

# Living with peripartum cardiomyopathy: A statement from the Heart Failure Association and the Association of Cardiovascular Nursing and Allied Professions of the European Society of Cardiology

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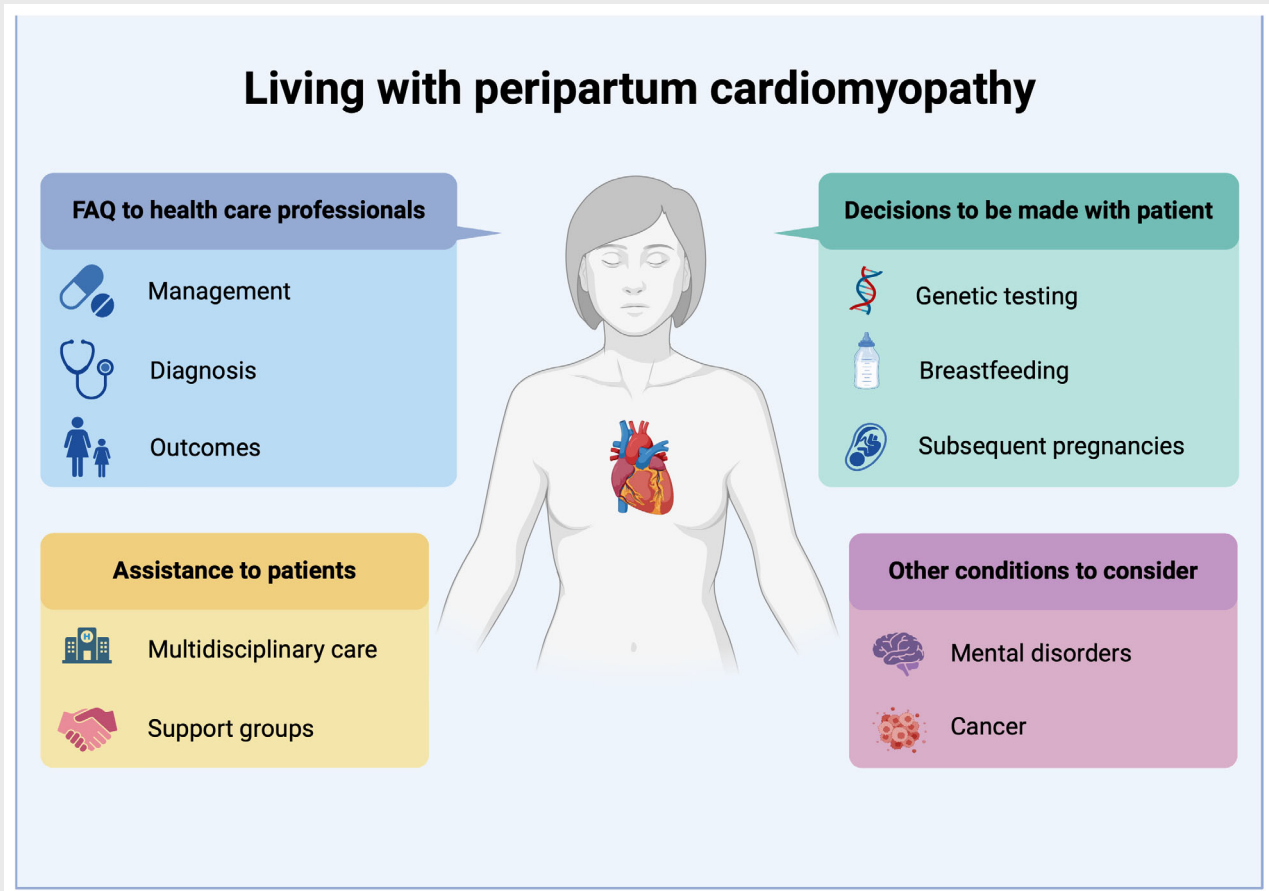
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This statement focuses on the fact that women with peripartum cardiomyopathy (PPCM) have a substantial mortality and morbidity rate. Less than 50% of patients have full recovery of their cardiac function within 6 months of diagnosis. Also, patients with recovered cardiac function often suffer from comorbidities, such as hypertension or arrhythmias, which require long-term treatment. This has major implications which extend beyond the life of the patient, as it may also substantially impact her family. Women with a new diagnosis of PPCM should be involved in the decision-making processes regarding therapies, e.g. the recommendation to abstain from breastfeeding, or the use of cardiac implantable electronic devices. Women living with PPCM face the uncertainty of not knowing for some time whether their cardiac function will recover to allow them a near-to-normal life expectancy. This not only impacts their ability to work, which may have financial implications, but may also affect mental health and quality of life for the extended family. Women living with PPCM must be informed that a future pregnancy always carries a substantial risk and, in case of poor cardiac recovery, is associated with a high morbidity and mortality. Patients with PPCM are best managed by an interdisciplinary and multiprofessional approach including e.g. a cardiologist, a gynaecologist, nurses, a psychologist, and social workers. The scope of this document encompasses contemporary challenges and approaches for the management of women diagnosed with PPCM.

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## Graphical Abstract



This position paper highlights the key considerations in managing patients living with peripartum cardiomyopathy (PPCM), including addressing frequently asked questions (FAQs) by affected patients and their families, collaborative decision-making, providing patient assistance and considering other conditions often encountered with PPCM.

### Keywords

Peripartum cardiomyopathy • Multidisciplinary care • Patient awareness • Therapy

## Introduction

Peripartum cardiomyopathy (PPCM) is a disease that occurs globally in all ethnic groups and should be suspected in any peripartum women presenting with symptoms and signs of heart failure (HF), towards the end of pregnancy (or in the months following delivery), with confirmed left ventricular (LV) dysfunction.<sup>1,2</sup> After good history taking, all women should be thoroughly assessed and alternative causes should be excluded. Urgent cardiac investigations with an electrocardiogram (ECG) and natriuretic peptide measurement (if available) should be performed, followed by echocardiography.<sup>3</sup> Referral for genetic work-up should be considered especially if there is a family history of cardiomyopathy and/or sudden death.

Peripartum cardiomyopathy carries a substantial risk for maternal and neonatal morbidity and mortality. The Heart Failure Association (HFA) of the European Society of Cardiology (ESC) Study Group on PPCM initiated the largest prospective global cohort study, under the umbrella of the EURObservational Research Programme (EORP), with more than 700 PPCM patients, providing novel data on presentation in various ethnic groups, as well as reporting a 6% maternal mortality at 6 months and 5% neonatal death.<sup>4</sup> Maternal mortality, no matter when and where it occurs, has major implications that extend beyond the loss of the life of a single woman. The central role of women in breastfeeding, nurturing, educating, and caring for children (and the next generation), is well described. Therefore, the death of a

mother may adversely influence the ability of her family to survive and thrive, especially under poor socioeconomic conditions.<sup>5</sup>

Remarkable advances in the comprehension of the pathogenesis, predictors of outcome, medical and device therapy have been achieved, largely due to team efforts and close collaboration between basic scientists, cardiologists, intensive care specialists and obstetricians.<sup>6–8</sup>

The diagnosis of PPCM carries a major threat to the patient and, if still pregnant, also to the foetus. Beyond the physical illness with acute HF to cardiogenic shock, and necessity of treatment in an intensive care unit, the psychologic and social stress is substantial – both during the acute phase, as well as thereafter. The disease also impacts the partner and other family members who need to support the patient. Patients who have access to the internet often look up the diagnosis of PPCM online and become aware of the substantial mortality and the risk of no recovery of their cardiac function and poorer life expectancy. This can be compared to the diagnosis of cancer, but the psychological consequences have not been as well addressed for women living with PPCM. Recently, it has been shown in a German PPCM cohort that the majority of PPCM patients displayed mental health disorders in the period following diagnosis, with a higher prevalence of major depressive disorders, post-traumatic stress disorder and panic disorder, as compared to healthy postpartum women (*Graphical Abstract*).<sup>9</sup>

If patients are not critically ill, the question of breastfeeding is of major importance, as is the initiation and, often, long-term continuation of a multi-drug treatment regimen for HF, along with participation in a cardiac rehabilitation programme. If the patient is critically ill, the implantation of short- and potentially long-term mechanical ventricular support, as well as heart transplantation, poses a significant psychological challenge to the patient and her family, as these interventions are serious and linked to substantial morbidity and even mortality.

This document is based on an expert consensus reached at a Workshop of the Committee on Peripartum Cardiomyopathy of the HFA, held in Prague in May 2023.

## What are the concerns of patients diagnosed with peripartum cardiomyopathy?

To convey a new severe medical diagnosis to a patient is a crucial but sensitive task that requires empathy, clear communication, and a supportive approach. As medical terminology may be overwhelming – and even confusing to patients – the clinician should explain the diagnosis using plain and understandable language. The physician should encourage the patient to ask questions and express their concerns. *Figure 1* summarizes the frequently asked questions (FAQs) from patients recently diagnosed with PPCM obtained by a survey conducted via the ESC EORP in July 2023 sent to the EORP PPCM registry participating doctors (for which answers are provided in the online supplementary material).

Upon initial diagnosis, women with PPCM (and their families) might be unfamiliar with the condition. Their managing clinician

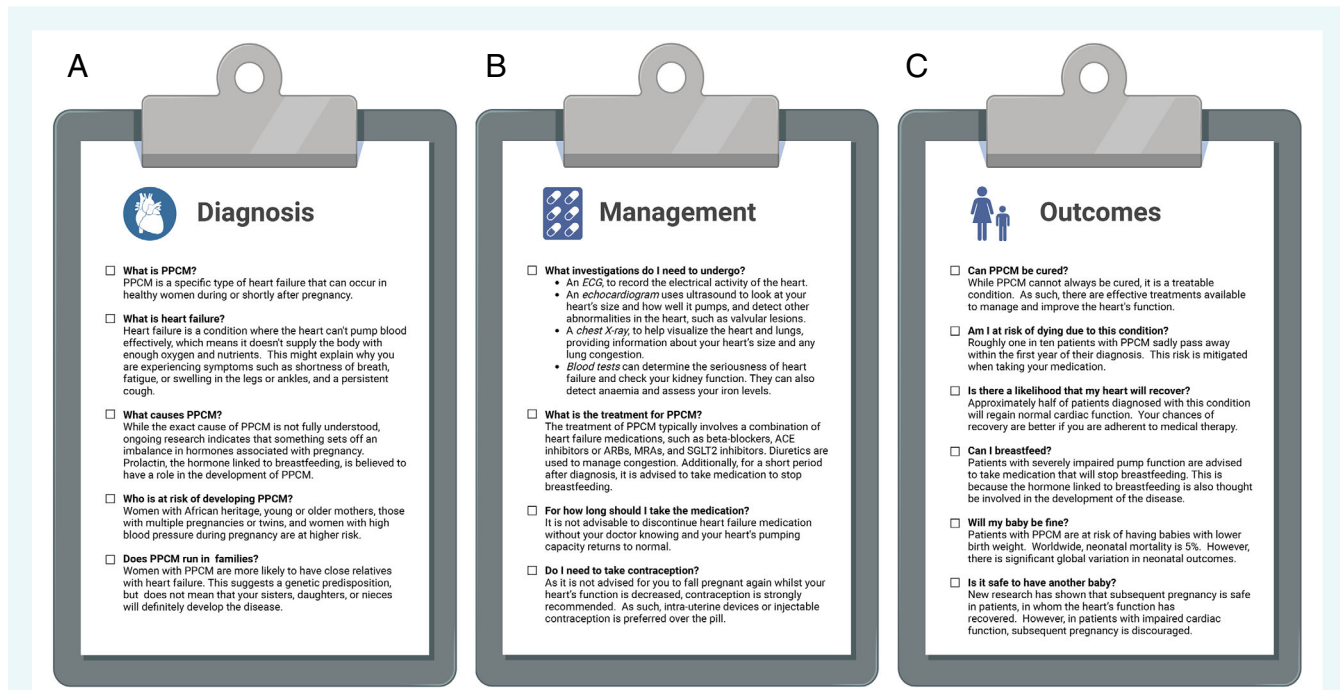
needs to explain that PPCM is a form of HF that occurs in previously healthy women during the latter stages of pregnancy, or in the first few months after birth.<sup>1</sup> The patient may also need further explanation as to what HF is and that her symptoms, such as shortness of breath, fatigue, or swelling in the legs or ankles and a persistent cough, are related to impaired LV systolic function.<sup>4,10</sup> Patients should be made aware of the seriousness of PPCM and its associated risks,<sup>11</sup> and be given ample time and opportunities with specialists to gain a clear understanding of the situation.

Patients often ask why they developed PPCM and what is the cause.<sup>12</sup> At this stage it is important to reassure the patient that they are not at fault for developing the disease. Although the aetiology of PPCM remains incompletely understood, patients should be counselled that the nursing hormone prolactin, responsible for breastfeeding, is believed to have an important role in the pathophysiology of the condition.<sup>13</sup> Patients at increased risk include women with African heritage, younger or older mothers, those with multiple previous pregnancies or twins, and women with hypertensive disorders during pregnancy.<sup>12</sup> Patients may ask if PPCM is a genetic disease and whether their sisters, daughters or nieces are at risk. Emerging research shows that women with PPCM are more likely to have close relatives with HF and that a genetic predisposition could contribute to development of PPCM, but that this does not mean that their relatives will necessarily develop the disease.<sup>3</sup>

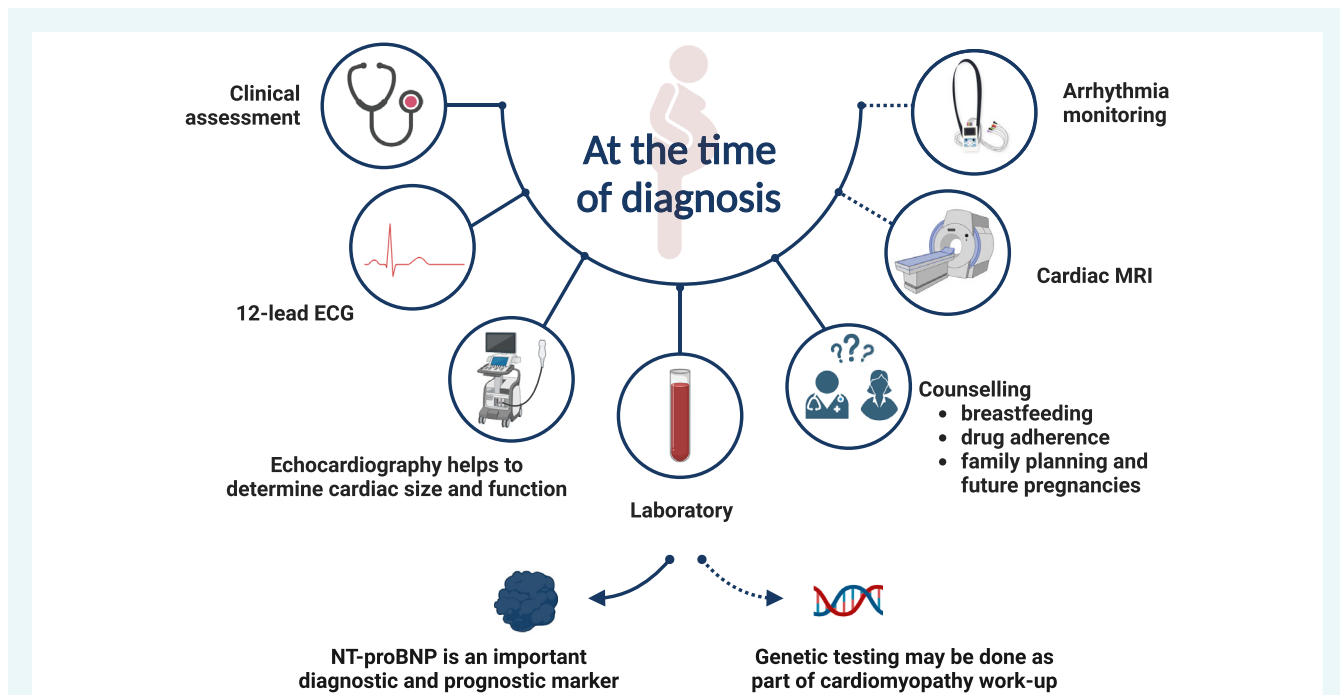
Patients should be informed about the investigations that are done to diagnose and monitor PPCM (*Figure 2*), such as an ECG, echocardiography and chest X-ray, and why these tests are performed.<sup>1</sup> Patients should also be told what blood tests will be done, and what the value of these tests are.

As patients with PPCM previously enjoyed good health, they are naturally concerned about whether they will be cured. The clinician needs to reassure the patient that PPCM is a treatable condition, but that it is not always possible to cure them. Nevertheless, patients should be reassured that there are effective treatments available for PPCM to improve cardiac function and that being pregnant or post-partum as well as breastfeeding has an impact of medication which can be prescribed. Patients should be informed about the combination of HF drugs that will be prescribed, such as beta-blockers, angiotensin receptor–neprilysin inhibitors or angiotensin-converting enzyme (ACE) inhibitors, mineralocorticoid receptor antagonists (MRAs), and sodium–glucose cotransporter 2 inhibitors, and should be encouraged to be adherent to their medical therapy.<sup>1,11</sup> Patients often ask how long they should take these drugs, and they should be advised not to discontinue this therapy, especially if their LV function has not recovered. Patients should be told about diuretics that could be used for congestion. They should also be advised about disease-modifying medications such as bromocriptine or, possibly, cabergoline to stop breastfeeding, and allow early initiation of guideline-directed HF medication, which could favourably interfere with the pathophysiology of PPCM.<sup>14</sup>

Patients with PPCM often ask about the safety of subsequent pregnancies. The 2018 ESC guidelines for the management of cardiovascular diseases during pregnancy warn about future pregnancies.<sup>15</sup> If their LV function has recovered, they should carefully



**Figure 1** Frequently asked questions (FAQs) by patients with peripartum cardiomyopathy (PPCM) to healthcare professionals regarding their diagnosis (A), management (B) and outcomes (C) with example answers. ACE, angiotensin-converting enzyme; ARB, angiotensin receptor blocker; ECG, electrocardiogram; MRA, mineralocorticoid receptor antagonist; SGLT2, sodium–glucose cotransporter 2.



**Figure 2** Diagnostic work-up of patients with peripartum cardiomyopathy. ECG, electrocardiogram; MRI, magnetic resonance imaging; NT-proBNP, N-terminal pro-B-type natriuretic peptide.

discuss any planned subsequent pregnancies with their managing physician. A subsequent pregnancy may be possible, if LV function remains stable after careful tapering of the HF medication such as ACE inhibitors or MRAs, which are contraindicated in pregnancy and under careful echocardiographic follow-up. Whether they ask about contraception or not, this should be discussed at the time of diagnosis and at each follow-up. As such, intra-uterine devices, or injectable contraceptive methods such as progesterone implants are preferred over oral contraception.<sup>1</sup> PPCM is associated with increased thromboembolic events, for which anticoagulation may need to be prescribed.<sup>16</sup>

Ultimately, a patient who has just been diagnosed with PPCM is concerned about both their own prognosis and that of their newborn. They will ask about mortality and LV recovery and should be advised that mortality is about 8–10% at 1 year after index diagnosis, but that guideline-directed medical therapy is associated with better survival.<sup>17</sup> Similarly, they should be counselled that adherence to HF treatment is associated with better rates of LV recovery to pre-pregnancy state.<sup>17,18</sup> Although there is global variation, they can be reassured that on average more than half of patients will display recovery of their LV function after 1 year.<sup>17,19</sup>

Patients with PPCM are similarly concerned about the well-being of their newborn. They should be counselled that they are at risk of delivering a neonate with a lower birth weight, and that the global neonatal mortality is about 5%.<sup>4,20</sup>

## Decision making for peripartum cardiomyopathy patients and family at diagnosis

### Diagnosing and managing arrhythmias

The EORP PPCM registry documented a 6-month all-cause mortality rate of 6% for 739 women with PPCM, across 49 countries. Approximately 30% of these deaths were assumed to be sudden cardiac deaths (SCD).<sup>4,21</sup> It is believed that arrhythmias play an important role in this regard, as patients with PPCM are at increased risk of developing arrhythmias. In a retrospective review of 9841 individuals hospitalized for PPCM, arrhythmias occurred in 18.7%. Among these patients, ventricular tachycardia (VT) was the prevailing arrhythmia (4.2%), followed by atrial fibrillation (1.3%) and ventricular fibrillation (VF) (1%).<sup>22</sup> Screening for arrhythmias has thus been confirmed as an important aspect of managing patients with newly-diagnosed PPCM.

Patients with severely impaired LV systolic function are at increased risk of life-threatening VTs.<sup>23</sup> Considering the potential substantial improvement in LV function with optimal HF drug therapy observed in patients with PPCM, early implantation of an implantable cardioverter-defibrillator (ICD) is generally not advisable. In cases of severe LV dysfunction persisting for 6–12 months after their initial presentation, despite receiving optimal medical treatment, an ICD should be considered, according to the 2021 ESC guidelines for the diagnosis and treatment of acute and chronic heart failure.<sup>24</sup>

The wearable cardioverter-defibrillator (WCD) offers a safe and non-invasive option for averting sudden arrhythmic death in individuals with a transient risk of malignant tachyarrhythmias, such as in PPCM. A recent German study examined the use of a WCD to prevent SCD in PPCM. Over a total cumulative wear time of 932 days, the WCD administered four appropriate shocks for VF to seven patients newly diagnosed with PPCM, and severely reduced LV ejection fraction (LVEF <35%).<sup>25</sup> In a subsequent multicentre study involving 49 patients with newly diagnosed PPCM and LVEF <35%, the WCD detected ventricular arrhythmias in five patients (12%). These was comprised of five episodes of VF, two instances of sustained VT and one case of non-sustained VT. All VF episodes were successfully terminated by a WCD shock. No inappropriate shocks were recorded throughout the study duration. These ventricular arrhythmias manifested between 40 and 165 days after the PPCM diagnosis.<sup>26</sup> These data highlight important therapeutic benefits. In fact, the WCD can serve as a valuable 'bridging' therapy, enabling the up-titration of HF therapy and providing protection against SCD resulting from VTs. However, WCDs are not available in large parts of the world.

This monitoring approach encompasses Holter monitoring for all patients with severely impaired LV systolic function during the acute phase of the disease. Additionally, implantable loop recorders may be appropriate if 24-h Holter monitoring yields inconclusive results or if symptoms indicative of arrhythmias manifest infrequently.<sup>27</sup> *Figure 2* summarizes the diagnostic tools and therapeutic devices used for the diagnosis and management in PPCM patients.

Additionally, patients with HF are also at risk of bradyarrhythmias. Severe bradycardia or electromechanical dissociation has been documented as the rhythm around the time of cardiac arrest in up to two-thirds of patients with advanced HF.<sup>28</sup> Indeed, a recent report on patients who received an implantable loop recorder early after PPCM diagnosis highlighted that SCD in PPCM may also be due to bradyarrhythmias.<sup>27</sup>

### Breastfeeding

Unbalanced peri/postpartum oxidative stress can lead to the proteolytic cleavage of the nursing hormone prolactin into the 16-kDa subform, which has been identified as a potent anti-angiogenic, pro-apoptotic, and pro-inflammatory component contributing to the pathophysiology of PPCM.<sup>29</sup> Blocking prolactin with bromocriptine, a dopamine D2 receptor agonist, has been effective in preventing the onset of PPCM in experimental models and has shown improved clinical outcome and survival in patients with PPCM.<sup>17</sup> According to the 2018 ESC guidelines for the management of cardiovascular diseases during pregnancy, the use of bromocriptine and termination of lactation may be considered in patients with PPCM, to improve LV recovery and clinical outcome (*Table 1*).<sup>15</sup> Furthermore, the compatibility of HF drugs with lactation has been a topic of discussion.<sup>1</sup> Individualized counselling and patient discussion are advised for long-term drug therapy and lactation, considering potential side effects and drug transfer to breast milk. The choice of HF therapy depends on breastfeeding status with careful consideration of benefits and

**Table 1** Benefits of breastfeeding and risks of stopping early

Breastfeeding benefit	Risks of terminating breastfeeding early
Termination of lactation and the use of bromocriptine in PPCM patients may help in managing the condition by reducing the levels of the nursing hormone prolactin.	Termination of lactation may have emotional and psychological implications for the mother, as breastfeeding is a bonding experience and source of nutrition for the infant.
Stopping lactation with bromocriptine in PPCM patients with moderate-to-severe HF may enable complete guideline-directed medical treatment for HF, potentially improving outcomes for both mother and infant.	In areas of unsafe water supply termination of breast-feeding may lead to diarrhoea of the infant resulting in significant disease and poor outcome including death.

HF, heart failure; PPCM, peripartum cardiomyopathy.

potential risks for both mother and infant. In PPCM patients with moderate-to-severe HF, the consensus view of the HFA PPCM Committee advises stopping lactation with bromocriptine, add anticoagulant in at least prophylactic dose to enable complete guideline-directed medical HF treatment. Recent data by Tromp *et al.*<sup>16</sup> showed that the majority of the thrombotic events occurred at time of presentation, and therefore long-term prophylactic dose is not needed.

## Decision making for peripartum cardiomyopathy patients and family related to chronic care

Treatment for PPCM includes HF pharmacotherapy, cardiac rehabilitation and potentially devices. Given the rather high rate of LV recovery in PPCM, early decisions about primary prevention ICDs should be considered carefully and patients should be risk stratified appropriately, ideally supported with data from genetic testing and cardiac magnetic resonance imaging where available. Many women with recovered PPCM are advised to remain on guideline-directed therapy lifelong. In the prospective TRED-HF (i.e. the withdrawal of pharmacological treatment for HF in patients with recovered dilated cardiomyopathy) study, almost half of patients in the treatment withdrawal group relapsed, compared to none in the treatment continuation group.<sup>30</sup> Although there are currently no specific studies investigating the withdrawal of medication for patients with PPCM, clinical experience suggests that in PPCM patients with recovered LVEF a careful tapering of HF drugs may be possible under close surveillance.

## Genetic testing

The role of genetic testing in women with PPCM is a further aspect of long-term management, which may also impact the wider family. In two studies, approximately 15% of women with PPCM were found to harbour changes in genes known to cause dilated cardiomyopathy, with the majority being truncating variants in the gene coding the protein titin.<sup>31,32</sup> This has important implications for genetic and clinical screening in family members, including children. Where services facilitate genetic counselling, this should be discussed. Furthermore, it has been shown that the incidence

of cardiovascular disease in children born to women with PPCM is three times higher than that of children born to healthy controls.<sup>20</sup>

## Contraception

An important aspect of long-term management, particularly while LV dysfunction persists and a woman is on potentially teratogenic therapies, is safe and effective contraception. Early counselling regarding contraception is crucial and, given the potential complexity, may require both cardiologist and obstetrician input. The use of barrier methods alone is not a reliable form of contraception, but reduce the risk of sexually transmitted infections. A safer contraceptive approach in women with PPCM is the combination of barrier methods with long-acting reversible contraception (LARC). However, peripartum women with HF are at risk of thrombo-embolic events and hypertension.<sup>4,16</sup> Thus, hormonal contraception with pro-thrombotic effects should be avoided.<sup>33</sup> The oestrogen component in combined oral contraceptives significantly increases the risk of venous (up to seven-fold) and arterial thrombosis, as well as hypertension.<sup>34</sup> Long-acting reversible forms of progestin-only contraceptives are the safest and most effective for women with PPCM. They do not have pro-thrombotic effects, do not potentiate bleeding during menstruation, and do not depend on patient adherence. Women can choose between LARCs such as intrauterine devices containing levonogestrel or subdermal implants with etonogestrel or levonogestrel. Subdermal implants are easily inserted and keep their contraceptive efficacy for 3–5 years. Levonogestrel-releasing intrauterine system (IUS, Mirena) is often preferred over banded copper-containing intrauterine device (copper-IUD) as, in the majority, it results in amenorrhoea.

## Future pregnancies

Women with PPCM frequently ask about future pregnancies. Many would not have intended on completing their family. The safety of a subsequent pregnancy is an important component of informed counselling for a woman with PPCM. Women should be offered comprehensive pre-pregnancy counselling to support them in their decision making. Current guidance is stratified according to whether or not LV recovery has occurred after the index presentation.<sup>15,35</sup> The 2018 guidelines for the management of

cardiovascular diseases during pregnancy<sup>15</sup> categorizes women with PPCM into one of two groups: modified World Health Organization (mWHO) III if recovered and mWHO IV (greatest maternal and foetal risk) if unrecovered. Relapse occurs in around 30% of pregnancies (approximately one in five with recovered cardiac function and almost one in two of those without recovered cardiac function).<sup>36–38</sup> Mortality tends to occur predominantly in women who enter a subsequent pregnancy with persisting LV dysfunction.<sup>35</sup> In those with recovery who wish to conceive again, although no standardized approach exists, close monitoring of LV function and biomarkers during tapering of drug treatment is sensible. During pregnancy, care should be provided by a specialist cardio-obstetric team where possible. In the future, routine use of more sophisticated imaging modalities (such as global longitudinal strain or stress echocardiography), better phenotyping and detection of high-risk gene variants in women with PPCM with apparent normalization of LV systolic function may help identify women at greater risk of recurrence.

## Mental disorders in peripartum women

According to Maternal Mortality Review Committees, 10–25% of pregnancy-related deaths are due to severe mental illness, referred to as perinatal psychiatric illness (PPI), demonstrating that PPI is more common in disadvantaged groups and minorities, and in low-income countries.<sup>39,40</sup> PPI is a contributor to poor outcomes throughout pregnancy, childbirth and postpartum. Rates of PPI are estimated to range from 7% to 15% in high-income countries, while the prevalence ranges from 19% to 25% in low- and middle-income countries.<sup>41</sup> In high-income countries, PPI is the most common morbidity in pregnancy and the leading cause of perinatal mortality.<sup>42</sup> PPI refers to any mental health disorder experienced from the beginning of pregnancy up to 1 year postpartum.<sup>43</sup> Although often attributed primarily to major depression, PPIs include different mental health conditions such as anxiety disorders, insomnia, post-traumatic stress disorder, obsessive-compulsive disorder and psychotic disorders.

Concerns about the future, questions concerning care of the child, breastfeeding issues, future pregnancies, and social and professional consequences of a HF could lead to distressing feelings, mental health conditions such as depression, and potentially to more severe PPIs. Listening to the patients concerns and careful counselling is advised. Stress reduction techniques such as progressive muscle relaxation and mindfulness-based stress reduction may alleviate the global stress level, although studies are lacking.

Mental disorders in PPCM may result from several conditions including the aforementioned psychosocial factors and biological factors. Psychosocial factors such as the threat of a potentially life-threatening disease, concerns about caring for a newborn, worries concerning close relationships and return to work, may lead to a combination of physical and psychological distress. Biological factors may include an impaired tryptophan metabolism with reduced levels of the anti-depressive neurotransmitter serotonin, increased levels of the pro-inflammatory kynurenine, and a dysregulation of depression-associated microRNAs.<sup>9</sup>

Untreated PPI can have adverse consequences for mothers, their partners, their children, workplaces and communities, and is associated with a range of negative outcomes, such as preterm birth, late initiating of prenatal care, difficulties bonding with the baby, and missing medical appointments.<sup>44,45</sup> In PPCM, increased rates of PPI were observed, particularly, depressive and anxiety disorders. When expert clinical interview was used to make the diagnosis, up to two-thirds of women with PPCM were found to have a mental health disorder. Among those, major depression (22.5%), panic disorder (10%) and post-traumatic stress disorder (10%) were found to be significantly increased, compared to the general population and compared to women with peripartum mental disorder (Table 2).

Awareness of PPI in PPCM is clinically important. Severe mental illness such as major depression or bipolar disorder increase the individual burden of an already severe physical illness, worsen the prognosis of HF and could lead to suicidality and late maternal deaths. To date, late maternal deaths arising from PPI, are understudied in PPCM, possibly leading to an underestimation, particularly in low- and middle-income countries.<sup>5</sup> In response to the mounting concerns related to PPI in pregnancy, it is advised to include at least one screening for perinatal depression with a validated measure.<sup>46–49</sup> A screening for common PPI and psychosocial risk factors should also be part of a standardized multidisciplinary approach to diagnosis and treatment in PPCM (Table 2).<sup>9,11,50,51</sup> Women who screen positive for psychiatric distress may be given a referral to care, based on the clinic's access to resources and information.

To date there is a need for better data on mental health in PPCM.<sup>5</sup> Given the overlap between the symptoms of cardiac disease and mental health disorders, it may be challenging to detect mental health disorders, in particular major depression and anxiety disorders, in PPCM. Considering the high prevalence of PPI in PPCM, it therefore seems justified to perform a universal screening using approved screening questions and/or validated screening tools. For patients who screened positive for mental health disorders, psychological and/or psychopharmacological interventions ought to be explored in collaboration with mental healthcare providers.

## Cancer and peripartum cardiomyopathy

In PPCM patients from Germany and Sweden, the prevalence of cancer was 16-fold higher than in age-matched women without PPCM.<sup>50,52</sup> Half of these patients were treated with cardiotoxic cancer therapies before pregnancy which may have contributed to reduced LV function when PPCM developed and may also have delayed cardiac recovery. However, in South African patients with PPCM, there was no association between cancer and PPCM,<sup>53</sup> but further research in this regard is needed.<sup>50,52</sup>

In women who survived cancer treatments, the absolute risk of pregnancy-induced HF is low, however, in female cancer survivors who received anthracycline chemotherapy or chest radiation the risk is higher than in healthy untreated female populations.<sup>54</sup> These

**Table 2** Characteristics of common perinatal psychiatric illness in peripartum cardiomyopathy and potential screening questions/tools

PPI	Characteristic symptoms	Estimated PPI prevalence in PPCM (vs. pregnancy)	Screening tool	Screening question (y/n)
Major depression	Low mood Low energy Loss of interests Sleep disturbances Suicidal thoughts/intentions	22.5% (vs. 5.8%)	HADS depression subscale (7 items)	Do you feel down, depressed, hopeless? Have you lost interest and pleasure in life?
Anxiety disorders	Fear Panic attacks Excessive thoughts and uncontrollable worries	10% (vs. 1.6%)	HADS anxiety subscale (7 items)	Do you suddenly feel fear or panic? Are you frequently unable to stop or control worrying?
Post-traumatic stress disorder	Nightmares Avoidance behaviours Negative appraisals to self and others related to the trauma	10% (vs. 0.7%)		Have you been exposed to a traumatic event? Do you suffer from nightmares or intrusive thoughts?

PPCM, peripartum cardiomyopathy; PPI, perinatal psychiatric illness.  
Modified according to Pfeffer *et al.*<sup>9,11,50,51</sup>

patients should be counselled about the potential cardiovascular risks associated with pregnancy and advised to have a cardiology assessment before pregnancy.<sup>3</sup>

## What have we learned from dedicated cardiac obstetric services and peripartum cardiomyopathy registries?

Establishing a cardiac-obstetric service has many benefits, including raising awareness of cardiac disease in the pregnant population among healthcare professionals, which results in an earlier diagnosis, prompt referral and improved management of cases of cardiomyopathy. A dedicated cardiac-obstetric clinic brings a group of skilled caregivers together to optimize patient management. The team should consist of a cardiologist, high-risk obstetrician, obstetric anaesthetist, a specialist nurse and a midwife. Essential links should be established with cardiac imaging services and foetal medicine services with specialized foetal cardiac imaging skills, and the team should have access to neonatologists, cardiac surgeons, pharmacists, geneticists, psychologists, psychiatrists and social workers as needed. The clinic not only provides excellent care to pregnant women with heart disease, but also acts as a focus for regional training and raising awareness of cardiac disease pregnancy. Establishing a cardio-obstetric service has been shown to improve the management of pregnant patients with cardiovascular diseases, increase adherence to guidelines, promote multidisciplinary teamworking (particularly between cardiologists and obstetricians) and improve teaching and training of both cardiology and maternal medicine fellows. In addition, such centres have

increased research activity in both national and international studies, leading to improved patient care and outcomes.<sup>4,55</sup> A prospective single-centre study conducted at the cardiac obstetric clinic at Groote Schuur Hospital, Cape Town, South Africa, on 269 peripartum women presenting with cardiovascular disease in pregnancy (or within 6 months postpartum), demonstrated how dedicated pragmatic referral algorithms and early follow-up with targeted pharmacological interventions led to a significant reduction in peripartum HF admission and mortality.<sup>56</sup>

Registries offer key insights into the interaction between the physiological changes of pregnancy and cardiac function. Our understanding of this interaction is poor and, consequently, our ability to manage cardiac disease that is present before pregnancy, or arises during pregnancy, is limited. Registries at their most basic give us information about the impact of heart disease on pregnancy outcomes and of the underlying cardiac disease. Given the spectrum of pre-existing structural heart disease, including congenital heart disease, rheumatic heart disease, pulmonary hypertension, cardiomyopathy, aortic disease and coronary artery disease and the heterogeneity within each group, registries are the only way to gain a comprehensive picture of the interaction with pregnancy. Currently, the information we use to advise patients and to develop our management protocols is inadequate. Registries have helped to provide invaluable information and guide our advice and management. Further, where randomized controlled trials are absent, they have allowed us to evaluate different management approaches and to select those with the best outcomes. As such they have driven the design of randomized trials and provided the infrastructure to complete these.

The EORP PPCM registry was designed to collect international data to study the demographic features, management and outcomes among patients with PPCM.<sup>4</sup> It was based on global



teamwork with strong collaborations and produced important position papers, published jointly with the HFA PPCM Study Group, focusing on the management of critically ill patients with PPCM, including those in acute HF with cardiogenic shock. Inevitably, the level of interest generated by the registry stimulated sub-studies, including a biorepository, which led to a recently published study on proteomic profiling of PPCM.<sup>6,57</sup>

The EORP PPCM registry stimulated several centres to establish local cardio-obstetric services. This led to improved patient care through earlier diagnosis due to increased awareness of heart disease in the pregnant population and, by greater adherence to guidelines, they enhanced the training of cardiology and obstetric medicine fellows and increased the confidence of obstetricians in dealing with patients with heart disease and PPCM.<sup>55,58</sup>

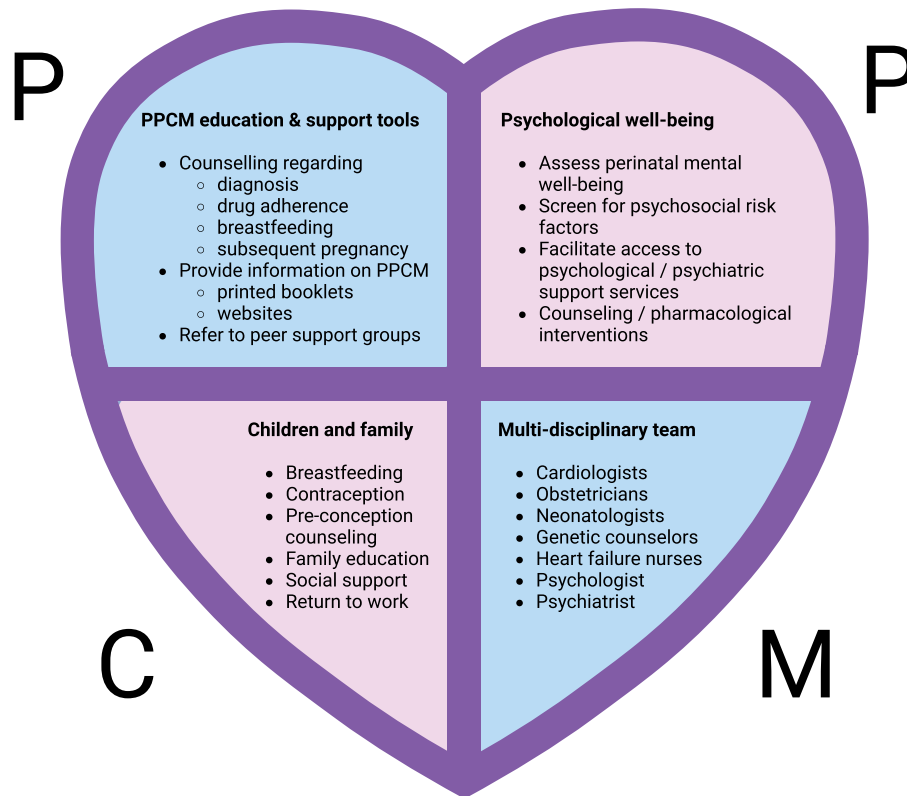
## Heart failure and peripartum cardiomyopathy patient support tools

Empowering patients to understand and manage HF improves outcomes and contributes to enhanced quality of life.<sup>59</sup> In women

with PPCM, quality of life often is significantly impaired. One survey of women with PPCM highlighted that 41% had not returned to their baseline activity, with only 26% of women stating that they had received appropriate counselling about the condition.<sup>60</sup> In the postnatal period, when women with PPCM are immersed in caring for their baby and family, it can be difficult to retain information and education related to PPCM and self-care. Women with PPCM have described the need for information to be repeated (also in the presence of a family member) to help them grasp the seriousness of the condition and to understand follow-up plans and how to escalate care when symptoms change.<sup>61</sup> Figure 3 summarizes options for support.

It is estimated that around 99% of self-care for long-term conditions are performed by the patient and their families, not including healthcare professionals.<sup>62</sup> Therefore, healthcare professionals should be aware of (digital) tools that patients and families can access for advice and support when they are not in the healthcare setting. There are a range of tools available to support self-care, including leaflets, booklets, websites, apps, videos, social media pages and support groups,<sup>63</sup> provided by third sector organizations, professional organizations, and patient-led organizations. HF specialists should ensure that they are aware of tools available in their local language and signpost appropriately. Online support

# Supporting women with PPCM



**Figure 3** Supporting women to live with peripartum cardiomyopathy (PPCM).

groups have been identified as a resource for women with PPCM. Participants of one group stated their desire to find the group stemmed from the challenge of other people in their lives not understanding what they were going through.<sup>64</sup>

Within the group they found other women with similar experiences, at different stages of PPCM management who could provide support, advice, and a feeling that they were not alone in their experiences. Providing women with PPCM and their families with information on their condition and living with PPCM is a core component of care provision. All healthcare professionals, including maternity professionals, should have an awareness of how to facilitate access to HF specialists and the tools available to support women with PPCM and their families and understand information to promote self-care, reduce anxiety and access support networks. Several cardiac society websites provide general information about HF symptoms and management. However, we have identified a gap in patient support for women with PPCM, as there is only very limited information about PPCM available on public websites.

## The need for multidisciplinary care

Due to different scenarios that may arise with PPCM, it is important to provide early specialized multidisciplinary care to improve cardiovascular outcomes and reduce maternal mortality up to the first year postpartum.<sup>65</sup> The main goal and, at the same time, the main challenge for the cardio-obstetrics team is to conduct a comprehensive analysis of risks and outcomes for both mother and foetus throughout pregnancy,<sup>66</sup> during delivery and to provide long-term care, as well as counselling about subsequent pregnancies. Therefore, besides cardiologists and obstetricians, this team should also include anaesthesiologists, maternal foetal medicine specialists, geneticists, psychologists, psychiatrists, neurologists, nurses, pharmacists, and social services.

## Conclusion

To improve the care for women living with PPCM, we suggest implementing the following:

1. Physicians need to have a detailed discussion with the patient and her next-of-kind on the severity of disease (i.e. rates of death, HF rehospitalization, myocardial recovery), the importance of treatment (and adherence thereto), the possible need for cardiac implantable electronic devices, potential discontinuation of breastfeeding, suggested contraception options, and the safety of subsequent pregnancies.
2. Awareness of how important mental well-being is for the woman and her family. Screening for mental health disorders is crucial and needs to lead to appropriate action in affected patients. Clinicians should recognize that the response to a PPCM diagnosis is similar to the diagnosis of any acute cardiac event/disease or cancer, and that the psychological burden is huge. PPCM patients face a particularly devastating situation because of their relative youth, impact on professional activity,

their expectations when starting a family, and their obligations to their wider family and to the new child. A full suite of educational, rehabilitative and psychological services should be offered to them, particularly in the context of PPCM, not in the context of general cardiac disease.

3. Shared decision making is fundamental for the long-term care of the patient. Indispensable for this is education regarding the patient's condition and enabling free exchange with the physician about the best options for her, her pregnancy or baby, her family and her future life.
4. Fragmented care, poor communication between healthcare professionals and missed opportunities of counselling of contraception and the risks of a subsequent pregnancy commonly leads to poorly planned subsequent pregnancies and late presentation to high-risk clinics.
5. Women with previous cancer treatments – especially when known cardiotoxic treatments have been used – are at higher risk for developing LV dysfunction and should undergo cardiovascular assessment before getting pregnant.
6. The lack of dedicated HF and PPCM patient groups should be addressed via national cardiac or civil societies.

## Supplementary Information

Additional supporting information may be found online in the Supporting Information section at the end of the article.

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