Treatment pathways defined as the sequence of visits to the public health system of patients with cardiomyopathies in Poland in the period 2016–2021

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ABSTRACT

Background: The diagnosis and management of cardiomyopathies (CMs) are subject to regional variations but no study to date has systematically evaluated the clinical pathways of patients with CMs.

Aims: We aimed to assess the management pathway of CM patients in Poland.

Methods: This population-based cross-sectional study was conducted based on data from 2016 to 2021 obtained from the national healthcare provider using ICD10 codes to identify CM patients. The treatment pathways of CM patients, defined as the sequence of visits to the public healthcare system and categorized as urgent hospitalization (UH) for disease exacerbation, elective hospitalization (EH), tertiary outpatient medical care (TMC), primary outpatient healthcare (general practice [GP]) were analyzed.

Results: Between 2016 and 2021, 65 383 CM patients were analyzed (mean age: 60 years, 65.4% men). Total healthcare services provided to these patients involved hospitalization (47.2%), TMC (16.5%), and GP (27.5%). The first registration CM diagnosis was made on an inpatient basis in 93.4% of patients (UH: 68.1%; EH: 25.1%). The mortality rate during the analyzed period was 39.8% for the total CM population, 43.9% for patients who were registered in the system only once (47% of all subjects), and 65.4% for patients with a Charlson Comorbidity Index ≥ 5.

Conclusions: The diagnosis of CMs in Poland is established very late mainly during hospitalization for exacerbation of the disease. This may have an impact on the poor prognosis of CM patients especially those with a high comorbidity burden. This study highlights the urgent need for improvement in CM management in Poland.

Key words: cardiomyopathies, clinical pathways, comorbidity, healthcare, public health

WHAT'S NEW?

So far no study has investigated clinical pathways for patients in Poland following an initial diagnosis of cardiomyopathies (CMs). This study provides, for the first time, data on the treatment pathways defined as the sequence of visits to the public health system of 65 383 patients with CMs in Poland. The study delivered evidence that CM diagnosis in Poland is made very late, mainly during hospitalization. In the majority of patients, CMs are diagnosed during exacerbation of the disease and most of the patients suffer from comorbidities. The CM mortality rate is very high, especially in patients who are registered in the system only once (47% of all subjects) and in patients with a Charlson Comorbidity Index ≥5. This study underscores the suboptimal care that CM patients receive in Poland and the need for more efficient CM management provided by tertiary reference outpatient care.

INTRODUCTION

Cardiomyopathies (CMs) are a heterogeneous group of heart muscle diseases with increasing importance in the incidence of illness and death [1]. Recent advances in the understanding of etiology and improvement in screening, diagnosis, and CM treatment carry significant implications concerning clinical practice. However, the CM therapeutic pathway has not been systematically addressed and, despite medical progress, diagnosis and therapy of cardiomyopathies (CMs) remain suboptimal [2–4]. The lack of a CM-dedicated network further impairs healthcare provision for this group of subjects. The quality of healthcare services and differences in genetic susceptibility of individual populations strongly modulate the adverse social effects of CMs [5].

Our recently published study [6] provides, for the first time, data on the registered prevalence and incidence of CMs in Poland. Despite the limitations of databases run by healthcare providers, the results are comparable to data from other countries and populations [7–9]. On the other hand, the registered incidence and prevalence of CMs are lower than in systematic population studies based on echocardiographic diagnosis [10] and demonstrate that the true number of patients with CMs in Poland and other countries have been substantially underestimated.

Taking into account the above-mentioned data, we suspect that there are differences between the recommended and implemented management of the CM population. The magnitude of the problem has not been evaluated yet. This article aims to assess the pathways for patients with a clinical diagnosis of CMs in Poland between 2016 and 2021.

MATERIAL AND METHODS

This population-based cross-sectional study was conducted on data from the national healthcare provider's (NFZ) sample using codes from the International Classification of Diseases and Related Health Problems (10th Revision [ICD10]) [11] to identify CM patients. The study utilized the data submitted during the study period from January 1st, 2016 to December 31st, 2021.

The NFZ database was queried within that timeframe to identify those patients with ≥1 ICD-10 diagnosis code: I42, I42.0, I42.1, I42.2, I42.3, I42.4, I42.5, I42.6, I42.7, I42.8 or I42.9 registered for the first time in the healthcare system. These patients were followed through the system to the end of the study period. The above-mentioned ICD-10 codes had to be reported during the patient's hospitalization at any stage of the disease. The exclusion criteria involved ICD codes consistent with ischemic heart disease: I24, I25, I21, and I20 at the time of CM diagnosis. It was possible to match the information about each patient through the hospital registry number and the national identification number. The collected data included information on the following services: urgent hospitalization (UH) for disease exacerbation, elective hospitalization (EH), tertiary outpatient medical care (TMC), and primary outpatient healthcare (general practice [GP]). If the patient was hospitalized again for cardiovascular diseases within 24 hours, both hospitalizations were considered one admission. The patient's pathway referred to the services registered as ICD-10 for CM codes as the main and coexisting health problem. Other long-term services such as palliative and hospice care, rehabilitation, nursing, and care services were provided to a limited number of patients and were not included in the analysis. The death rate from 2016 to 2021 was estimated based on data from the public healthcare system and the Ministry of Digitization. For all the subjects involved in the analysis, the Charlson Comorbidity Index (CCI) was calculated [12], which was used to allocate study participants to subpopulations: the CCI 0–2, CCI 2–5, and CCI ≥5 subpopulations. All data was anonymized.

Statistical analysis

Data were presented as numbers and percentages and, with regard to age, as mean values and standard deviations. Regarding patient progression through the pathway in the healthcare system (abnormal distribution), data were represented as medians and quartiles Q1–Q3. The details of the methodology of data collection and analysis were presented elsewhere [6]. Data were presented as flowchart figures showing patients' consecutive steps (patients' pathway) in the healthcare system, as well as numerical and percentage data for both the whole CM population and for groups divided according to the CCI. The flowcharts represent the history of the subject from the first registered CM diagnosis with the corresponding code in the NFZ database; the range of the individual flow is proportional to the number of patients who received services of each type. The Markov chain figure was obtained using data

Table 1. The baseline characteristic of the CCI subpopulations of CMs patients

	CCI subpopulations of CMs patients		
	CCI 0–2	CCI 2–5	CCI ≥5
Mean age (SD)	56 (18.4)	70 (13.5)	75 (10.3)
Males (%)	72.5	60.7	56.1
Pathway steps in the healthcare system:			
Median	2	1	1
Q1–Q3	1–5	1–3	1–2
Total contribution to CM healthcare:			
Hospitalization (%)[a]	39.5	53.9	63.8
TMC (%)	20.3	13.4	6.3
GP (%)	35.5	20.5	8.9
Deaths during analyzed period (%)	20.9	41.6	65.4

[a]Hospitalization — both urgent and elective

Abbreviations: CM, cardiomyopathy; CCI, Charlson Comorbidity Index; GP, first-line out-patient health care; SD, standard deviation; TMC, tertiary out-patient medical care

from patients who were registered with the ICD-10 CM code at least twice within a year, with the first registration in the healthcare system at the moment of diagnosis and the second registration coming within 12 months. In the Markov chain figure, both UH and EH were presented as a total "hospitalization".

RESULTS

General data

We analyzed care pathways, defined as the sequence of visits to the public healthcare system in Poland in 2016–2021, for 65 383 CM patients provided due to a given disease entity, i.e., ICD-10 for CMs. The mean age of subjects was 60 (17.4) years with male predominance (42 747/65.4%). The median value of the patient's pathway steps in the healthcare system was 2 (Q1–Q3: 1–4). All services in CM healthcare included hospitalization (47.2%), TMC (16.5%), and GP (27.5%).

As many as 26 043 (39.8%) of all CM patients died during the observation period.

There was the following distribution of CCI subpopulations among all CM patients:

- 22.5% of patients with CCI 0–2; mean age: 56 (18.4) years; males: 72.5%;
- 65.3% of patients with CCI 2–5; mean age: 70 (13.5) years; males: 60.7%;
- 12.2% of patients with CCI ≥5; mean age: 75 (10.3) years; males: 56.1%.

We observed the following distribution of the CCI subpopulations among the patients with CCI ≥5: 52.3% of patients with a CCI score of 5; 27.6% of patients with a CCI score of 6; 13.2% of patients with a CCI score of 7; 4.9% of patients with a CCI score of 8; 2% of patients with a CCI score ≥9.

The median value of pathway steps of patients in the healthcare system varied depending on the CCI: for CCI 0–2, it was 2 (Q1–Q3: 1–5); for CCI 2–5, it was 1 (Q1–Q3: 1–3); for CCI ≥5, it was 1 (Q1–Q3: 1–2). Total contribution of the CCI subpopulations to CM healthcare involved:

- hospitalization: CCI 0–2 — 39.5%; CCI 2–5 — 53.9%; CCI ≥5 — 63.8%;
- TMC: CCI 0–2 — 20.3%; CCI 2–5 — 13.4%; CCI ≥5 — 6.3%;
- GP: CCI 0–2 — 35.5%; CCI 2–5 — 20.5%; CCI ≥5 — 8.9%.

As many as 20.9% of CCI 0–2, 41.6% of CCI 2–5, and 65.4% of CCI ≥5 patients died during the analyzed period. A summary of the baseline characteristics of CM subpopulations according to their CCI is presented in Table 1.

First registration in the healthcare system

CM diagnosis, as the first registration of CM ICD-10 code, was made during hospitalization in 93.4% of patients, in TMC in 3.3% of patients, and in GP in 3.0% of patients; with the diagnosis made during UH in 68.1% and during EH in 25.1% of patients. We demonstrated an increase in the proportion of hospital admissions with the first registration of the CM ICD-10 code over consecutive years (hospitalization: 2016 — 93.1%, 2017 — 93.2%, 2018 — 93.2% 2019 — 93.8%, 2020 — 94.3%, 2021 — 95.5%).

Regarding comorbidities, CM diagnosis at first registration of CM ICD-10 code was established for:

- CCI 0–2 during hospitalization in 92.5% of patients (UH — 66.6%, EH — 25.9%), and in 3.6% of patients in TMC and GP equally;
- CCI 2–5 during hospitalization in 93.9% of patients (UH — 66.0%, EH — 27.8%), in TMC — 3.0%, and in GP — 2.7%;
- CCI ≥5 during hospitalization in 96.2% of patients (UH — 71.9%, EH — 24.3%), in TMC – 1.5%, and in GP – 1.6% of patients (Figure 1).

The further course in the healthcare system after hospitalization as the first step of the pathway

As many as 18% of patients after being diagnosed during EH died without a subsequent contact with a healthcare professional and 44% of patients were not registered again in the public healthcare systems with the CM ICD-10 codes (Table 2, Figure 2).

Analogous data for the CCI subpopulations were as follows (Figure 1):

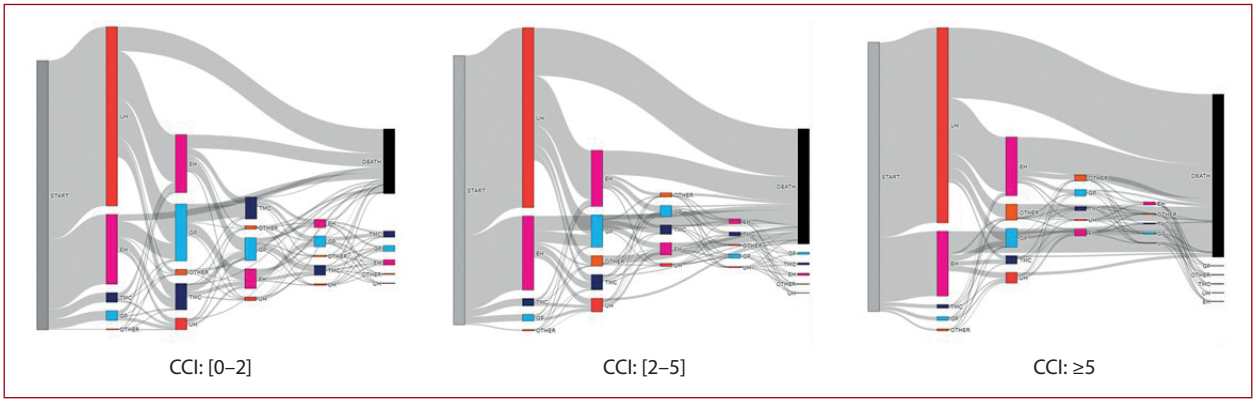

Figure 1. Treatment pathways of patients with cardiomyopathies in Poland in the period 2016–2021 in the subpopulations regarding to Charlson Comorbidity Index (CCI)

Table 2. The second step in the patients' pathways after the first registration during UH and EH

The second step in the patients' pathway	The first registration: UH n = 44 526	The first registration: EH n = 16 411
Death	10 241 (23%)	2 954 (18%)
Hospitalization[a]	12 022 (27%)	1 313 (8%)
GP	6 679 (15%)	2954 (18%)
TMC	2 676 (6%)	1 969 (12%)
Other[b]	467 (28%)	7 221 (44%)

[a]Hospitalization — both urgent and elective. [b]Patients not registered again in the public health systems as the CMs ICD-10 codes and not died during the registered period
Abbreviations: EH – elective hospitalization, UH – urgent hospitalization, other — see Table 1

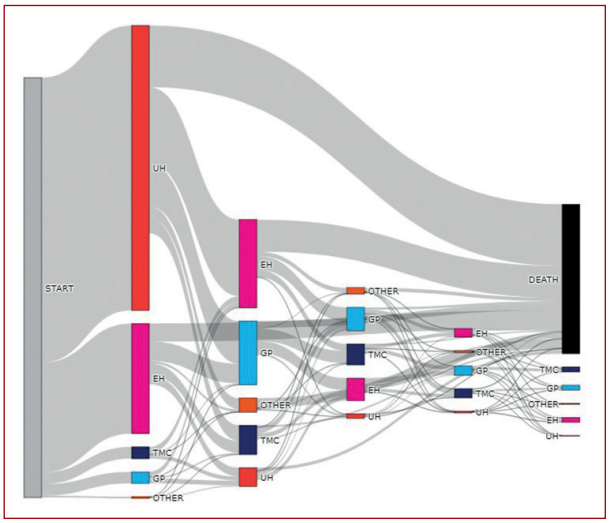

Figure 2. Treatment pathways of patients with cardiomyopathies in Poland in the years 2016–2021

- percentage of deaths after EH: CCI 0–1: 9.4%, CCI 2–5: 22.1%, CCI ≥5: 36.1%;
- percentage of patients after EH who were not registered again in the public health systems as the CMs ICD-10 codes: CCI 0–1: 45.2%, CCI 2–5: 39.2%, CCI ≥5: 34.5%.

Similarly, as many as 23% of all CM patients diagnosed during UH died and 28% did not enter the healthcare system again with the CM ICD-10 codes (Table 2, Figure 2).

Analogous data for the CCI subpopulations were as follows (Figure 1):

- percentage of deaths after UH: CCI 0–1: 13.6%, CCI 2–5: 29.0%, CCI ≥5: 38.2%;
- percentage of patients after UH who were not registered again in the public healthcare systems with the CMs ICD-10 codes: CCI 0–1: 27.1%, CCI 2–5: 22.5%, CCI ≥5: 17.4%.

After CM diagnosis during elective or urgent hospitalization, as many as 7.4% of patients (EH: 6%, UH 12%) were managed by TMC and 16% (EH: 15%, UH: 18%) by GP.

The further course in the healthcare system — Markov chain figure

The Markov chain figure was based on the data from the patients who were already registered with the ICD-10 CM code at least twice within a year in the healthcare system. In the analyzed population, 12 812 patients met the above-mentioned criteria. The majority of patients were transferred to GP (39.3%) or TMC (18.1%) after hospitalization, but almost 43% were re-admitted. Among the patients who were under TMC care, 56.2% were re-admitted by TCM, 25.4% were transferred to GP, and 18.5% were hospitalized. The majority of patients initially managed by the GP remained there for the second visit (Figure 3).

The number of steps in the healthcare system and the percentage of deaths in patients registered with CM ICD-10 codes

The analysis showed that the largest number of patients with CM ICD-10 codes was registered in the system only

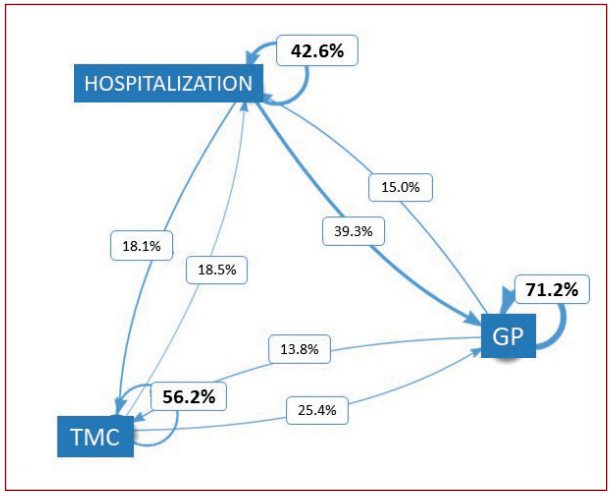

Figure 3. Markov chain figure based on the data of the patients who were already registered as ICD-10 CMs code at least twice a year in the visits in the health care system. Hospitalization – both elective and urgent

Abbreviations: see Table 1

once (30 730/47%) with no further service registration in the system. In this subgroup, there were as many as 13 490 (43.9%) deaths. The number of patients who were registered in the system more than once was decreasing due to a constantly high percentage of deaths in each subgroup (Figure 4).

DISCUSSION

The presented study is the first population-based cross-sectional analysis summarizing pathways of CM patients in the healthcare system in Poland. This is by far the first report in the literature concerning the approach to CM patients' treatment trajectories. The analysis was conducted using data acquired from the NFZ using the ICD10 system from 2016 to 2021.

The crucial finding is the high percentage of patients who were registered in the database with the CM code only once and the high percentage of patients who died after that first registration without returning to the healthcare system. On the other hand, our data clearly shows that the first CM diagnosis was primarily established during a hospital stay. This indirectly confirms that an effective diagnostic process is mainly provided in tertiary reference centers. As argued in our previous publication, the annual incidence of CM diagnosis was 16 801 subjects (43.72/100 000, 0.044%) in 2016 and decreased by 2020 to 6 729 (17.59/100 000, 0.018%) CM patients [6]. It is consistent with the number of subjects included in the current analysis. The decrease in CM diagnoses in the years 2020–2021 corresponds to the COVID-19 pandemic, which led to the widespread limitation of access to the healthcare system for elective patients.

At the same time, the average age of Polish patients with CM diagnosis reported for the first time was high and indicated a late diagnosis and justified the high prevalence of comorbidities. It is worth noting that 65% of the CM population were men, which is consistent with the results of other published epidemiological data [8, 9]. Both our first publication based on the NFZ database [6] and the current analysis show that the presence of CMs was a significant factor in worsening the prognosis. Among the patients with the ICD-10 CM code, 39.8% died during the observation period. Nearly 47% of patients were registered in the system only once without further follow-up. The study showed a very high mortality rate of 43.9% in patients with a single consultation, which gradually decreased with more interactions with the healthcare provider.

The next critical finding regards the number of patients lost from the healthcare system. Among subjects diagnosed during elective hospitalization, nearly 47% of patients were not registered again in the public health

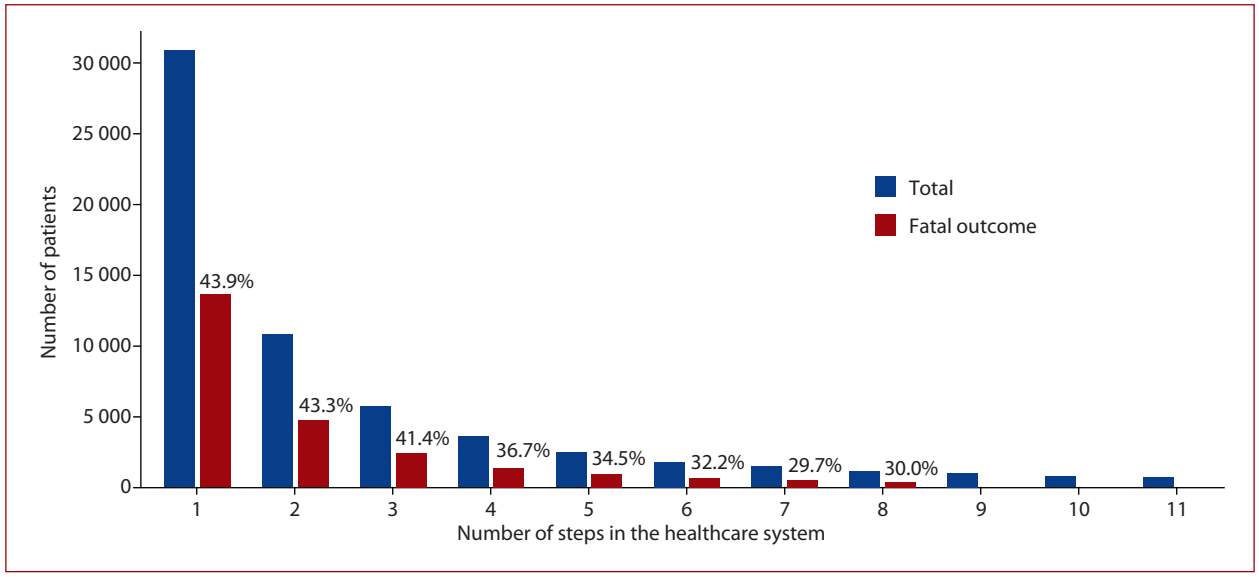

Figure 4. Total number of patients and percentage of deaths corresponding to the number of the registrations ("steps") as ICD-10 for CMs in the health care system in the years 2016–2021

systems with CMs ICD-10 codes. Similarly, up to 26% did not enter the healthcare system again after urgent hospitalization.

Assessment of the analyzed population in terms of comorbidities shows that as many as 65.3% had CCI in the range 2–5, 12.2% had CCI ≥5, and only 22.5% had CCI in the 0–2 range. We observed increasing age of the patients in the subpopulations with higher CCI scores. This explains why a large percentage of individuals with late CM diagnosis had numerous comorbidities. A similarly high number of comorbidities was recorded in a large European Society of Cardiology registry [5].

Analyzing the total contribution of the CCI subpopulations to CM health, we observed that hospitalization dominated in the CCI ≥5 subpopulations (63.8%), with a more important role of outpatient care in the subpopulation of CCI 0–2.

Our observation highlights the significant percentage of deaths in patients with comorbidities; in the subpopulation with CCI ≥5, the death rate reached as many as 65.4%; 36.1% of patients diagnosed during EH and 38.2% of those diagnosed during UH. These subjects were the oldest and the most burdened with coexisting diseases. The results are consistent with the very idea of the CCI assessment — the higher the calculated score, the lower the one-year survival rate [12]. At the same time, our results show the scale of the problem among Polish CM patients.

We are aware that the coexistence of comorbidities can contribute to failure of CM therapy and increase the mortality risk. However, there is little data on this topic. It has been reported that the most frequent comorbidities in CM patients are hypertension, obesity, diabetes mellitus, atherosclerotic disease with coronary artery disease, cerebral vascular accidents [8, 13], and atrial fibrillation that is the most common arrhythmia in patients with hypertrophic CM (HCM) [14]. Similarly, obstructive sleep apnea is diagnosed even in 70% of patients with HCM [15]. We have not analyzed particular comorbidities or included them in the CCI analysis. This is why the direct comparisons are not available. On the other hand, the CCI may be regarded as a surrogate of cardiac and extracardiac comorbidity burden and constitutes an advantage of the study. In the literature, there are only single studies on CMs including the CCI in analysis [16, 17]. Similar to our results, an increasing percentage of women among patients in an HCM Korean population presented a higher CCI [16].

The Markov chain figure shows further limitations in the elective care of CM patients. Most of the subjects had consultations in GP and only a minority were under TMC care.

That is not an optimal form of care; however scarce, the literature also indicates this problem [18]. We confirmed that the clinical pathway for HCM patients outside tertiary care is even more suboptimal. According to the current European Society of Cardiology guidelines [2], the CM Team should comprise geneticists and specialists in imaging, electrotherapy, and electrophysiology, which is the best form of healthcare provision.

Limitations of the study

Our analysis was conducted using data from the national healthcare provider (ICD10 codes) and shares standard limitations specific to this form of analysis.

ICD-10 codes had to be reported during the patient's hospitalization at any time during the course of the disease. This criterion was introduced for two reasons taken: the necessity for differentiation between CMs and myocardial disorders secondary to other diseases; and the fact that CM diagnosis requires specialized tests carried out in a hospital setting. Patients with codes relevant to ischemic heart disease at the time of diagnosis were excluded from analysis. In experts' opinions, the above design limited the analysis to patients with clinical problems with CMs. The article presents data for all CMs; an analysis of dilated CM and HCM will be a topic for a separate publication.

Data from the NFZ database has been collected since 2009. Considering the improvements since then in diagnostic and therapeutic options, our analysis was limited to the years 2016–2021. This is the most current period that we could analyze in which the results correspond to the current recommendations. On the other hand, data from 2020–2021 was included in the analysis with some caution. Due to the COVID-19 pandemic in this period, most elective hospital admissions and outpatient visits were deferred. This may have affected patient pathways. However, inclusion of these data allowed us to analyze a longer period, which has added clinical value to the study. We have no data on the causes of death in the analyzed population.

CONCLUSION

This study presents, for the first time, data on the treatment pathways defined as the sequence of visits to the public health system of Polish CM patients. The results are novel with regard to the literature and can be a source of critical information. CM diagnosis in Poland is made at a very late age, mainly during hospitalization, unfortunately, in the majority of patients during disease exacerbation, with a large number of patients without regular care after diagnosis. The mortality rate of CM patients is very high, especially in patients who were registered in the system only once (47% of all subjects) and in patients with CCI ≥5. More efficient CM diagnostics and treatment should be provided by tertiary reference outpatient care to improve prognosis in CM patients in Poland.

Article information

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