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ORIGINAL ARTICLE

Current management of transition and multidisciplinary care of patients with inherited and rare cardiomyopathies in Europe: results of the European Reference Network for rare and low prevalence complex diseases of the heart

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Aims

Cardiomyopathies are a heterogeneous group of genetic disorders requiring specialised, multidisciplinary management to optimize patient outcomes. A critical aspect of care is the transition of paediatric patients to adult services, which varies significantly across healthcare systems.

This study assessed current practices in care transition and multidisciplinary management of inherited and rare cardiomyopathies across specialised European centres within the European Reference Network for rare and low prevalence complex diseases of the heart network.

Methods and results

A 21-question survey was distributed to healthcare providers within the network. A single participant (i.e. cardiologist with expertise in the diagnosis and management of inherited and rare cardiomyopathies) from each centre was approached. Responses from 26 centres across 12 European countries were analysed using descriptive statistics to evaluate institutional characteristics, transition protocols, and multidisciplinary team involvement. While 81% of centres reported having a transition plan, only 42% implemented it for all patients, and 19% had no formal protocol. Multidisciplinary care was well integrated, with regular team discussions, though key professionals such as psychologists and nurses were often absent. The lack of structured transition programmes, inconsistent use of standardized protocols, and a shortage of specialists in cardiogenetics emerged as major unmet needs.

Conclusion

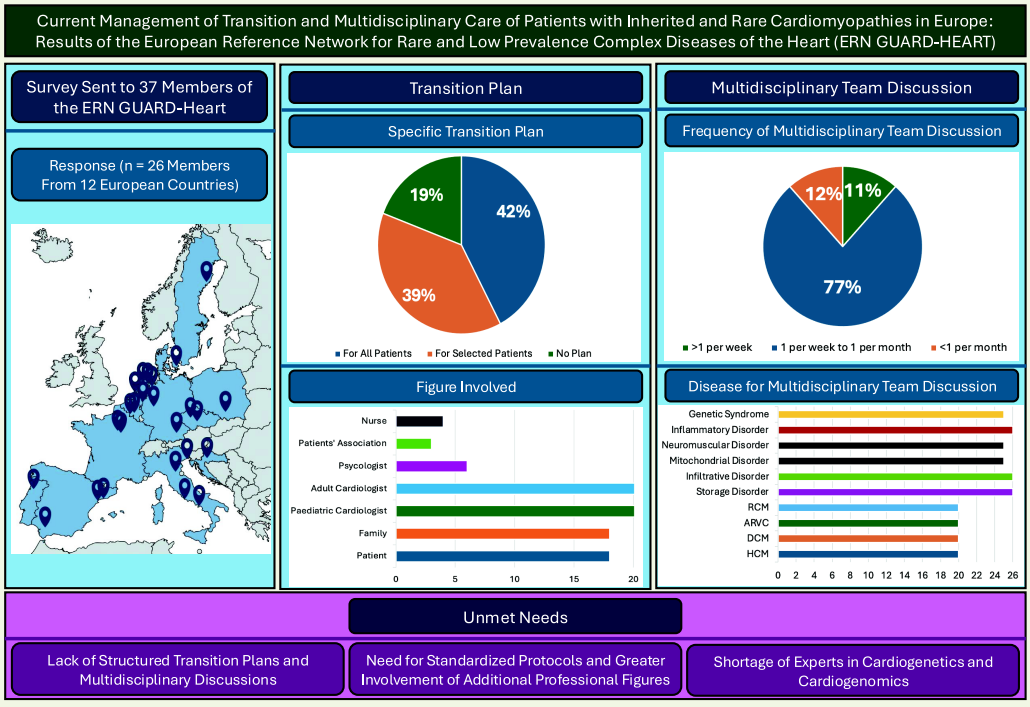
Significant variability exists in the transition and multidisciplinary care of patients with inherited and rare cardiomyopathies. Standardized transition protocols, greater involvement of multiple healthcare professionals, and enhanced training in cardiogenetics are needed to ensure continuity of care and improve patient care across Europe.

Graphical abstract

Key Question
This study evaluated current practices in care transitions and the multidisciplinary management of inherited and rare cardiomyopathies across specialised European centres within the European Reference Network for Rare and Low-Prevalence Complex Diseases of the Heart (ERN GUARD-Heart).

Key Finding
A 21-question survey was distributed to 37 centres in the network, yielding responses from 26 participants across 12 European countries. The findings highlight data on multidisciplinary team discussions and transition planning.

Take Home Message
Key unmet needs identified include the absence of structured transition programs, inconsistent use of standardised protocols, and a shortage of cardiogenetics and cardiogenomics specialists.



Keywords Cardiomyopathy • Transition • Multidisciplinary care

Key Learning Points

What is already known:

- Management of inherited and rare cardiomyopathies requires multidisciplinary expertise and lifelong follow-up.
- Structured transition programmes and multidisciplinary team involvement improve outcomes in congenital heart diseases, but data specific to cardiomyopathies are limited.
- The European Reference Network (ERN) GUARD-Heart supports collaboration among specialized centres for rare cardiovascular diseases across Europe.

What this study adds:

- This is the first Europe-wide survey evaluating transition protocols and multidisciplinary care for inherited and rare cardiomyopathies across expert centres within ERN GUARD-Heart.
- The study highlights significant variability in transition practices and identifies key unmet needs.
- Findings support the development of harmonized transition pathways, expanded multidisciplinary care, and enhanced training in cardiogenetics to improve care continuity and outcomes for patients with rare cardiomyopathies.

Introduction

Cardiomyopathies are a diverse group of genetic disorders that affect the heart muscle, leading to structural and functional abnormalities.[1] The management of cardiomyopathies often requires an individualized pathway to deliver optimized care by a multidisciplinary team of experts, including not only cardiologists but also several other healthcare professionals, with the aim of reducing the morbidity and mortality associated with these diseases and improving the quality of life[1–3]. A particular challenge in the care of patients with cardiomyopathies is the transition of paediatric patients to adult care at the age of maturity, which can pose significant challenges due to differences in treatment protocols, hospital settings, and healthcare systems.[4,5]

The European Reference Network for rare and low prevalence complex diseases of the heart (ERN GUARD-Heart) was established to create a network between specialized centres in the management of inherited and rare heart diseases.[6] This network brings together specialists from various fields to offer comprehensive care, with, among others, a focus on the genetic aspects of these diseases. ERN GUARD-Heart also works to create a platform for sharing best practices and promoting collaboration among healthcare providers.

Despite the growing recognition of the importance of structured care transitions, there is a significant variation in management across Europe, and the available data primarily come from congenital heart disease practice.[7–9] Moreover, while some centres have developed transition plans that ensure continuity of care, others still rely on case-by-case discussions without standardized protocols. Furthermore, the involvement of multidisciplinary teams in the care of cardiomyopathy patients is often inconsistent with clinical standards and patients expectations.[10,11]

The aim of the study is to provide an overview of the current practices in the management of transitions and multidisciplinary care of patients with inherited and rare cardiomyopathies within the ERN GUARD-Heart network.

Methods

Study design and participants

This study was conducted under the ERN GUARD-Heart, a collaborative virtual network of 44 expert healthcare providers across 16 European countries. The network is dedicated to patient-centred care of, among others, genetically transmitted heart diseases.

Within this network, 37 healthcare providers specialize in managing patients with cardiomyopathies (Thematic Area 2 of the ERN GUARD-Heart), such as hypertrophic cardiomyopathy (HCM), dilated cardiomyopathy (DCM), arrhythmogenic right ventricular cardiomyopathy (ARVC), and restrictive cardiomyopathy (RCM). The definitions of the different cardiomyopathy phenotypes refer to those used in the 2023 European Society of Cardiology guidelines for the management of cardiomyopathies.[1]

Survey instrument

An online questionnaire was developed and distributed to healthcare providers involved in the management of cardiomyopathy patients. The survey, consisting of 21 multiple-choice questions (Supplementary Material), was administered via email and the ERN GUARD-Heart newsletter, which is regularly shared with all members to keep them informed about important updates and initiatives (https://guardheart.ern-net.eu). The survey was conducted between August and October 2024. The questionnaire assessed aspects such as institutional characteristics, patient demographics, clinical practices, multidisciplinary care, and the availability of transition plans for cardiomyopathy patients. A single participant (i.e. cardiologist with expertise in the diagnosis and management of inherited and rare cardiovascular diseases) from each centre was approached, and only one response per centre was included in the analysis.

Statistical analysis

Descriptive statistical methods were used to analyse the collected data. Categorical variables were summarized using absolute frequencies and percentages (%).

Results

Demographics

The questionnaire was completed by a total of 26 participants from 12 European countries within the ERN GUARD-Heart community, including the Netherlands ($n = 5$), Italy ($n = 4$), Belgium ($n = 3$), Spain ($n = 3$), the Czech Republic ($n = 2$), France ($n = 2$), Germany ($n = 2$), Croatia ($n = 1$), Denmark ($n = 1$), Poland ($n = 1$), Portugal ($n = 1$), and Sweden ($n = 1$) (*Figure 1*).

Most of the participants worked at university hospitals ($n = 25$, 96%), while only one participant worked at a private centre. The years of experience in managing patients with cardiomyopathies were as follows: more than 20 years for 10 participants (38%), between 16 and 20 years for 8 (31%), between 11 and 15 years for 5 (19%), between 6 and 10 years for 2 (8%), and between 1 and 5 years for 1 (4%).

Most participants reported following more than 100 HCM and 100 DCM patients annually (58% and 67%, respectively). For ARVC, 50% of participants followed between 1 and 25 patients per year, while smaller proportions followed more than 100 (4%), 76–100 (7%), 51–75 (31%), and 26–50 (8%) patients annually. For RCM, 84% of participants

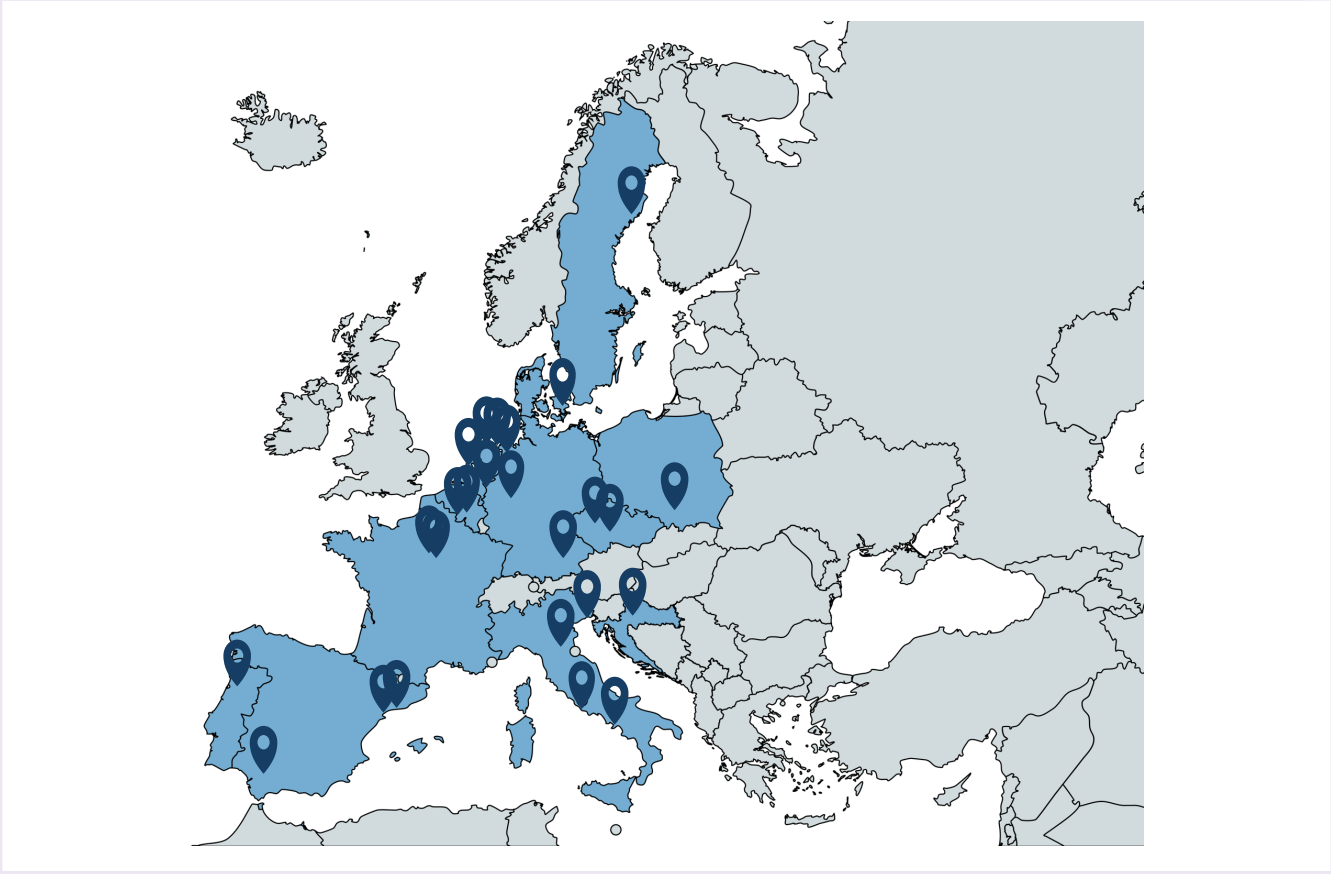


Figure 1 European Reference Network for rare and low-prevalence complex diseases of the heart participating centres.

reported following between 1 and 25 patients annually, with smaller proportions following 76–100 (4%), 51–75 (8%) and 26–50 (4%) patients per year. The distribution of the number of cardiomyopathy patients followed annually by the participants is shown in *Figure 2*.

Thirteen participants manage adult patients (50%), 5 (19%) manage paediatric patients, and 8 (31%) manage both adult and paediatric patients. Participants managing adult patients begin following patients between the ages of 16 and 25, while those managing paediatric patients or both adult and paediatric patients start managing patients from birth or even during prenatal life.

Transition plan

Among the 26 participants, 11 (42%) have implemented a transition plan for all patients with cardiomyopathy, while 10 (39%) use it only for selected cases (*Figure 3*). Five participants (19%) do not have a transition plan in place. Among the 21 participants with an active transition plan, both the patient and the family are involved in the process in 18 cases (86%). Additionally, the transition process involves an adult and paediatric cardiologist in all participating centres, a psychologist in six centres, patient associations in three centres, and a nurse in four centres.

Among the 26 centres, 8 reported following both adult and paediatric patients. These centres were contacted to obtain further information. Six of them indicated that adult and paediatric patients are seen in the same hospital but are managed by two distinct groups of cardiologists (one specializing in paediatric care and the other in adult cardiology), while both groups are supported by the same team of clinical geneticists. In contrast, two centres reported having a single team of cardiologists with expertise in both paediatric and adult cardiology, allowing for continuous care from childhood to adulthood without the need for a formal transition process.

Participants reported that for all patients, clinical reports and related documents are transferred from the paediatric to the adult care centre during the transition, except in one case where documentation is only transferred for selected cases. In contrast, specific discussions between the paediatric and adult cardiologists during the transition process occur in all centres, but only for selected cases in 95% of centres.

Multidisciplinary care

In the institutions of the participants, the following cardiological services are available in all 26 centres: outpatient cardiology, cardiology wards, and electrophysiology units. Heart failure units, interventional cardiology units, intensive care units, and cardiac surgery are present in 25 centres (96%). In contrast, paediatric cardiology units are available in 23 centres (88%), dedicated cardiomyopathy units in 18 centres (69%), and heart transplantation in 16 centres (61%).

In the institutions of the participants, the following multidisciplinary specialists are available in all 26 centres (*Figure 4*): nephrologists, neurologists, and pathology services. Gastroenterologists are available in 25 centres (96%), haematologists, dermatologists, endocrinologists, and clinical geneticists in 24 centres (92%), paediatricians and molecular geneticists in 22 centres (85%). Participants reported that for specialists not available within their institution, they have long-term collaborations with external hospitals.

A multidisciplinary team discussion is conducted for the diagnosis and management of patients with cardiomyopathies in all centres, with the frequency as follows: more than once per week in 3 centres (12%), once per week to once per month in 20 centres (77%), and

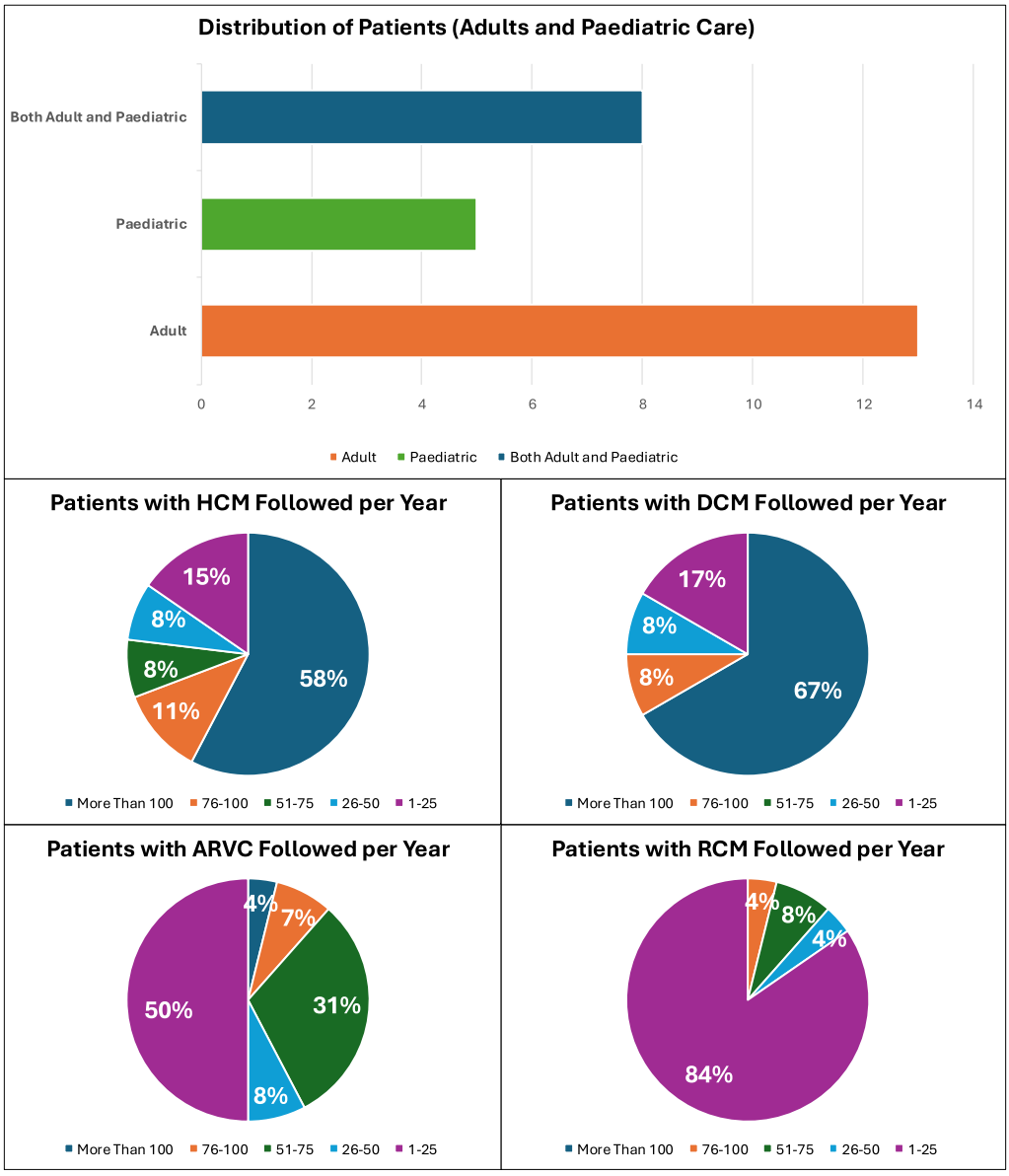


Figure 2 Annual number of cardiomyopathy patients followed per centre and distribution of patients (paediatric vs. adult) at participating centres. ARVC, arrhythmogenic right ventricular cardiomyopathy; DCM, dilated cardiomyopathy; HCM, hypertrophic cardiomyopathy; RCM, restrictive cardiomyopathy.

less than once per month in 3 centres (12%). A multidisciplinary team discussion is performed for the following conditions in nearly all centres: storage disorders (e.g. Pompe disease, Danon disease, PRKAG2 disease); infiltrative disorders (e.g. amyloidosis); mitochondrial disorders; neuromuscular disorders (e.g. Duchenne/Becker disease, myotonic dystrophy); inflammatory disorders (e.g. sarcoidosis); genetic syndromes (e.g. Noonan syndrome). In 20 centres (77%) a multidisciplinary team discussion is also performed in selected cases of patients with HCM, DCM, ARVC, and RCM.

Unmet needs

Twelve participants identified several possible unmet needs in the management of patients with cardiomyopathies. First, both transition plans and multidisciplinary team discussions are currently conducted on a case-by-case basis, with no organized programme in place. There is a general lack of a clear pathway, dedicated resources or guidelines for all patients, as case-based discussions prevail without standardized protocols, especially in rare conditions. Participants suggested the need for better-defined protocols, such as the establishment of age limits for transition.

Additionally, there is a call for greater involvement from other disciplines, such as psychology and nurses, to provide more comprehensive care. The need for specific transition consultations was also highlighted, with participants emphasizing the importance of having a designated person in charge of the transition process for each patient.

Moreover, participants noted the necessity of a structured programme for all patients, which would ensure that each individual receives the appropriate care throughout the transition. Another key

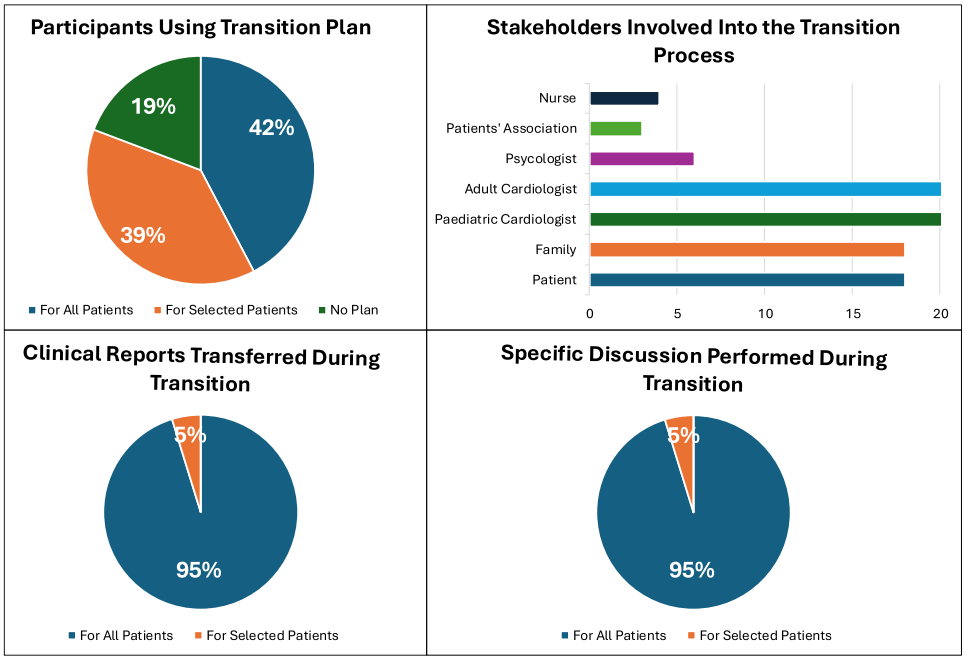


Figure 3 Transition plan and professionals involved at participating centres.

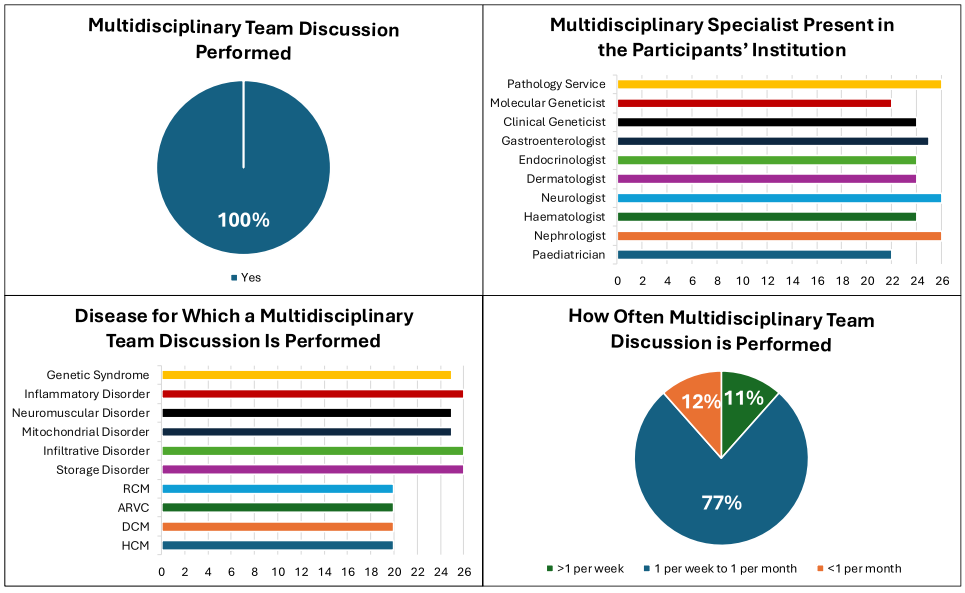


Figure 4 Multidisciplinary team discussions at participating centres: frequency, professionals involved, and diseases addressed. ARVC, arrhythmogenic right ventricular cardiomyopathy; DCM, dilated cardiomyopathy; HCM, hypertrophic cardiomyopathy; RCM, restrictive cardiomyopathy.

concern was the shortage of experts in cardiogenetics and cardiomyopathies, which limits the available specialized knowledge for patient care. Finally, it was suggested that transitioning to adult hospitals is particularly challenging for patients with special mental health needs, highlighting the need for tailored approaches in these cases.

Discussion

The survey results from the ERN GUARD-Heart network provide insights into the current management of care transitions and the role of multidisciplinary teams in patients with inherited and rare

cardiomyopathies. The participating institutions involved in the survey are recognized for their expertise in the management of these conditions.

Cardiomyopathies encompass a broad spectrum of disorders that can affect individuals at any age.[1] However, when the disease manifests in childhood, it is more frequently associated with syndromic, metabolic, or neuromuscular disorders,[12] necessitating a multidisciplinary approach to management.[13] For instance, HCM diagnosed in adulthood is commonly linked to pathogenic variants in sarcomeric genes.[14] In contrast, when HCM presents during infancy, up to 60% of cases are associated with specific conditions such as RASopathies or inborn errors of metabolism, often involving multiple organ systems.[13,15] Given the rarity of these disorders, optimal care should be provided in expert centres, where multidisciplinary teams comprising physicians and other healthcare professionals can offer specialized support.

A critical aspect of managing paediatric patients with inherited and rare cardiomyopathies is the transition to adult care, which frequently occurs in a different centre under the supervision of different physicians.[4] Ensuring a structured and well-coordinated transition process is essential to maintaining continuity of care and optimizing long-term outcomes.

Transition management

The importance of structured transition programmes is increasingly recognized in both cardiological and non-cardiological settings, highlighting the need for integrated care throughout the patient journey.

The survey highlights significant variations in how transition management is handled across Europe. Even though these centres are all specialized in the management of rare and complex cardiovascular disorders, 19% of them ($n = 5/26$) do not have an established transition plan.

Among the remaining centres, half have reported having an established transition plan, while the other half applied it only for selected cases. This variability is concerning, as it suggests the absence of a standardized, universally accepted protocol for transitioning paediatric patients to adult care. In patients with congenital heart diseases, the lack of a transition plan has been shown to contribute to lapses in care, often leading to increased emergency department visits and poorer outcomes.[16,17]

The involvement of both paediatric and adult cardiologists during this process, as reported by all participating centres, is a positive step towards bridging these gaps. However, other key professionals who have been shown to positively impact transitional care (e.g. nurses, psychologists)[18,19] are rarely involved, highlighting an area for improvement. Two centres reported having a single team of cardiologists with expertise in both paediatric and adult cardiology, and that patients are followed from childhood to adulthood without the need for a formal transition process. This model may enhance long-term patient adherence, improve monitoring of disease progression, and support more cohesive family-based care. Nonetheless, it requires cardiologists with dual expertise in paediatric and adult cardiology and inherited heart diseases, something not widely available.

Despite the growing body of literature on transition management in congenital heart diseases, patients with cardiomyopathies, although similarly chronic and requiring lifelong follow-up, have not benefited from the same level of attention or standardized protocols regarding transitional care. However, there are important parallels between congenital heart diseases and cardiomyopathies that support the application of established transition practices to this latter group. Both conditions require multidisciplinary, lifelong management, and are frequently diagnosed in early life, with ongoing monitoring needed into adulthood.[12]

Cardiomyopathies present unique challenges, including genetic counselling, family screening, and the potential for late-onset manifestations in asymptomatic individuals.[1] These features highlight for tailored transition strategies that incorporate genetic and psychosocial support in addition to cardiology follow-up.

The challenges seen in Europe are echoed in other healthcare systems. A nationwide survey conducted in Japan across 151 paediatric cardiology departments reported a particularly poor status of transitional care for childhood-onset cardiomyopathies.[20] Only 19% of responding facilities had any transition programme in place, and most of those were congenital heart disease based. Notably, 72% of centres lacked a program altogether, despite 92% acknowledging its necessity. Furthermore, centres already transferring congenital heart disease patients had significantly higher transfer rates for cardiomyopathies as well, highlighting how structured congenital heart disease frameworks can support cardiomyopathy transition efforts. These findings suggest that leveraging transition models from congenital heart disease care could be a useful starting point to address current gaps in managing cardiomyopathies globally.

Multidisciplinary care

The survey results reveal a strong commitment to multidisciplinary care in the management of cardiomyopathies. All participating centres offer a wide range of cardiological services, and a broad spectrum of specialists, including nephrologists, neurologists, gastroenterologists, and molecular geneticists, are available at most centres. This comprehensive approach to patient care is critical, given the complex nature of cardiomyopathies and the need for a holistic treatment strategy that addresses both the medical and psychosocial needs of patients.

Multidisciplinary team discussions, which occur in all centres, are crucial for developing a comprehensive management plan.[10,21,22] These discussions are held at varying frequencies, with most centres conducting them once per week to once per month. The involvement of diverse specialists, such as geneticists and psychologists, further ensures that all aspects of patient care, including genetic counselling and mental health support, are appropriately addressed.[23,24]

Unmet need and implications for future care

The survey respondents identified several unmet needs. The lack of structured transition plans, especially for patients with specific needs, remains a significant challenge. The study participants suggested that standardized protocols for transition, including clear age limits and the designation of responsible individuals for overseeing transitions, are needed to improve the continuity of care. Furthermore, the need for greater involvement of other health professionals, including psychologists and nurses, was a recurring theme in the responses. Another major concern raised by participants was the shortage of experts in cardiogenetics and cardiomyopathies. This gap in specialized knowledge limits the ability of healthcare providers to deliver the most effective care to patients with these rare and complex conditions.[25] There is a clear need for continued education and training in these areas to ensure that healthcare professionals are equipped with the knowledge and skills to manage these diseases effectively.[26,27]

Study limitations

The study provides information on current practices in care transition and multidisciplinary management of inherited and rare cardiomyopathies across specialized European centres. Although transition and multidisciplinary care are distinct concepts with different goals and organizational structures, we chose to address both within a single manuscript due to the limited available data on these aspects in the context of cardiomyopathies. Additionally, both are considered by key stakeholders—including the European Commission and the ERN

organization—as essential criteria for evaluating the quality of care in referral centres.

This study has several limitations (see Supplementary material online, *Table S1*). First, the survey respondents were exclusively healthcare professionals, and only a single participant per centre was included in the analysis. Additionally, the absence of patient involvement represents an important limitation.

Second, data were collected only from centres that completed the survey. As no information was obtained from non-responding centres, it was not possible to perform a comparative analysis to assess potential differences in institutional characteristics or care practices, which may have introduced selection bias. The limited representativeness of the participating centres also warrants consideration: only 26 of 37 eligible centres responded, and the majority were large academic hospitals, which may not reflect practices in smaller or non-academic institutions across Europe.

Third, while the survey collected data on the existence of transition plans, it did not include specific questions regarding the transition models implemented (e.g. joint clinic, introductory, paediatrician-in-adult-care, or transition coordinator models.[4]) As a result, we were unable to categorize the approaches used by each centre or evaluate their alignment with existing recommendations for congenital heart diseases. Moreover, the survey did not assess whether centres with formal transition programmes differed in terms of resources, structure, or clinical outcomes compared with those without such programmes. This limits the ability to draw conclusions about the effectiveness or quality of different transition strategies.

Similarly, multidisciplinary care was assessed based on the reported availability of various specialists, which may not accurately reflect the presence of structured, integrated multidisciplinary team approaches.

Future directions

Future efforts should aim to develop standardized transition protocols that can be adapted across the diverse healthcare systems in Europe. To enhance the quality of multidisciplinary care, the integration of additional professionals—particularly psychologists, nurses, and dedicated transition coordinators—into cardiomyopathy care pathways should be encouraged. Well-structured, Europe-wide training programmes in cardiogenetics and cardiomyopathy management are essential to address the current shortage of specialized expertise. Furthermore, existing transition frameworks from congenital heart disease care could be integrated and adapted to the cardiomyopathy setting to promote continuity and cohesion in patient management. Expanding data collection to include outcome metrics and detailed information on institutional resources will also allow for a more comprehensive evaluation of care models.

Future studies should incorporate patient input and be designed to collect detailed information on transition models, institutional resources, and care outcomes. This would provide a more comprehensive understanding of best practices and improve the general clinical applicability of the results.

Conclusions

This study highlights the significant variability in the management of care transitions and multidisciplinary care for patients with cardiomyopathies across Europe. While many specialized centres within the ERN GUARD-Heart network have structured transition plans and multidisciplinary teams, a lack of standardized protocols and limited involvement of key professionals remain challenges. Addressing these gaps through harmonized guidelines, enhanced multidisciplinary collaboration, and increased access to cardiogenetics expertise could improve continuity of care and long-term outcomes for these patients.

Supplementary material

Supplementary material is available at *European Heart Journal—Quality of Care and Clinical Outcomes* online.

Author contributions

G.L. and E.M.: conceptualization, data curation and analysis, writing—original draft. P.C., A.W., A.S.A., and N.H.: data validation, writing—review & editing. All the authors: survey participation, revision and approval of the final text.

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Data availability

The data supporting the results of this article are available from the corresponding author upon reasonable request.

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