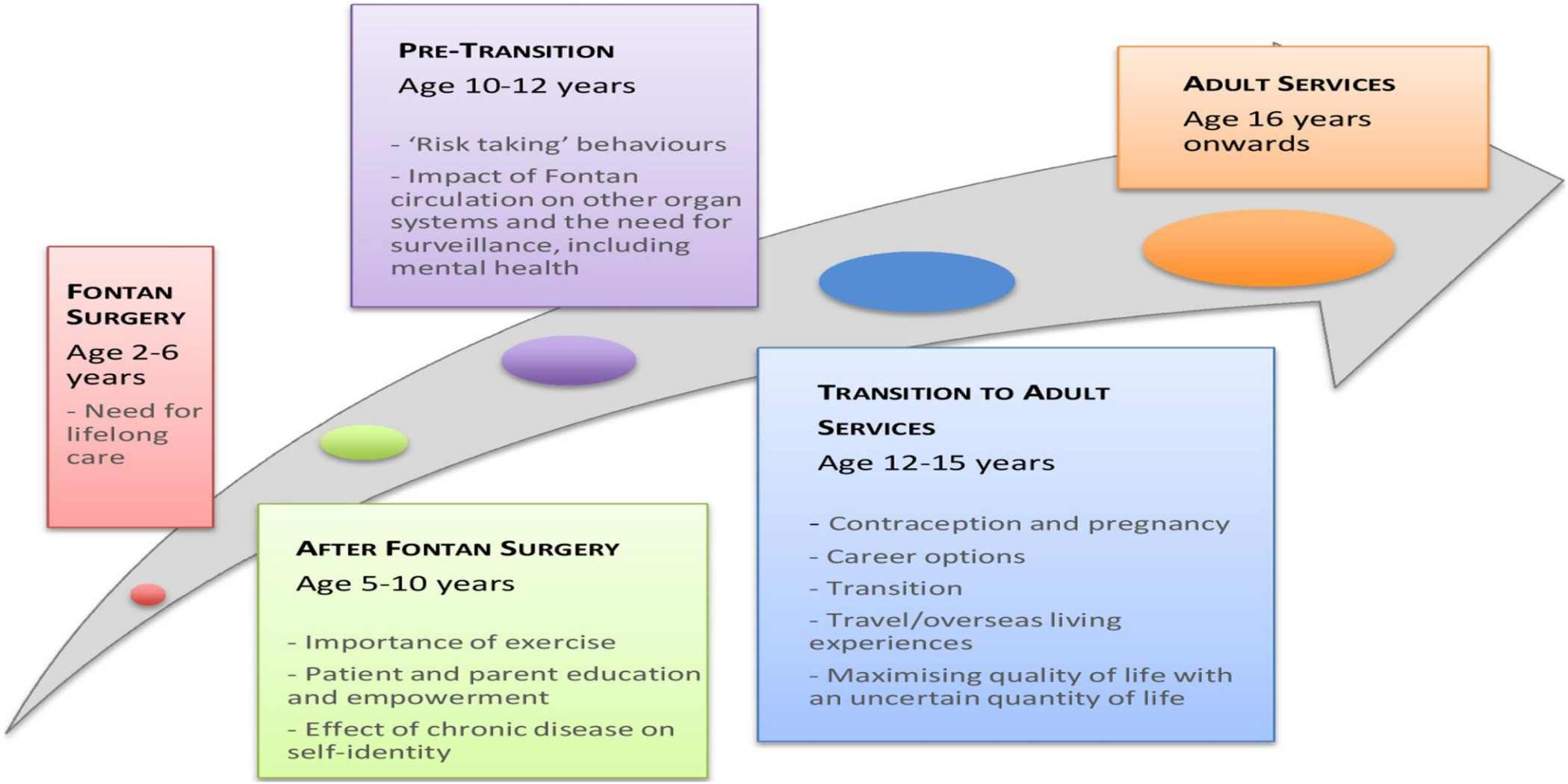
– from the crib to old age



Sexual Health Education

- Sexual health is an important aspect of one's quality of life
- Despite its widely recognised importance, education to promote sexual health remains a sensitive and, occasionally, controversial issue
- Sexual dysfunction is common in individuals with CHD affecting 28% of CHD patients
- Everyone's experience is unique and many people with CHD enjoy a healthy sex life, many encounter difficulties (e.g.: orgasmic dysfunction, erectile dysfunction, intercourse dissatisfaction, lower sexual desire, and an increased incidence of dyspareunia (painful intercourse)
- The CHD team should provide an open inclusive environment to discuss sexual health for male and female and individual with special and additional needs
- Psychological and physical barriers to having a fulfilling sexual life are often treatable.

Sex Education – Difficult Area



CONCERNS

- Sex will cause another arrythmia's, heart failure etc
- Reduced sexual drive/functioning
- Partner's fears

One to one discussion with CHD patients

Chest pain

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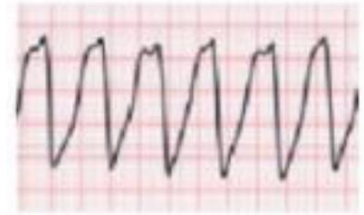
Breathlessness

Fainting episodes

Risk of recurrence



Palpitations

Physical exertion of Sex

Exertion is similar to mild to moderate exercise

BP and HR mildly increase during sexual intercourse and quickly come down to baseline

Special circumstances can increase strain such as a new place, new partner, heavy meal and Alcohol

Intimacy Is Important

Intimate	Intimate relationships involve affection, trust and closeness Individual should talk to their partner to discuss what they find challenging
Include	Intimacy can include physical contact of a sexual nature, but can also be expressed in other ways, practicing all the other ways of connecting/touching
Be	Intimate relationship can be protective against the harmful effects of stress

Impaired Sexual function

Medication Side effects

Diuretics, BP meds, antiarrhythmics, antidepressants

Medical Illness and recovery

Depression

Fear and worries

Body image concerns and self esteem

Pregnancy and CHD

- Congenital heart disease is the most common aetiology of CVD during pregnancy
  - 1% of live births associated with CHD
  - 5% if there is maternal history of CHD
  - Maternal death during pregnancy in women with heart disease is rare

- Pregnancy in CHD is likely to continue to increase
  - Most CHD patients reaching puberty
  - More complex anatomies reaching childbearing age
  - Women with CHD now comprise the majority of pregnant women with heart disease seen at referral centers
  - Individual who have survived CHD disease into adulthood often have a strong desire to have a family

Discussion with health care team

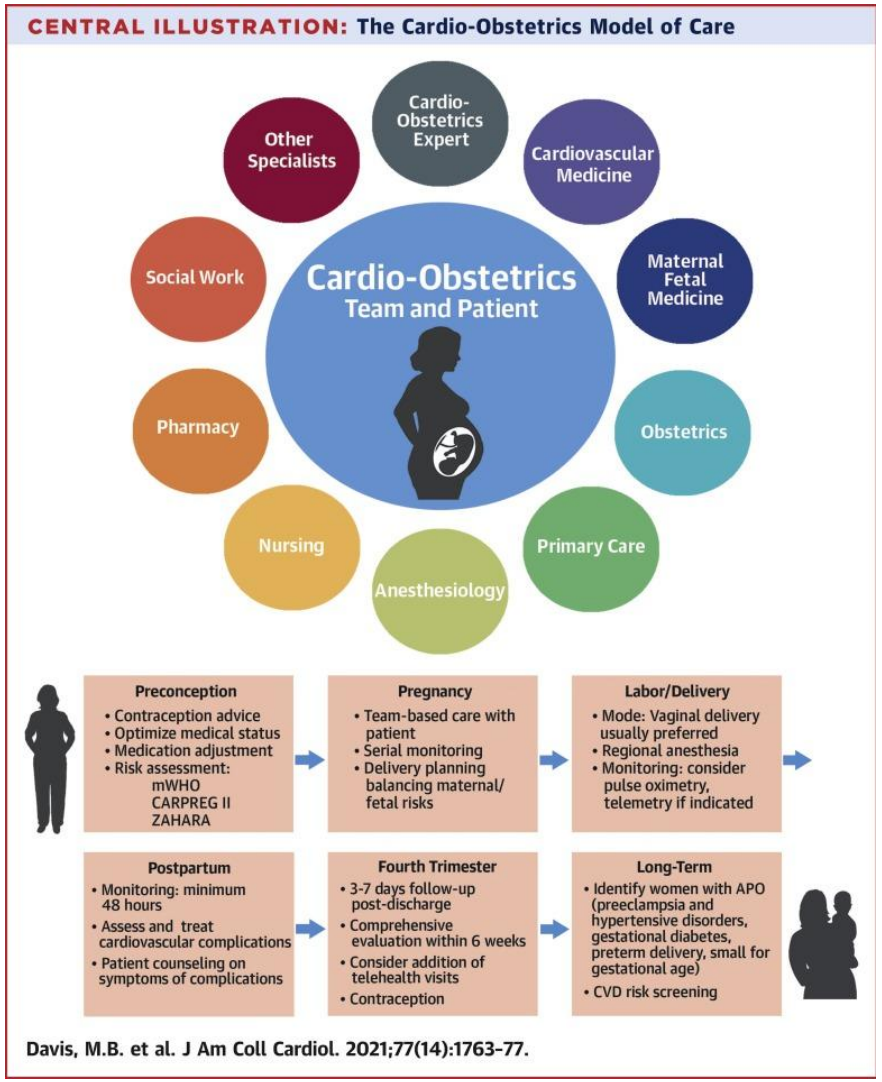
- **Is your heart condition impacting on any other areas of your life?**
- **How is your relationship doing?**
- **How is your partner dealing with your health issues?**
- **More specific questions such as any sexual or relationship problems?**
- **Has your ability to enjoy sex changed?**
- **Are you scared to have sex?**
- **Baseline assessment of physical fitness and symptoms**
- **Plan for optimising cardiac function**
- **Contraception advise**
- **Review of medications**
- **Lifestyle issues**
- **Psychological well-being**
- **Further investigations and/or expert referral**

Pregnancy planning

- Ideally, pregnancies should be planned
- Pre-conception counselling
- Cardiac medications can be harmful to a foetus
- Stopping medications can be harmful to the mother
- Allows time to investigate symptoms
- Allows time to treat before embarking upon pregnancy
- Informed decisions

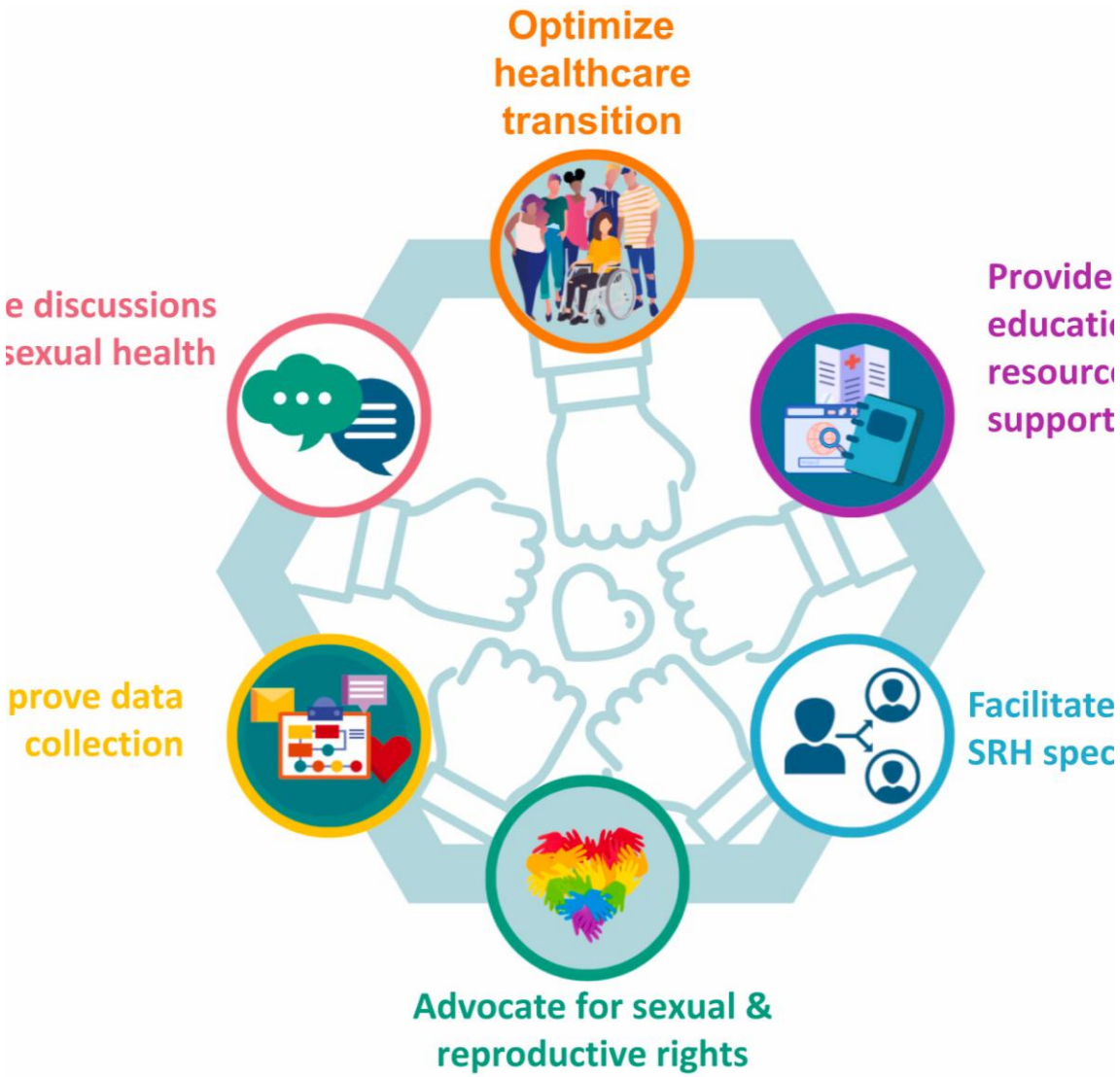
Counselling

- In counselling, the following **six areas** should be considered:
- The underlying cardiac lesion
- Maternal functional status
- The possibility of further palliative or corrective surgery
- Additional associated risk factors
- Maternal life expectancy
- Ability to care for a child
- The risk of CHD in offspring
- Psychosocial considerations
- Hospital delivery- Preferable at tertiary care center



Team approach

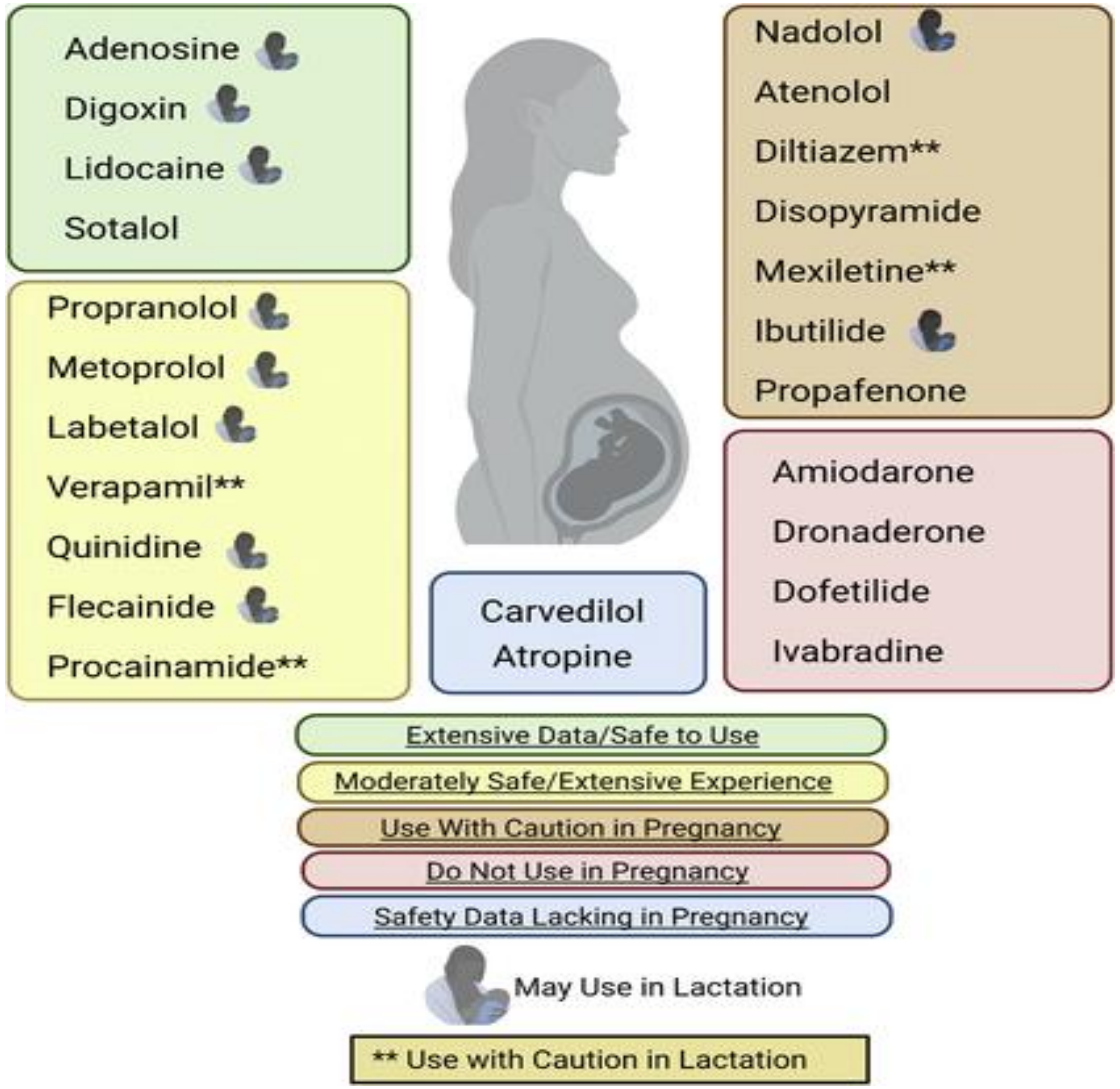
- Optimum care of these potentially complicated pregnancies can only be achieved by a combined approach by cardiologists and obstetricians clinical nurse specialist etc
- Pregnant women with heart disease do remain at risk for other complications including heart failure, arrhythmia, and stroke
- Cared in specialist centers with an understanding of the obstetric and cardiac complications that can arise



Family Planning

- Extremely Important for both females and males
- Females – high risk WHO Class III or Class IV
- If you are considering having children early the better
- Preconception counselling is a must as it’s a journey for the mother, baby and physician looking after both
- Medications needs addressing
- Psychological and social aspects taken into consideration
- Contraception and type of contraception

Medication


Adenosine
Digoxin
Lidocaine
Sotalol
Propranolol
Metoprolol
Labetalol
Verapamil**
Quinidine
Flecainide
Procainamide**
Carvedilol
Atropine
Nadolol
Atenolol
Diltiazem**
Disopyramide
Mexiletine**
Ibutilide
Propafenone
Amiodarone
Dronaderone
Dofetilide
Ivabradine
Extensive Data/Safe to Use
Moderately Safe/Extensive Experience
Use With Caution in Pregnancy
Do Not Use in Pregnancy
Safety Data Lacking in Pregnancy
May Use in Lactation
** Use with Caution in Lactation

Case study

- 34 y
- Fontan operation (TCPC)
- Recurrent miscarriages
- Was planning to adopt a child
- Pregnancy in 2021
- Close monitoring in clinic with regular investigations (Echo, ECG, medication and symptom monitoring, blood test, Fetal growth scan, etc
- Delivered at 32 weeks

We are still on Cloud 9 following the smooth and safe arrival of our tiny but mighty miracle

There were times we feared we might never be parents in the natural way, but your perseverance, encouragement and positivity carried us through and has changed our lives forever, and we and our families will be forever grateful

Watching him grow into the most loving, happy, curious and funny little boy over this last year has honestly been the greatest gift to us and to our families. Hands down, it's been the best year of our lives, and we can never thank you all enough for all you did to make our dreams of having a family come true

Conclusion

- Sexual education and advice is important
- Recognition and acknowledgment of the importance of sexual health and education for both individuals
- Pregnancy in most women with heart disease has a favorable maternal and fetal outcome
- In some circumstances, patients may feel uncomfortable about accessing information on sexual health directly from their ACHD provider. The use of websites and written material may be less challenging
- Education resources from relevant charities that is inclusive on cardiac specific information (LHM, TSF, BHF, etc)
- CHD team should implement customised sexual health education, including providing information on appropriate contraception methods

Key Takeaways for Healthcare Professionals

Individualised Care: Each patient requires a tailored approach based on their specific cardiac lesion, functional status, and reproductive goals (healthy lifestyle and mental health support and exercise)

Contraceptive Counselling: Safe options must be provided, with contraindications carefully considered

Pre-Pregnancy Assessment: Comprehensive risk stratification is critical in reducing maternal and Fetal risks

Multidisciplinary Collaboration: Essential for optimising outcomes in pregnancy and sexual health for CHD patients

Delivering care to women with congenital heart disease: the role of clinical nurse specialist

Abstract

Congenital heart disease is now the most common reason for women to attend a high-risk joint cardiac–obstetric clinic. With advances in medical care and surgical techniques, most children born with congenital heart disease reach childbearing age and have a good prognosis for long-term survival with a good quality of life. Pregnancy remains a major life event for these women, posing additional risks with the potential for severe morbidity and mortality. The hemodynamic changes induced by pregnancy can unmask undiagnosed congenital heart disease or exacerbate pre-existing conditions. Therefore, specialist care is essential for a successful pregnancy outcome. Women with complex congenital heart disease embarking on pregnancy need the support of a multidisciplinary team, including cardiologists, obstetricians, anaesthetists, midwives and adult congenital heart disease clinical nurse specialists. Clinical nurse specialists in particular play a crucial role in coordinating, supporting, educating and advocating for the mother and fetus through preconception, pregnancy, the puerperium and beyond.

Keywords

Assessment | Clinical nurse specialist | Congenital heart disease | High-risk pregnancy | Team approach | Transition

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Cardiac disease is the most common cause of indirect maternal death globally (Sanghavi and Rutherford, 2014; Lameijer et al, 2020; Knight et al, 2023). The complex physiological changes induced by pregnancy to meet the metabolic demands of the mother and the growing fetus (Taranikanti, 2018) can precipitate cardiac decompensation in women with pre-existing heart disease, increasing the risk of heart failure and arrhythmia, as well as having a negative impact on maternal and fetal outcomes (Ramage et al, 2019). Pre-pregnancy counselling and close monitoring during pregnancy and the puerperium are critical to the early detection of complications such as heart failure, arrhythmia and thromboembolic events.

In the UK, as in the rest of the world, 1 in 100 babies are born with congenital heart disease (Bakker et al, 2019). At least 97% will survive to adulthood, highlighting the need for long-term management strategies (Mandalenakis et al, 2020). With improved survival, an increasing number of women with congenital heart disease are opting to become pregnant and make up the majority of women seen in cardiac–obstetric clinics (Elkayam et al, 2016; Ramlakhan et al, 2021).

Pregnancy in women with complex congenital heart disease is associated with an increased risk compared with simple congenital heart disease lesions, independent of whether they were clinically stable at the time of conception (Canobbio et al, 2017). The modified World Health Organization classification categorises women into four pregnancy risk groups, classes I–IV (Essa et al, 2023). Class III is associated with a significant risk and class IV carries an extremely high risk of maternal mortality or severe morbidity; hence, in this category, pregnancy is strongly advised against (Canobbio et al, 2017).

The care of this emerging patient population needs careful assessment and management, starting with pre-pregnancy counselling and continuing through pregnancy and the puerperium (Canobbio et al, 2017). A fundamental role of the clinical nurse specialist is patient education and empowerment of pregnant women

Reference list

- Fischer AJ, Grundlach C, Helm PC, Bauer UM, Baumgartner H, Diller GP; German Competence Network for Congenital Heart Defects Investigators. Erectile Dysfunction in Men With Adult Congenital Heart Disease: A Prevalent but Neglected Issue. Korean Circ J. 2022 Mar;52(3):233-242. doi: 10.4070/kcj.2021.0184. Epub 2021 Nov 5. PMID: 34877826; PMCID: PMC8907987.
- MBRRACE-UK 2023: Mothers and Babies: Reducing Risk Through Audits and Confidential Enquiries across the UK
- Swan, L, Windram, J, Burchill, L. et al. Sexual Health and Well-Being in Adults With Congenital Heart Disease: A International Society of Adult Congenital Heart Disease Statement. *JACC Adv.* 2023 Dec, 2 (10) .https://doi.org/10.1016/j.jacadv.2023.100716
- Kamala P. Tamirisa et al. *J Am Coll Cardiol EP* 2021; 8:120-135.