Cardiology in the Young

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Dilated cardiomyopathy in the young: a patient-scientist informed review of unmet needs

Emma R. Jennings[1,2], Rachel Mackay[2], Catherine Renwick[2], Katherine S. Josephs[1,2], Rachel J. Buchan[1,2,3], Paul J.R. Barton[1,2,3], James S. Ware[1,2,3,4,5] and Kathryn A. McGurk[1,3,4]

[1]National Heart and Lung Institute, Imperial College London, London, UK; [2]Royal Brompton & Harefield Hospitals, Guy's and St. Thomas' NHS Foundation Trust, London, UK; [3]MRC Laboratory of Medical Sciences, Imperial College London, London, UK; [4]Program in Medical and Population Genetics, The Broad Institute of MIT and Harvard, Cambridge, USA and [5]Hammersmith Hospital, Imperial College Healthcare NHS Trust, London, UK

Review

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Corresponding author:
Kathryn A. McGurk;
Email: k.mcgurk@imperial.ac.uk

Abstract

Dilated cardiomyopathy (DCM) is a leading cause of heart failure and the most common indication for a heart transplant. Guidelines are regularly based on studies of adults and applied to the young. Children and adolescents diagnosed with DCM face different lifestyle challenges from individuals diagnosed in adulthood that include medical trauma and are influenced by maturity levels and confidence with advocacy to adults.

Using a UK patient-scientist's perspective, we reviewed the age-specific challenges faced by the young with DCM, evaluated current guidelines and evidence, and identified areas requiring further recommendations and research. We highlight the importance of (i) the transition clinic from paediatric to adult services, (ii) repeated signposting to mental health services, (iii) standardised guidance on physical activity, (iv) caution surrounding alcohol and smoking, (v) the dangers of illegal drugs, and (vi) reproductive options and health.

Further research is needed to address the many uncertainties in these areas with respect to young age, particularly for physical activity, and such guidance would be welcomed by the young with DCM who must come to terms with being different and more limited amongst healthy peers.

Introduction

Dilated cardiomyopathy (DCM) is the leading cause of heart failure (HF) in young people and the most common indication for a heart transplant.[1,2] DCM has an estimated population prevalence of 1 in 250 adults (0.4%) and is rarer in children (1 in ~ 15,000 children, 0.007%) but represents one-half of all cardiomyopathies in children.[2–6] Risk factors for death or transplantation in DCM include younger age at diagnosis, family history of cardiomyopathy, and severity of left ventricular dysfunction. Death or transplantation occurs in 26% of people with childhood cardiomyopathy within 1 year of diagnosis and ~ 1% per year thereafter.[7]

The 2023 European Society of Cardiology (ESC) Guidelines for the management of cardiomyopathies describe disease penetrance during childhood as approximately 5% under 10 years old.[4] In the United States and Australia, paediatric DCM has a higher incidence in children under 1 year of age (44 cases per million/year) than over three years (3.4 cases per million/year).[6,8] Many diagnosed children survive to adulthood, requiring continual guidance and support through lifelong follow-up.

The symptoms of DCM and HF in children can be non-specific and misinterpreted as other, more common, paediatric illnesses. Symptoms include faltering growth, poor feeding, excessive sweating, oedema, and tachypnoea[4,8,9] which can be triggered by myocarditis, in-utero gestational diabetes, and vitamin D deficiency.[4] For paediatric myocarditis, recovery (ejection fraction > 55%) is predicted in 50–80% of cases within 2 years of presentation from single-centre studies.[10,11] There is a set of aetiologies that present in infant DCM that differ from those presenting later in childhood. The survival and prognosis of infant cardiomyopathy are worse than those diagnosed later, with those diagnosed later typically presenting as early manifestations of the same genetic aetiologies observed in adults.

More research is needed specifically in children with DCM and HF. Treatment for childhood HF is based on the evidence and guidelines in adults as there are few clinical trials in children.[4,6,8,12,13] This may be due to ethical challenges, but observational studies could be more frequent in hospital settings. The classification of HF in adults is based on the NYHA classes, [14] which do not apply to those < 5 years old; instead, the Ross HF classification system was developed, but it is not validated against outcomes.[9] Clinicians use ejection fraction (the percentage of blood ejected from the ventricles with each contraction of the heart) as a measure

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Table 1. Summary of the key recommendations

- Young people with dilated cardiomyopathy (DCM) and their families require specialised mental health support to equip them for lifelong clinical care.
- Genetic testing results should be revisited with the young person in the transition to adulthood.
- Current exercise guidelines suggest it is safe to exercise to perspiration with the ability to hold a conversation and avoid exercising when feeling unwell or tired.
- Alcohol and caffeine are regularly consumed in adults, but the evidence surrounding their negative impacts is non-specific, and the advice is to avoid them in excess, hydrate more before and after consumption, and avoid taking them in combination. They can also oppose the effects of some therapeutic drugs used for DCM treatment.
- Smoking, vaping, cannabis, cocaine, 3,4-methylenedioxymethamphetamine, and ketamine negatively influence the cardiovascular system, with cocaine described as the most cardiotoxic.
- Pregnancy can be contraindicated in some people with DCM, and progesterone-only contraception is recommended to avoid the risks associated with oestrogen-based alternatives.

of cardiac function for adults while fractional shortening (the percentage by which linear left ventricle dimensions reduce between diastole and systole) is often used for children as it can be difficult to assess their left ventricular volumes.[15,16]

Around 30% of individuals of all ages with DCM carry a causative genetic variant.[4] With the increasing availability of genetic testing and the progression of newborn screening programmes, there is a need for registries to understand the natural history of the disease, assess the holistic well-being of the affected young, audit physical and psychological care, and understand different genetic subtypes of the disease.[17,18]

DCM is a clinically heterogeneous disease; diagnosis and management can be challenging. For those with reduced ejection fraction that recovered to an ejection fraction of > 50% with treatment, there is a dilemma faced by clinicians and people with cardiomyopathy regarding whether to cease or remain on pharmacotherapy for life. The TRED-HF trial (2019) studied the cessation of pharmacotherapy for adults with DCM. Of 50 adults who began pharmacological weaning, 40% relapsed during the study period, [19] and of those who could cease pharmacotherapy, it is suspected that DCM was secondary to a primary insult.[19] Current guidance recommends caution surrounding decreased treatment.[4]

The unique experience of the young with DCM and their families complicates the availability of specific guidance and treatment responses. Females (discussed in this article denoting biological sex only), children, and people of non-European ancestry are less represented in clinical trials used to inform guidelines.[20,21]

In this review, we look beyond the diagnosis and clinical treatment of DCM to the lifestyle changes experienced by a young person with a DCM diagnosis. Young people face specific lifestyle challenges that current research and the untailored guidelines for children and adolescents fail to address (Table 1).

Methods

Here, we incorporate a UK patient-scientist's experience of London National Health Service clinical services (perspective cited as [ERJ]) to investigate the literature and guidelines surrounding the impact of DCM on the young and life's challenges (Figure 1). ERJ was diagnosed with DCM in the early 2000s at 1 year old. She has a family history of sudden cardiac death and long-QT syndrome (genetically unrelated to the DCM). She carries a genetic variant that was recently upgraded from uncertain significance to likely pathogenic, allowing for cascade testing and screening in her wider family. She is an advocate for young people with cardiomyopathy through the Youth Panel for the charity Cardiomyopathy UK.

The importance of the transition clinic from paediatric to adult services

Managing a diagnosis of DCM or HF at a young age separates a child from healthy peers because of the requirement to navigate additional challenges and responsibilities. The child must develop responsibility and advocacy for their health outside parental care, such as at school or friends' houses. This requires maturity and confidence beyond that of a healthy peer; in discussions with supervising adults regarding medications and selective involvement in physical activities (ERJ).

Children with DCM experience more educational disruption and time spent catching up. This can be due to susceptibility to illnesses and hospital appointments. Parents or guardians may be more protective so milestones may be delayed or impacted.[22,23] The cardiomyopathy and/or interventions (e.g. beta-blockers) can cause lethargy and tiredness, affecting the progression of motor skills, limiting physical activity, and causing difficulty sleeping.[24] Angiotensin-converting enzyme (ACE) inhibitors can cause dizziness, which can be compounded by concurrent beta-blocker therapy.[25] In the United Kingdom, the Department of Education (2014) provided guidance for supporting pupils at school with medical needs; governing bodies should ensure that pupils with medical conditions have full access to education, school trips, and physical education and that any needs are fully understood and supported.[26] However, it is recognised that schools are often understaffed with limited resources.

The transition from paediatric to adult services is important to children diagnosed with DCM. Transition clinics aim to equip young people with the knowledge, independence, and responsibility for their health and management of their condition.[27,28] Processes for transition vary widely between countries and may be less available or standardised than in the United Kingdom. For example, Australia has services to assist people with long-term conditions to transition, but it is unclear whether all hospitals have a fixed programme or guidelines.[29] In the United States, the transition to an adult provider is initiated when the medical decisions and appointments become the responsibility of the individual rather than their guardian. There is limited evidence for planning and supporting this transition (in the United States), particularly in those with pre-existing medical conditions.[30]

Transition clinics in the United Kingdom aim to check the understanding of the details of a condition and aid the initiation of responsibility for care as independent adults. This includes teaching young adults how to self-advocate and advising healthy living. Clinics are usually between the ages of 16–25 years, based on maturity. The National Institute for Health and Care Excellence, United Kingdom, has guided setting up transition services from 12 years old. The guidance is not disease-specific and applicable to all chronic childhood medical conditions.[31]

The inclusion of disease-specific guidance, such as the understanding of genetic testing results, should be a locally

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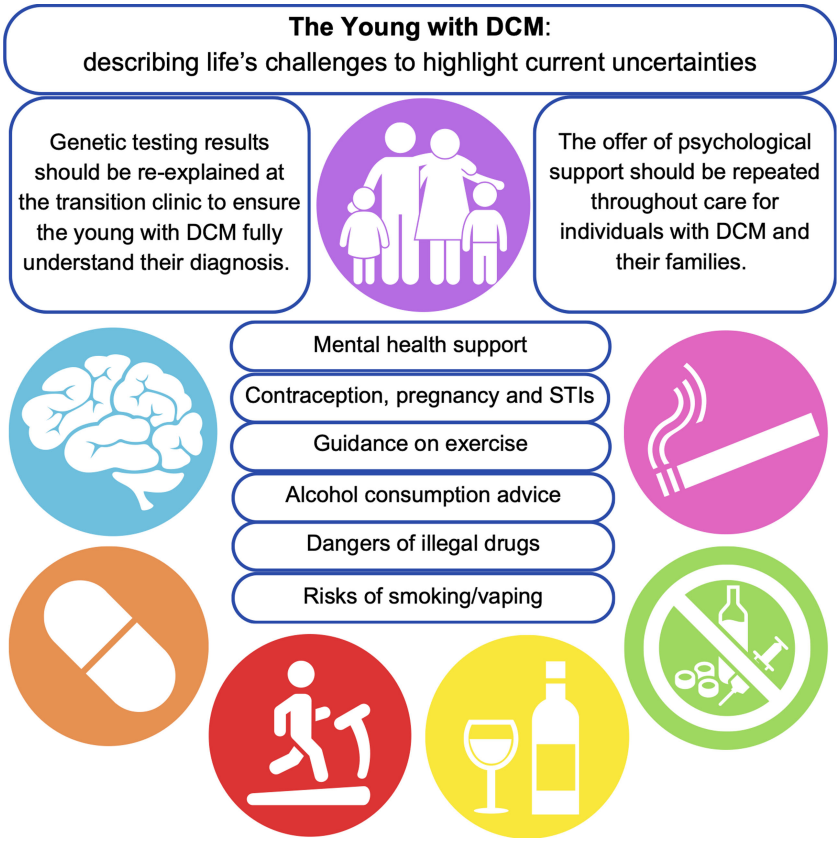

Figure 1. Summary of the paper and key recommendations. DCM = dilated cardiomyopathy; STIs = sexually transmitted infections. This figure was created with Canva.

included element of the transition process. As cardiomyopathies are often inherited, genetic counselling is an integral part of care. As a child, it is the parents and guardians who usually consent to genetic testing and receive the results. They in turn explain the result to the affected child. It is important that genetic testing results, clinical interpretations, discussion of previous screening, and the young adult's understanding are assessed and re-discussed. This provides an opportunity for variant re-interpretation and ensures the young adult understands the impact on their future risk of cardiac events, access to interventions, severity, and family planning.

A challenge faced by the transition clinic is that it is at a time of significant change in a young adult's life, including puberty, exam pressures, and moving to university, and can be complicated by changing centres of care, hospitals, and healthcare teams. The time of diagnosis is variable (from birth to the transition clinic), requiring the transition clinic to be bespoke for the young with cardiomyopathy. We recommend a clinic with short, in-person meetings with interdisciplinary members of the clinical care team including genetic counsellors, psychologists, and nurses, to answer diverse questions and provide support.[32]

The importance of repeated signposting to mental health services

A diagnosis of DCM can have a psychological impact on children and adolescents due to a lack of understanding and coping mechanisms for medical trauma.[18] Psychological challenges in children vary and can manifest later in life. This can be due to differing understanding, the impact of their diagnosis on their lifestyle, the feelings of being different, feeling alone in their experiences, undergoing major surgeries, or experiencing cardiac arrests, at different time points during the life course. Access to counselling and other psychological services should be offered regularly to the person with cardiomyopathy and their families throughout routine care, not only at the point of diagnosis, hospital admission, or when mental health is worsening.[18] The clinical criteria for mental health referrals must be met before support is provided [33] and may miss those with longer-term or milder mental health presentations or at risk of requiring future support. The United Kingdom uses the Patient Health Questionnaire and General Anxiety Disorder questionnaire for depression and anxiety, respectively.

In adults, the Cardiomyopathy UK charity's State of Cardiomyopathy Care National Cardiomyopathy Report (2023) stated that over 50% of respondents said they struggled to cope emotionally over the last 6 months due to their cardiomyopathy and 46% felt that access to counselling and therapy would help. Only 9% had been offered mental health support as part of their care.[34]

Unaffected family members should not be overlooked as they often experience a traumatic event with affected family members.[18] For those who have received an implantable cardioverter defibrillator or have experienced the sudden cardiac death of a family member, the 2023 ESC Guidelines for the management of cardiomyopathies states that "clinical psychological support for patients and their families affected by inherited cardiomyopathies is an important aspect of the multidisciplinary team's care approach and should be available as required."[4] Trauma that is experienced by parents of affected children can impact their parenting style, leading to over-protection and perceiving their child as vulnerable. They may experience ongoing stressors and

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concerns around their child's safety and health. This can impact the child.[22]

The need for standardised guidance on physical activity

Exercise plans should be organised by the child's cardiac team to help them make decisions regarding inclusion in activities.[35] *Children must remind teachers and have confidence and understanding of their differences in ability to peers. Exercise guidance can confuse individuals with DCM as the advice can be non-specific and sport and activity options vary* (ERJ). The information in this section is based on research and recommendations in adults as there are very few studies available on children.[36] Clinical exercise capacity tests include ambulatory monitors and stress tests where electrocardiogram tracing is used to monitor heart rate and blood pressure changes. Specific guidance on the age of initiation of these tests in children is lacking, and they are often implemented at about 7 years of age when children can follow instructions.[37]

People with DCM are often eager to improve and maintain their health (ERJ). For those able, physical activity is recommended to improve quality of life and reduce HF hospitalisation.[38] The 2020 ESC guidelines for sports cardiology and exercise in people with cardiovascular disease and the British Heart Foundation, United Kingdom, suggest using the Borg scale to measure perceived exertion. Moderate-intensity exercise leads to perspiration and increased heart and breathing rates; however, individuals should still be able to hold a conversation throughout the exercise.[39,40] The British Heart Foundation and Cardiomyopathy UK advise individuals to warm up and cool down, avoid physical activity when unwell or tired, and avoid exercise with sudden exertion such as sprinting or heavy weightlifting, opting instead for smaller weights with higher repetitions.[39,41]

The ESC Guidelines on Sports Cardiology and Exercise (2021) [4,40] state that intensive exercise and competitive sports may trigger fatal arrhythmias and can cause sudden cardiac death. The guidelines recommend moderate exercise (150 minutes per week) in stable adults with DCM, healthy adults of all ages, and individuals with known cardiac disease. Symptomatic individuals with DCM should not partake in moderate or high-intensity competitive and leisure sports or recreational exercise. *The symptomatic or asymptomatic criteria are challenging guidance for people with cardiomyopathy; for example, comparing a person unable to walk 100 m on flat ground without stopping to someone who becomes breathless if they run up three flights of stairs* (ERJ).

Certain DCM interventions may prohibit specific types of exercise and sports. Beta-blockers inhibit adrenaline that acts on the sympathetic nervous system. Contact sports should be avoided if a pacemaker or implantable cardioverter defibrillator has been inserted.[42] High adrenaline activities are contraindicated for individuals with cardiomyopathy due to the risk of arrhythmias. Activities such as skydiving, rollercoasters, and bungee jumping are not recommended.[43] *Adrenaline experienced from everyday events such as stress, running for the bus or a sports team winning, cannot be avoided*, and *people with DCM want advice regarding the potential for over-exertion in their sex life* (ERJ). The British Heart Foundation advises that if a person with cardiomyopathy can walk a mile on flat ground in 20 minutes or climb two flights of stairs comfortably, it should be safe to have sex.[44]

Alcohol, caffeine, smoking, and vaping

Adolescents with cardiomyopathy often have questions about alcohol, caffeine, smoking, and vaping (Figure 2). Making informed decisions can be challenging if the guidance is non-specific. Transition clinics should incorporate specific information such as is discussed below to ensure patients are well informed of the risks, instead of generic abstinence advice (ERJ). The studies discussed in this section include research from adult studies because of the ethical and legal complications of teenagers accessing alcohol, cigarettes, and vapes under the legal age limit. There is limited evidence on the impacts of these substances on people with pre-existing cardiovascular disease. It is inadvisable to take anything in excess that could influence heart rate, blood pressure, and the lungs, which are also the targets of pharmacotherapy used to treat cardiovascular diseases.

Alcohol and caffeine are diuretics and dehydrating so they should be avoided in excess.[4,45] People with cardiomyopathy should hydrate more before and after alcohol or caffeine intake. Alcohol abuse is the leading cause of secondary DCM in adults (denoted alcoholic cardiomyopathy). "Heavy drinking" (heterogeneously described in different studies over a range of 10–13 units per day for 2–5 years) is associated with adverse outcomes and increased mortality in people with HF.[46–48] Grubb et al. (2021) found that in people with HF, small to moderate amounts of alcohol increase the risk of developing atrial fibrillation, a risk factor for mortality,[46] but otherwise, information surrounding the risk of modest alcohol consumption is limited.[48] It has been suggested that 1–2 drinks (unspecified units) per week may have a low risk of adverse events in HF.[46]

In the context of heart disease, caffeine is considered safe in moderation (approx. 300 mg/day). Caffeine stimulates greater cortisol and adrenaline circulation, which can increase heart rate and blood pressure and cause palpitations. This may act in opposition to prescribed beta-blockers and ACE inhibitors.[49] Individuals with DCM should be cautious about mixing caffeine and alcohol. The full mechanism of how these compounds work concurrently is not fully understood and could lead to arrhythmogenesis.[50]

Smoking cigarettes is a known cardiovascular disease risk factor. Nicotine influences vasoconstriction.[51] The ESC Guidelines (2023) state that there is no data to show an interaction between tobacco and cardiomyopathy.[4] However, smoking tobacco has been linked to worsening outcomes for people with HF and increases broad cardiovascular mortality and morbidity.[46] This may be due to smoking increasing the myocardial oxygen demand, coronary vasodilation impairment, and the acceleration of atrial collagen, which can lead to symptomatic atrial fibrosis.[46,52] Many of the associated risks of smoking are not specific to cigarettes and apply to inhalation of any drug or the intake of nicotine via other methods (patches, gum, vaping, etc.).

Vaping has gained recent popularity as a "healthier" alternative to smoking, particularly in cancer development. There is very little evidence on the long-term effects of vaping on health, and it has been suggested that it could be damaging to cardiovascular health, particularly nicotine and other E-cigarette chemicals.[51] Like smoking, vaping can increase heart rate and blood pressure and the development of HF.[51,53] Vaping poses a risk of lung damage. which, in combination with existing cardiovascular disease, could cause health complications.[54] Recent studies have found an increased link between smoking, vaping, and self-reported hypertension.[55]

The impact of illegal recreational drug use on the heart

Most of the information and guidance surrounding drug use is based on adults. *As adolescence is a complex time with navigating*

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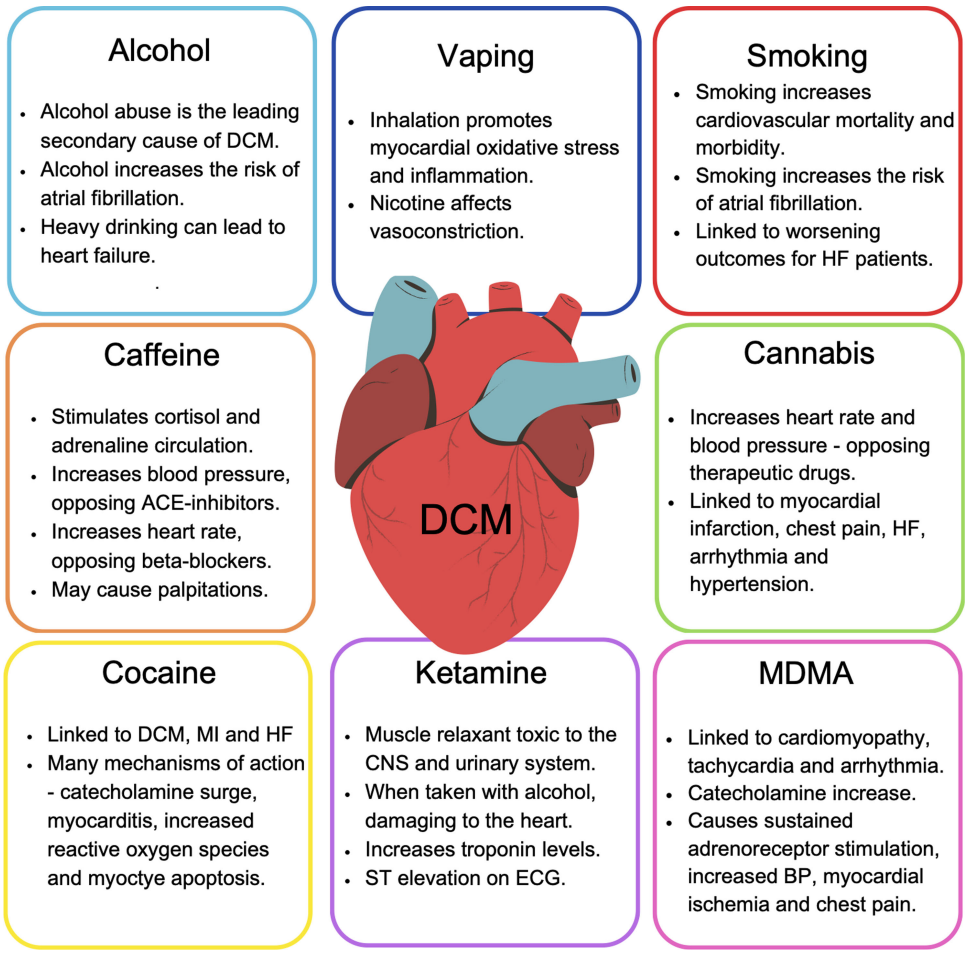

Figure 2. The impact of alcohol, vaping, tobacco, caffeine, cannabis, cocaine, ketamine, and MDMA, on the heart and in dilated cardiomyopathy. DCM = dilated cardiomyopathy; HF = heart failure; MDMA = 3,4-methylenedioxymethamphetamine; MI = myocardial infarction; CNS = central nervous system; ECG = electrocardiogram; BP = blood pressure. This figure was created with Canva.

social pressures, the risks of drugs and reasons for advocating abstinence need to be addressed during the transition clinic (ERJ). The UK government's Focal Point annual report (2021) reported that in 2018, 38% of 15-year-olds reported having ever used drugs. The most used drugs were cannabis, powder cocaine, 3,4-methylenedioxymethamphetamine (MDMA), ketamine, and amphetamine.[56] These substances can be damaging for those with existing cardiac conditions (Figure 2),[46] and the ESC cardiomyopathy guidelines (2023) recommend avoiding drug consumption.[4]

Despite the suggested benefits of cannabis intake, such as the treatment of chronic pain, it can influence the cardiovascular system. Delta-9-tetrahydrocannabinol (THC) is the main psychoactive compound in cannabis. THC can increase heart rate, blood pressure, and sympathetic output, inhibit the parasympathetic system and oxygen demand, and decrease ejection fraction.[57,58] Like caffeine, these effects oppose the therapeutic effects of common DCM treatment.[59] Other than psychiatric diagnoses, the most common primary diagnoses linked to cannabis use are acute myocardial infarction, chest pain, HF, arrhythmia, and hypertension.[57–59]

Cocaine is potentially the most cardiotoxic drug and causes variable damage to the cardiovascular system. It is highly arrhythmogenic and can cause myocardial scarring. The mechanism of cocaine-induced cardiomyopathy and HF is through catecholamine surge, eosinophilic myocarditis, impaired intracellular handling, apoptosis of myocytes, and elevated levels of reactive oxygen species.[60]

Ketamine is a drug used in a medical context as a muscle relaxant and for sedation. It can cause toxicity in the central nervous system and the urinary system. Its potential adverse effects on the heart have not been fully explored. Chan et al. (2011) used a mouse model to investigate this, and alongside the co-use of alcohol, long-term ketamine treatment increased troponin levels and electrocardiogram severity (ST elevation).[61]

MDMA has been linked to cardiomyopathy, particularly DCM, as well as tachycardia and arrhythmia.[62,63] This may be due to a catecholamine increase, which leads to a sustained stimulation of adrenoreceptors and can cause increased blood pressure, chest pain, and myocardial ischaemia.[64] Catecholamine surges have been linked to takotsubo cardiomyopathy, a reversible cardiomyopathy. It is mostly identified postmenopausal, but if seen in people with cardiomyopathy under the age of 45 years and in males, it can be associated with drug abuse.[58,65]

Experimentation with drugs can vary in combination, dose, and time, which is difficult to study. HF has been documented as an after-effect in those with cardiomyopathy taking drugs, although acute events are rare.[51,66] Amirahmadi et al. (2021) reported a case of a 19-year-old with no family history of sudden cardiac death or congenital heart disease and a 3-year history of using electronic

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cigarettes, vaporised marijuana, recreational benzodiazepine, and oral opioid use. She presented with acute cardiac dysfunction and cardiomyopathy.[66]

Reproductive health

The care team should offer genetic counselling and discussions surrounding reproductive options (with both parties) if one person has DCM (regardless of sex) before family planning commences. The patient should be aware of their options, including natural conception, pre-implantation and prenatal testing (if a genetic cause has been identified), donor gametes, and adoption or fostering.

Forms of contraception should be discussed during the transition clinic to prevent unplanned pregnancy and sexually transmitted infections (STIs). These are important for individuals with cardiomyopathy as they may have added risks.[67] *Where contraceptives are provided in combination with treatment due to adverse effects of a cardiac intervention on a foetus, the reasons for its prescription must be discussed* (ERJ). The risk of an unplanned pregnancy in a particular case should be considered by the person with cardiomyopathy and their clinician.[67] *However, young people should be made aware that the decision is ultimately theirs* (ERJ).

Progesterone-only contraception is recommended for females with DCM due to the increased risks of deep vein thrombosis and hypertension with oestrogen-based options.[3,4,67] Other non-oestrogen options for contraception are the implant (in the arm), depot (injection), intrauterine device, copper coil, and barrier methods (condoms).[4,67] The progesterone emergency contraceptive pill ("morning after pill") is safe for individuals with DCM as there are no relevant medication interactions. *People with DCM should inform their hospital or healthcare team that they have taken an emergency prescription* (ERJ).

Once an individual is sexually active, the risks of contracting STIs must be considered. There is little research on the impact of STIs on the prognosis and outcomes of people with cardiomyopathies, and it is important to note that the cases described here are rare and mostly result from long-term infection without treatment. DCM can be caused by myocarditis, and some triggers include STIs, such as chlamydia, gonorrhoea, and syphilis.[68,69] Late-stage syphilis infection can cause multiple organ failure in healthy individuals and complications for individuals with cardiovascular disease.[70] HIV-infected individuals are at a higher risk for cardiovascular disease and HF, particularly after a myocardial infarction.[71] People with DCM should be informed of the preventative measures for STIs (correct and consistent use of condoms) and regular testing when changing partners or once per year.[72] If an STI is contracted, the treatment options are the same, regardless of a diagnosis of cardiomyopathy, and infections should be treated early to avoid complications.

For females with cardiovascular disease who are seeking to conceive, there are specific risks of pregnancy to consider. Pre-pregnancy counselling is required as there are additional physiological stresses associated with pregnancy.[4,67] Electrocardiograms, exercise tests, and MRIs are recommended to establish heart function and health before conception. Pregnancy can be poorly tolerated due to the increased blood volume, cardiac output, and stroke volume associated with pregnancy.[3,67] The increased blood volume but stable blood count can cause anaemia, which can worsen the prognosis of HF.[3]

Pregnancy has a significant risk of deterioration of ventricular function, exemplified by the development of post-partum cardiomyopathy in those without existing disease. People with moderate or severe ventricular dysfunction and/or NYHA class III/IV are at a higher risk of complications. The most common complications during pregnancy in cardiomyopathy patients are arrhythmia and HF, even in patients without HF or with stable, mild HF.[3] Conversely, females with mild dilation of their left ventricle and no history of cardiac events can have a major cardiac event-free pregnancy.[73]

Some HF medications are incompatible or contraindicated in pregnancy. Intake must be ceased before conception and in preparation for a pregnancy to avoid foetal harm. In the event of an unplanned pregnancy, the contraindicated medications should be stopped as soon as possible, and the person with cardiomyopathy and foetus should be closely monitored.[67,74] Monitoring cardiac alterations with medication withdrawal is required, and the safety of a pregnancy should be reconsidered if ejection fraction reduces.[67,74] These include ACE inhibitors, angiotensin receptor blockers, angiotensin receptor neprilysin inhibitors, mineralocorticoid receptor antagonists, and ivabradine.[38] Some diuretics and digoxin are considered safe, and beta-blockers are recommended to be continued throughout pregnancy with regular foetal heart rate monitoring. Foetal growth may be impacted by beta-blocker use.[75] After delivery, most medications can be restarted and are not contraindicated for breastfeeding.[3,67] Breastfeeding is not recommended in people in NYHA class III/IV due to its high metabolic demand.[3,67]

Conclusions

Children and adolescents with DCM require the correct resources and support to come to terms with having limitations amongst healthy peers. There is a lack of research in children and adolescents with cardiomyopathy, in many areas of treatment and care. Emphasis and teaching on self-advocation for medical decisions in the transition clinic is imperative. In the school setting, activity inclusion and medication intake are generally advocated by the child, despite a care plan provided by medical teams. Charities can provide support, advice, and guidance and provide a meeting place for the young with DCM.

Useful support resources

European Heart Network: https://ehnheart.org/ehn-members/

Cardiomyopathy UK young people resources: https://www.cardiomyopathy.org/young-people

Cardiomyopathy UK youth panel: https://www.cardiomyopathy.org/youth-panel

Cardiomyopathy UK Facebook group: https://www.cardiomyopathy.org/facebook-groups

Cardiac Risk in the Young support: https://www.myheart.org.uk/services/

British Heart Foundation health unlocked: https://healthunlocked.com/bhf

British Heart Foundation young people resources and support: https://www.bhf.org.uk/informationsupport/support/children-and-young-people

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