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**ORIGINAL ARTICLE**

# Quality of life and societal costs in patients with dilated cardiomyopathy

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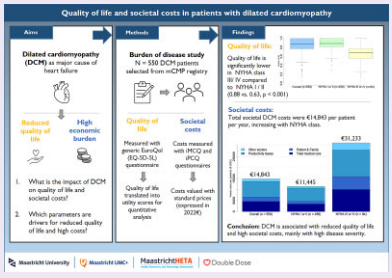
**Aims** Dilated cardiomyopathy (DCM) is a major cause of heart failure impairing patient wellbeing and imposing a substantial economic burden on society, but respective data are missing. This study aims to measure the quality of life (QoL) and societal costs of DCM patients.

**Methods and results** A cross-sectional evaluation of QoL and societal costs of DCM patients was performed through the 5-level EuroQol and the Medical Consumption Questionnaire and Productivity Cost Questionnaire, respectively. QoL was translated into numerical values (i.e. utilities). Costs were measured from a Dutch societal perspective. Final costs were extrapolated to 1 year, reported in 2022 Euros, and compared between DCM severity according to NYHA classes. A total of 550 DCM patients from the Maastricht cardiomyopathy registry were included. Mean age was 61 years, and 34% were women. Overall utility was slightly lower for DCM patients than the population mean (0.840 vs. 0.869, $P = 0.225$). Among EQ-5D dimensions, DCM patients scored lowest in 'usual activities'. Total societal DCM costs were €14 843 per patient per year. Cost drivers were productivity losses (€7037) and medical costs (€4621). Patients with more symptomatic DCM (i.e. NYHA class III or IV) had significantly higher average DCM costs per year compared to less symptomatic DCM (€31 099 vs. €11 446, $P < 0.001$) and significantly lower utilities (0.631 vs. 0.883, $P < 0.001$).

**Conclusion** DCM is associated with high societal costs and reduced QoL, in particular with high DCM severity.

**Graphical Abstract** Observational burden of disease study measuring the quality of life and societal costs in 550 patients with dilated cardiomyopathy (DCM).




**Keywords** Burden of disease • Dilated cardiomyopathy • Healthcare resource utilisation • Societal costs • Quality of life

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## Key Learning Points

What is already known

- Dilated cardiomyopathy (DCM) is a leading cause of heart failure, often with a genetic background.
- Data on the quality of life and societal costs of DCM is limited.

What this study adds

- Patients with DCM have reduced quality of life, especially in more advanced severity stages.
- DCM is associated with a high economic burden, increasing with disease severity.
- These data are valuable for economic evaluations and may guide financing and reimbursement decisions in healthcare.

# Introduction

Dilated cardiomyopathy (DCM), defined as left ventricular dilatation and contractile dysfunction in the absence of an abnormal loading condition and ischaemic aetiology,[1] is a common cause of heart failure and the leading indication for heart transplantation worldwide.[1] DCM frequently has a genetic background with up to 50% of cases being familial.[2,3] As DCM often appears asymptomatic, family members are advised to undergo regular screening for an early detection of any underlying disease.[2,4] After disease onset, lifestyle changes and medications can prevent and slow down disease progression; later more invasive treatments might be initiated to alleviate symptoms.[2,4,5] Next to the physical disease burden, affected patients often face psychological stress and reduced quality of life (QoL) due to restrictions in social life and fears about the future.[5,6] The disease management of DCM is likely to cause substantial costs for patients and society as a whole; however, the societal and economic burden of DCM remains largely undetermined.[7]

Understanding the economic burden of a disease and its cost drivers is important to guide planning and prioritisation decisions within healthcare policy.[8] A burden of disease (BoD) study gathers information in terms of QoL and medical, societal, and work-related costs of illness, which is further essential for the conduct of economic evaluations aiming to optimise care.[9] BoD studies on heart failure in general or on hypertrophic cardiomyopathy (HCM) in the USA already showed that HCM causes considerable medical costs due to inpatient-, outpatient- and emergency care as well as medications.[10–14] However, available studies are limited and leave out information about costs beyond regular health care, which limits the full picture of the economic disease burden.[7] Given the familial nature of cardiomyopathies, patients might be very young and family members often need to support their relatives, which is likely to cause immense productivity losses and time costs in addition to costs arising for regular medical care.

This BoD study aims to gain insights into the QoL and societal costs of DCM patients measured from a Dutch societal perspective. Further, this study explores predictors for QoL and costs to reveal the driving factors of the disease burden. The study is part of the Maastricht cardiomyopathy registry (mCMP-registry) and uses a bottom up, prevalence-based approach. This enables the inclusion of broader cost beyond medical care (e.g. productivity losses), which allows a more holistic assessment of the societal and economic impact of DCM.

# Methods

## Study design and population

Non-ischaemic, non-valvular DCM patients were enrolled between January 2004 and December 2021 as part of the mCMP-registry: a registry including among others DCM patients referred to the DCM outpatient clinic at the Maastricht University Medical Centre (MUMC+).[15] Inclusion criteria for patients were: (i) DCM defined as LVEF <50% with an indexed left ventricular end diastolic diameter (LVEDDI) > 33 mm/m$^2$ (men) or >32 mm/m$^2$ (women) measured by echocardiography; or a hypokinetic non-DCM defined as LVEF <50% with an LVEDDI ≤33 mm/m$^2$ (men) or ≤ 32mm/m$^2$ (women) measured by echocardiography.[16] This mixed population is further referred to DCM in this paper; (ii) age ≥16 years; and (iii) written informed consent. To gain cross-sectional data on the disease burden of DCM patients across all disease stages, patients were invited to complete the five-level EuroQol five-dimensions questionnaire (EQ-5D-5L),[17] the institute for Medical Technology Assessment (iMTA) Medical Consumption Questionnaire (iMCQ),[18] and the iMTA Productivity Cost Questionnaire (iPCQ),[19] regardless of time since enrolment in the mCMP-registry. The study was performed according to the declaration of Helsinki and was approved by the institutional Medical Ethics Committee. The STROBE and CHEERS 2022 reporting guidelines were followed to guarantee full transparency. The respective study protocols are attached to the Supplementary material online, *Section A*.

## Data collection

QoL was measured using the EQ-5D-5L questionnaire, which contains 5 questions about the patients' current health within the dimensions mobility (i.e. walking), self-care (i.e. washing or dressing), usual activities (i.e. work, study, housework, family, or leisure activities), pain/discomfort, and anxiety/depression. In each dimension, patients were able to choose between 5 different response levels: 'no problems', 'slight problems', 'moderate problems', 'severe problems', and 'extreme problems'.[17] Based on the patient's answers, individual health profiles were derived and translated into utility scores. Utility scores express QoL in numeric values, in which 0 corresponds to death and 1 indicates perfect health. For the translation of the health profiles into utility scores, the Dutch value set, a reference dataset of the general population, was used.[17,20]

Cost data were obtained in 4 categories: (1) medical costs, (2) patient and family costs, (3) productivity losses (due to paid work), and (4) costs in other sectors (due to unpaid activities/voluntary work).[21] Medical consumption was quantified using the iMCQ, except for in-hospital medical care, which were collected through diagnosis treatment combination (DBC) codes stored in the patient electronic record system for declaration of medical costs by hospitals to healthcare.[18,22,23] The iMCQ measures the amount of different health services used by patients such as general practitioner, social worker, physical therapist, occupational therapist, logopaedic, dietician, alternative medical therapist (i.e. homeopathy, acupuncture), psychologist/psychiatrist, company physician, home care provided by care organisations, emergency care, hospitalisations, and medication in use. In addition, the iMCQ contained questions on patient and family costs, i.e. costs for unpaid home care provided by family members (in case patients cannot take full care of themselves) and travel expenses for patients due to hospital consults. All iMCQ items measured the resource use

retrospectively for the last 3 months. For both, medical consumption and patient and family costs, an average resource utilisation was calculated for the whole sample by setting volumes to 0 if a patient indicated not having claimed any health service. Final costs were determined by multiplying the amount/hours of healthcare services used by standard prices listed in the costing guideline of the Dutch Healthcare Institute (i.e. 'Zorginstituut Nederland').[24] For medications, conservative prices, i.e. the cheapest price option was selected. This was done by choosing the generic product (if available) over the brand name drug and by selecting the tablet variant, which corresponds to the defined daily dosage.[25] If health services were not listed in the costing guideline, prices were taken from the Dutch Healthcare Authority (NZA).

Productivity losses for paid work and costs in other sectors due to unpaid activities (i.e. voluntary work, housework, leisure activities, etc.) were measured in detail using the iPCQ.[19] More concrete, the iPCQ gathered information about the patients' ability to perform paid work (disability), the amount of lost working hours due to sickness (absenteeism), the reduced productivity at work due to sickness (presenteeism), and the amount of hours of unpaid activities (costs in other sectors), focussing on a recall period of 4 weeks. Lost working days/hours were multiplied with standard tariffs as listed in the costing guideline.[24] Productivity losses for the inability to work (disability), sick leave (absenteeism), and lost hours of unpaid or voluntary activities (costs in other sectors) were calculated with the friction cost approach as recommended by the Dutch guideline.[26] This approach values all lost productivity until a worker returns to work (short-term absence) or until the employer replaces the sick worker (long-term absence or disability). According to the Dutch guideline, the friction period, i.e. the time needed to replace a sick worker, is assumed 12 weeks. After this period, the calculation of productivity losses due to long-term absence or disability stops.[24]

Final costs were extrapolated to 1 year and are reported in costs per patient per year (PPPY), respectively. As the iPCQ has a recall period of 4 weeks, also productivity losses for which the friction cost method applied were extrapolated to the predefined friction period of twelve weeks. All reference prices were adjusted for inflation with data from the Dutch Central Bureau for Statistics (CBS) and are reported in 2022 Euros.[27] As the time period does not exceed 1 year, no discounting was applied. Supplementary material online, *Tables B.1–B.6* summarise all reference prices and assumptions made.

## Statistical methods

Categorical variables were summarised using frequencies (percentages); continuous variables are presented as mean ± standard deviation (SD) or median. Normality was checked for continuous variables using histograms and tested by means of the Shapiro–Wilk test. As QoL and costs showed a high degree of skewness, non-parametric bootstrapping (2000 replications) was performed and corresponding 95% confidence intervals (CIs) were computed based on the percentile method. Correlation was analysed with the Spearman and Kendall correlation coefficient, as appropriate. Multiple linear regression analyses were performed for utility and total yearly DCM costs as dependent variables. Covariates for the initial model were selected based on data availability and discussions within the research team. A backward elimination procedure was implemented to identify the final model specification. Relevant predictors were selected based on a significance level of $P < 0.05$. Multicollinearity between independent variables was checked by means of the variance inflation factor (VIF >10). To account for skewness and outliers, regression coefficients were bootstrapped using 1000 replications and 95% CI were calculated using the percentile method, respectively. Non-parametric tests, such as the Mann–Whitney *U* test and the one-sample Wilcoxon signed rank test, were used to test differences between two independent subgroups and to test the median value of the sample. Tests were two-sided and used a level of significance of $P < 0.05$. Due to the observational study design, the same alpha level was kept throughout the analyses. All statistical analyses were performed using R 4.2.2.

Subgroup analyses were performed according to DCM severity using the median LVEF (i.e. an LVEF of 48%) at the time of questionnaires as cut-off, and an NYHA of ≥3. Several scenario analyses were performed to check the robustness of the results. First, societal costs were compared to costs calculated from the healthcare system perspective. Second, productivity losses and costs in other sectors were calculated with the human capital approach, which extrapolates all costs to 1 year, and contrasted to those calculated under the friction cost approach. Third, an updated friction period of 20 weeks, as calculated with recent CBS data, was used and compared to the baseline result.

# Results

## Demographics

Invitations for the questionnaires were sent in December 2021. Of the 673 invited patients, 550 patients (81.7% response rate) completed the questionnaires (Supplementary material online, *Table C.1*). No statistical differences between the patients group that completed the questionnaires and those who did not complete the questionnaires were found, except for the two comorbidities COPD and diabetes type 2 (Supplementary material online, *Table C.2*). The final cohort ($n = 550$) had a mean age of 61.4 years (SD = 11.8), with 34.4% women. Genetic testing was performed in 80.2%, in 19.5% of those being tested a class VI or V mutation was present. Mean LVEF at time of questionnaires was 46.3% and NYHA at time of questionnaires was ≥3 in 94 patients (17.1%). In total, 207 patients (37.6%) had a cardiac device. Details about the patient characteristics at time of questionnaires found in *Table 1*.

## Quality of life

Worst QoL was reported in the dimensions of pain/discomfort, mobility, and usual activities of daily living, with more than 40% of DCM patients having problems, as shown in *Figure 1*. In the dimensions of self-care and anxiety/depression, QoL was valued higher with a total of 88.6 and 72.9% of patients showing no problems. Across all dimensions, slight problems were reported fewest in the category self-care (7.6%) and highest in pain/discomfort (26.6%) and usual activities (24.4%). Moderate and severe problems were mostly reported in mobility and usual activities. Extreme problems were rarely reported in all categories. Details can be found in the Supplementary material online, *Table C.3*.

Based on the derived utility scores of the EQ-5D-5L health states, the average utility of the overall DCM cohort was 0.840, which is slightly lower than the national average of 0.869 ($P = 0.225$).[20] Men and women had comparable utility, however, men showed a significantly lower score ($P = 0.012$) compared to the population mean. Utility was highest for DCM patients between 30 and 39 (0.940) and lowest for DCM patients between 40 and 49 (0.806). DCM patients aged 30–39 and 60–69 reached significantly higher utility scores than the population average ($P = 0.023$ and $P \leq 0.001$, respectively). Less symptomatic DCM patients (NYHA classes I and II) had significantly higher utility than the national average (0.883, $P < 0.001$), more symptomatic DCM patients (NYHA classes III and IV) had significantly lower utility than the national average (0.631, $P < 0.001$). Further, patients with LVEF ≤48% had significantly lower utility compared to the general population (0.828, $P = 0.020$). Generally, results in terms of mean utility scores based on the collected data were similar to those obtained using non-parametric bootstrapping. Only in the overall DCM utility, bootstrapping resulted in a lower mean utility score (0.834, 95% CI 0.826–0.845). Details about the comparison of the utility scores with the Dutch general population can be found in *Table 2*.

**Table 1 Patient characteristics at time of questionnaires**

| | DCM patients ($n = 550$) |
|---|---|
| **General and medical history** | |
| Age in years, mean ± SD | 61.4 ± 11.8 |
| Female, *n* (in %) | 189 (34.4) |
| Body mass index, mean ± SD | 26.9 ± 5.0 |
| LVEF, mean ± SD | 46.3 ± 10.9 |
| NYHA ≥ III, *n* (in %) | 94 (17.1) |
| Genetic testing performed, *n* (in %) | 441 (80.2) |
| (Likely) pathogenic cardiomyopathy gene mutation, *n* (in %) | 107 (19.5) |
| Cardiac device, *n* (in %) | 207 (37.6) |
| Atrial fibrillation/flutter, *n* (in %) | 118 (21.5) |
| TIA or stroke, *n* (%) | 61 (11.1) |
| COPD, *n* (in %) | 29 (5.3) |
| Asthma, *n* (in %) | 42 (7.6) |
| Sleep apnea, *n* (in %) | 80 (14.5) |
| Diabetes mellitus type 2, *n* (in %) | 50 (9.1) |
| Arterial hypertension, *n* (in %) | 160 (29.1) |
| (Previous) cancer, *n* (in %) | 61 (11.1) |
| **Highest educational degree**[a] | |
| Elementary school, *n* (in %) | 114 (20.7) |
| Secondary school/educational training, *n* (in %) | 248 (45.1) |
| Bachelor/Master, *n* (in %) | 188 (34.2) |
| **Occupational status** | |
| Paid work, *n* (in %) | 222 (40.4) |
| Pension, *n* (in %) | 182 (33.1) |
| Unable to work, *n* (in %) | 100 (18.2) |

TIA, transient ischaemic accident; COPD, chronic obstructive pulmonary disease.
[a]Elementary school = No school degree, elementary school, domestic school; Secondary school/educational training = Mavo/VMBO, HAVO/VWO, MBO; Bachelor/Master = HBO, University.

## Recourse use and costs

Total average societal DCM costs were €14 843 PPPY. Of the four cost categories, productivity losses were the main cost driver with €7037€ PPPY due to absenteeism, presenteeism, or full disability. Medical costs were second highest with €4621 PPPY, mainly attributable to inpatient care. Patient and family costs and costs in other sectors made up the least amount with €2001 PPPY and €1184 PPPY, respectively.

Within medical costs, inpatient care (€2231 PPPY) caused the most costs, followed by outpatient care (€863 PPPY) and medications (€805 PPPY). Inpatient care costs were mainly driven by on average 3.2 DBC codes registered by the cardiology department, including cardiologist consultations as well as performed interventions for diagnostic and treatment purposes, which account for €740 PPPY. Costs for hospital stays formed the second highest amount of inpatient care. The whole DCM cohort had on average 1.1 hospital days per year, accounting for €635 PPPY. Regarding only those who had a hospital stay, the average number of hospital days per year was 22.7 days, which corresponds to €12 938 PPPY. Outpatient costs were mainly composed of on average 3.8 general practitioner visits (€153) and 10.8 physiotherapy sessions (€437) per year. Homecare provided by care organisations was highest for domestic activities (e.g. cleaning, grocery shopping) and least for self-care (assistance with showering or dressing) and nursing (assistance with medications devices).

Patient and family costs were primarily driven by family members performing practical (€850 PPPY) and domestic support (€824 PPPY), both around 1 h per week. Similar to professional organisations, costs for support in self-care activities were fewest. Generally, relatives provided homecare more frequently than professional care organisations. In productivity losses, costs for patients being fully disabled to perform work were highest (€3124 PPPY), followed by costs for absenteeism (€2232 PPPY) and presenteeism (€1681 PPPY). Details about all types of healthcare resource utilisations and costs are summarised in *Table 3*. The non-bootstrapped means based on the observed sample data are available in Supplementary material online, *Table C.4*.

## Regression analyses

Utility and yearly DCM costs were modelled using multiple linear regression (*Tables 4* and *5*). For both outcomes, the final model

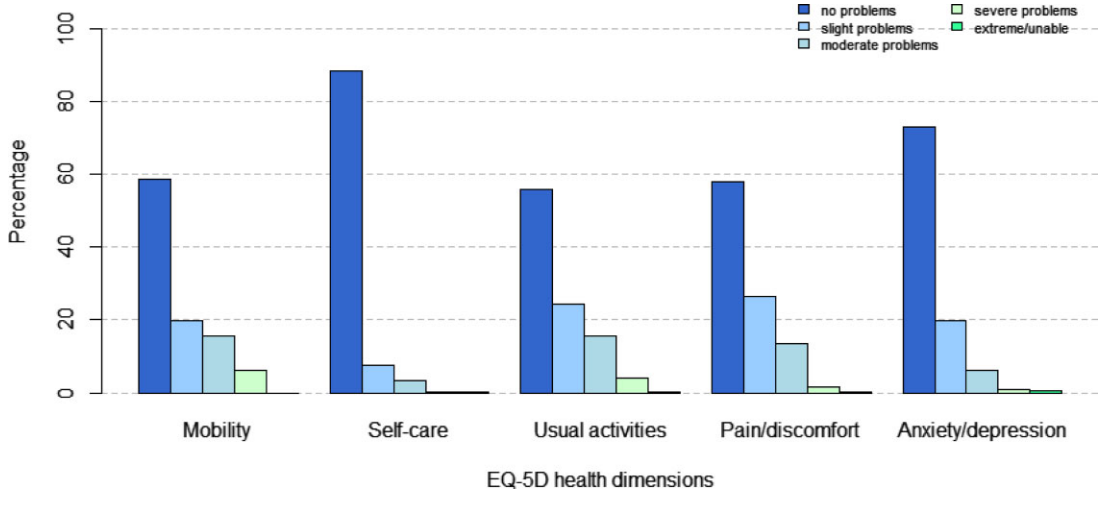


**Figure 1** Quality of life of DCM patients according to EQ-5D-5L dimensions.

**Table 2 Quality of life measured in utility scores derived from the EQ-5D-5L**

| | DCM mean ± SD | Bootstrapped 95% CI | Population mean ± SD[20] | *P* value |
|---|---|---|---|---|
| Average ($n = 550$) | 0.840 ± 0.169 | 0.834 [0.826; 0.845] | 0.869 ± 0.17 | 0.225 |
| Sex | | | | |
| Men ($n = 361$) | 0.839 ± 0.167 | 0.834 [0.822; 0.855] | 0.881 ± 0.172 | 0.012* |
| Women ($n = 189$) | 0.840 ± 0.173 | 0.840 [0.815; 0.864] | 0.858 ± 0.168 | 0.467 |
| Age | | | | |
| 20–29 ($n = 8$)[a] | 0.877 ± 0.134 | - | 0.908 ± 0.146 | 0.527 |
| 30–39 ($n = 20$)[a] | 0.940 ± 0.104 | - | 0.903 ± 0.134 | 0.023* |
| 40–49 ($n = 57$) | 0.806 ± 0.197 | 0.806 [0.753; 0.855] | 0.850 ± 0.196 | 0.647 |
| 50–59 (n = 141) | 0.837 ± 0.163 | 0.837 [0.809; 0.862] | 0.857 ± 0.183 | 0.999 |
| 60–69 ($n = 184$) | 0.862 ± 0.148 | 0.862 [0.840; 0.883] | 0.839 ± 0.179 | <0.001** |
| 70 & higher ($n = 139$) | 0.810 ± 0.189 | 0.809 [0.777; 0.839] | 0.852 ± 0.148 | 0.246 |
| Severity stage/symptomatology | | | | |
| NYHA class <3 ($n = 456$) | 0.883 ± 0.124 | 0.883 [0.871; 0.894] | 0.869 ± 0.17 | <0.001** |
| NYHA class ≥3 ($n = 94$) | 0.631 ± 0.200 | 0.630 [0.589; 0.668] | 0.869 ± 0.17 | <0.001** |
| LVEF >48% ($n = 263$) | 0.853 ± 0.167 | 0.853 [0.832; 0.873] | 0.869 ± 0.17 | 0.493 |
| LVEF ≤48% ($n = 287$) | 0.828 ± 0.170 | 0.828 [0.807; 0.846] | 0.869 ± 0.17 | 0.020* |

*P*-values (*$P < 0.05$; **$P < 0.01$) based on the Wilcoxon signed rank test with continuity correction. Source population mean: Dutch Tariff for the Five-Level Version of EQ-5D[20].

[a]Sample size in age groups 20–29 and 30–39 insufficiently high to perform bootstrapping.

was identified using a backward selection procedure based on model fit criteria ($R^2$) and the relevance of the selected predictors. For utility, significant predictors were the NYHA class, variables determining the occupational status of a patient (employed and freelancing), yearly DCM costs and having a cardiac device. In detail, the NYHA class and yearly DCM costs had a negative coefficient, indicating that patients with higher NYHA classes or higher DCM costs tend to have lower expected utility scores. The independent variables of being employed, freelancing, or having a cardiac device were positively associated with utility.

Significant predictors for total DCM costs were the NYHA class, variables of the occupational status (employed and disabled), utility, and having two or more comorbidities. The coefficients for NYHA class III and IV, employment and two or more comorbidities showed a positive association with total DCM costs. Hence, these predictors are likely to increase the total expected costs of a DCM patient. In accordance with the previous regression model, the variable of utility was found to have a negative association with DCM costs, i.e. that patients with higher utility scores tend to have lower expected DCM costs. In both models, age, sex, and LVEF were no significant predictors. The regression coefficients obtained with multiple linear regression were similar to those obtained with bootstrapping.

## Subgroup analyses

*Figure 2* shows the DCM costs PPPY according to the NYHA class subgroups. Compared to the total DCM costs of the overall cohort, the bootstrapped total costs for patients in NYHA class I or II were lower (€11 445 PPPY, 95% CI [€9762; €13 266]) and around three times higher for patients in NYHA class ≥3 (€31 233 PPPY, 95%CI [€24 456; €39 404]). Patients in NYHA class III or IV had higher costs across all medical costs (*Figure 2A*) and all broader cost categories, i.e. patient and family costs, productivity losses, and costs in other sectors (*Figure 2B*). In the LVEF subgroups, patients with LVEF above our study population median of 48% showed slightly lower yearly DCM costs (€14 272 PPPY, 95%CI [€11 315; €17 530]) comparted to those patients with an LVEF below the median of 48% (€15 333 PPPY, 95%CI [€12 851; €18 137]). Patients with LVEF >48% had fewer medical costs, patient and family costs, and costs in other sectors but reported higher productivity losses. Supplementary material online, *Figure C.5* provides more details about the cost distribution within the LVEF subgroup.

## Scenario analyses

Total DCM costs PPPY from a societal perspective are much higher than costs considered from a healthcare perspective, i.e. only medical costs (€14 843 vs. €4621). Healthcare costs alone account for only around one third of the societal costs, which means that the majority of costs is caused by other costs types. Productivity losses calculated with the human capital approach, i.e. also costs due to long-term sickness and full disability were extrapolated to 1 year and not stopped after 12 weeks, were highest with €8233 PPPY (95%CI [€6720; €9756]) compared to the baseline value of €7037 PPPY. Costs in other sectors have been most sensitive towards changes. Calculated with the friction cost method, costs for unpaid/voluntary activities were €1184 PPPY compared to €5132 PPPY (95%CI [€3735; €6734]) after extrapolation to 1 year. The results of all scenario analyses can be found in Supplementary material online, *Table C.6*.

# Discussion

This BoD study examined the impact of DCM on different QoL dimensions and quantified the cost burden on society. More than 40% of DCM patients reported health-related issues with pain/discomfort, mobility, and usual activities of daily living. Converted into utilities, QoL was slightly lower for DCM patients compared to the national average. From a societal perspective, the total economic burden of a single DCM patient averages €14 843 euros PPPY, and was vastly different from the healthcare perspective which only considers costs for medical care (€4621 PPPY). QoL decreased and costs increased significantly with DCM disease severity, with NYHA class found to be a significant predictor for both outcomes.

**Table 3 Bootstrapped mean healthcare resource utilisation and mean costs per PPPY of DCM according to cost types (after 2000 replications)**

| Total cohort ($n$ = 550) | HCRU | 95% CI HCRU | Costs PPPY (2022 Euros) | 95% CI Costs |
|---|---|---|---|---|
| Total medical costs | | | €4621 | [€3800; €5693] |
| Outpatient care (in consultations) | | | €863 | [€732; €998] |
| General practitioner | 3.8 | [3.3; 4.5] | €153 | [€131; €180] |
| Practice assistant (POH) | 1.2 | [1.0; 1.5] | €26 | [€21; €31] |
| Social worker | 0.3 | [0.1; 0.7] | €27 | [€9; €52] |
| Physiotherapy | 10.8 | [8.8; 12.8] | €437 | [€356; €517] |
| Occupational therapy | 0.3 | [0.0; 0.7] | €10 | [€1; €25] |
| Logo therapy | 0.3 | [0.1; 0.5] | €12 | [€5; €21] |
| Dietician | 0.4 | [0.3; 0.6] | €17 | [€11; €24] |
| Homeopathy | 0.2 | [0.1; 0.3] | €8 | [€3; €14] |
| Psychotherapy | 1.4 | [0.8; 2.1] | €158 | [€94; €236] |
| Company physician | 0.4 | [0.2; 0.6] | €15 | [€8; €24] |
| Homecare (in hours) | | | €435 | [€196; €733] |
| Domestic support | 11.5 | [4.2; 21.6] | €324 | [€119; €607] |
| Self-care support | 1.4 | [0.3; 2.8] | €83 | [€16; €171] |
| Nursing | 0.3 | [0.0; 0.8] | €28 | [€0; €75] |
| Medications | | | €805 | [€725; €885] |
| Emergency care | | | €286 | [€194; €386] |
| First aid | 0.3 | [0.2; 0.4] | €228 | [€153; €310] |
| Ambulance | 0.2 | [0.1; 0.3] | €58 | [€34; €85] |
| Inpatient care | | | €2231 | [€1542; €3243] |
| CV-related consults & examinations (DBC) | 3.2 | [2.9; 3.5] | €740 | [€666; €814] |
| Other non-CV specialist consults | 2.5 | [2.1; 2.9] | €276 | [€229; €327] |
| Hospital stay (days) | 1.1 | [0.6; 1.8] | €635 | [€336; €1017] |
| Other facilities examinations | 0.1 | [0.0; 0.3] | €61 | [€9; €141] |
| Other facilities stay (days) | 0.2 | [0.0; 0.4] | €519 | [€42; €1391] |
| Total patient & family costs | | | €2001 | [€1248; €2976] |
| Domestic support family (hours) | 48.2 | [23.2; 88.5] | €824 | [€396; €1513] |
| Self-care support family (hours) | 3.6 | [1.0; 7.1] | €62 | [€18; €121] |
| Practical support family (hours) | 49.7 | [20.7; 88.3] | €850 | [€354; €1510] |
| Time and travelling | | | €265 | [€114; €498] |
| Total productivity losses | | | €7037 | [€5818; €8277] |
| Absenteeism (days) | | | €2232 | [€1363; €3224] |
| Presenteeism (days) | | | €1681 | [€1127; €2299] |
| Disability | | | €3124 | [€2539; €3699] |
| Total costs other sectors (lost days for unpaid activities) | | | €1184 | [€862; €1554] |
| Total DCM costs | | | €14 843 | [€12 905; €16 927] |

* Abbreviations: HCRU, healthcare resource utilisation; PPPY, per patient per year; CI, confidence interval; POH, Praktijkondersteuner; CV, cardiovascular; DBC, diagnosis treatment combination; inflation adjustment based on https://opendata.cbs.nl/statline/#/CBS/nl/dataset/83131ned/table?fromstatweb.

Generally, literature on the QoL and costs of DCM patients is scarce. Studies on the QoL in patients with different cardiovascular diseases found that cardiac patients had a reduced QoL compared to national averages, in accordance with our findings.[6,28,29] Similar to our DCM cohort, cardiac patients mostly suffer from restrictions in physical and social functioning.[6,28,29] A direct comparison to our study remains however difficult as QoL was often measured with different instruments than the EQ-5D based on a different patient population. Although the QoL of our DCM cohort was overall lower than the Dutch general population, some age subgroups (age groups 30–39 and 60–69) had higher utility mean scores than the population average. In the younger age group, the differences may be caused due to an insufficient sample size ($n$ = 20) and is therefore probably not of clinical relevance, whereas for the older age group 60–69 a larger sample size ($n$ = 184) was reached. Steptoe and colleagues got a similar finding and reported that older DCM patients showed higher scores in vitality and overall health perception than younger DCM patients, but reported no potential reason for this observation (6). Generally, as we only compare a small subgroup of our sample to a much larger and broader population, the comparison of the mean scores to the general public has to be taken with a certain degree of caution. Moreover, multiple linear regression revealed that age was not identified as a significant predictor for QoL, leaving the role of age unclear. Notably, variables of the occupational status of

**Table 4 Regression table—quality of life expressed in utility**

| | Results regression analysis—utility | | |
|---|---|---|---|
| | (1) Utility (OLS model)[a] | (2) Bootstrapping (1000 replications) | 95% CI of coefficient |
| Constant | 0.901 (0.011) | 0.901 | [0.876; 0.922] |
| NYHA II | −0.067 (0.012) | −0.067 | [−0.089; −0.045] |
| NYHA III | −0.242 (0.017) | −0.243 | [−0.288; −0.201] |
| NYHA IV | −0.225 (0.042) | −0.228 | [−0.385; −0.079] |
| Employed | 0.046 (0.013) | 0.046 | [0.024; 0.070] |
| Freelance | 0.050 (0.021) | 0.051 | [0.017; 0.084] |
| Yearly DCM costs (per 1000€) | −0.002 (0.0002) | −0.002 | [−0.002; −0.001] |
| Cardiac device | 0.036 (0.012) | 0.037 | [0.014; 0.059] |
| Observations | 549 | | |
| $R^2$ | 0.439 | | |
| Adjusted $R^2$ | 0.431 | | |
| Residual standard error | 0.127 ($df = 541$) | | |

[a]OLS model: Standard errors in brackets.

**Table 5 Regression table—total DCM costs in 2022 Euros**

| | Results regression analysis—total DCM costs | | |
|---|---|---|---|
| | (1) Total DCM costs (OLS model)[a] | (2) Bootstrapping (1000 replications) | 95% CI of coefficient |
| Constant | 43 061 (6844) | 43 486 | [22 406; 71 927] |
| NYHA II | −436 (2126) | −490 | [−4573; 3183] |
| NYHA III | 4782 (3423) | 4653 | [−3722; 12 853] |
| NYHA IV | 15 297 (7270) | 14 973 | [−5798; 40 068] |
| Employed | 8604 (2153) | 8530 | [4542; 13 004] |
| Disabled | 15 122 (2603) | 15 119 | [8573; 21 022] |
| Utility (per 0.1) | −4387 (702) | −4424 | [−7509; −2289] |
| ≥2 comorbidities[b] | 4718 (1904) | 4696 | [1630; 8197] |
| Observations | 549 | | |
| $R^2$ | 0.238 | | |
| Adjusted $R^2$ | 0.228 | | |
| Residual standard error | 21 652 ($df = 541$) | | |

[a]OLS model: Standard errors in brackets.
[b]Comorbidities include medical history of ischaemia, acute coronary syndrome, COPD, asthma, sleep apnea, diabetes, hypertension, and cancer.

patients had a significant impact on QoL. The ability to perform work (employed or freelancing) appeared to positively affect QoL. This could be explained by the maintained stability and structure in daily life and the remaining social contact in contrast to those unable to perform work. Noteworthy is that having a cardiac device was associated with an increase in QoL, mostly consisting in improvements in the EQ-5D dimensions of pain/discomfort and anxiety/depression. This could be caused due to an improved feeling of security as ICDs are proven to reduce sudden cardiac death, or symptom relieve in those patients with a dyssynchronopathy improving after a CRT-D implantation. Prior conducted studies often came to varying conclusions. Most studies reported that the overall QoL was improved after ICD implant[30,31]; however, some studies reported a worsening of QoL due to received shocks or due to the fear of receiving inappropriate shocks in future.[30,32]

Next to QoL, this study quantified the economic burden of DCM in different cost categories. Productivity losses were identified as the main cost driver with the highest impact on the total yearly DCM costs. This is an interesting finding as previous studies only looked at healthcare costs and therefore likely underestimated the full economic burden.[10,11] In our cohort, healthcare costs were second highest, with inpatient care as driving factor. Two studies from the United States on

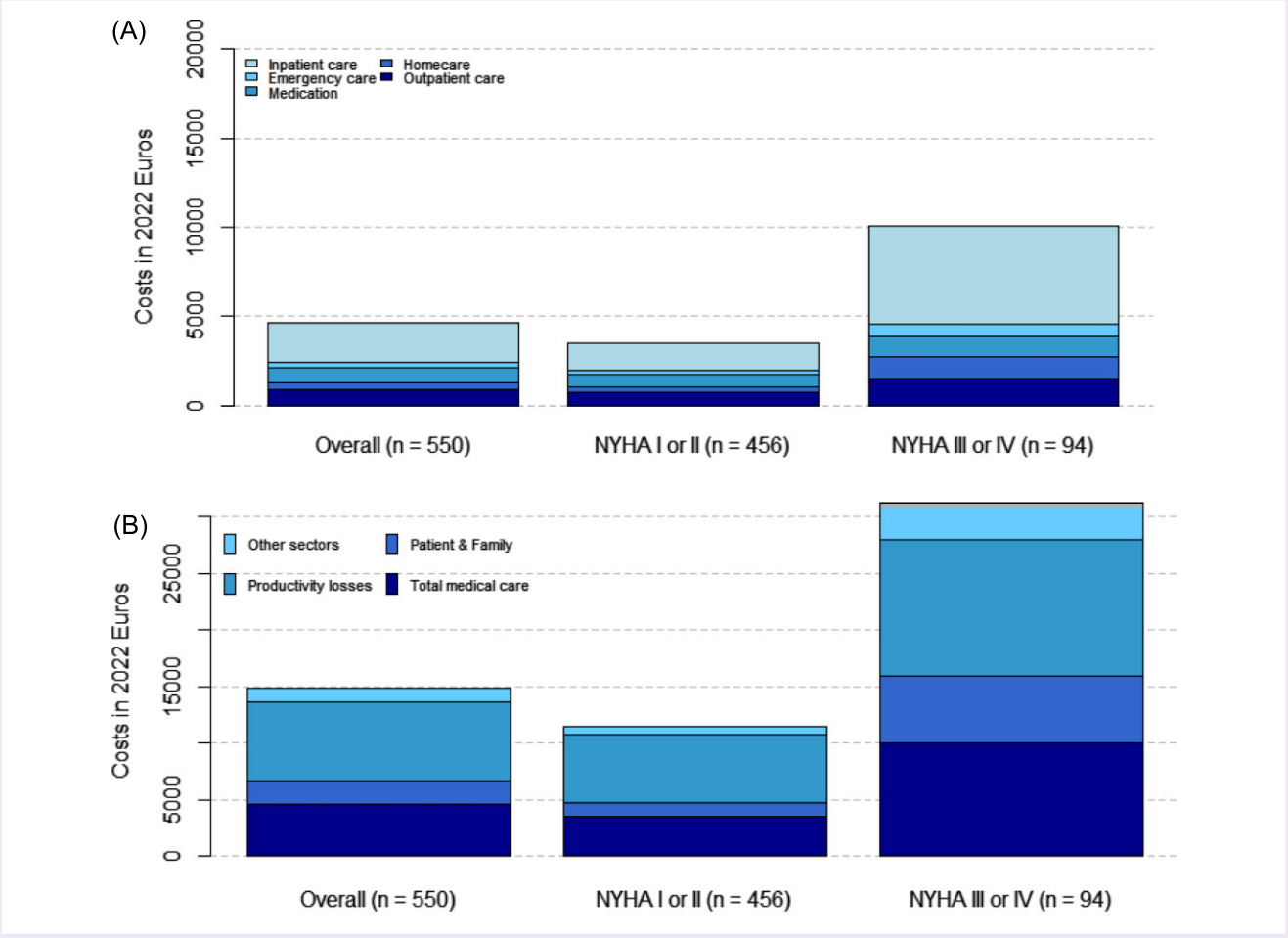


**Figure 2** Total costs per PPPY according to NYHA class. (*A*) Medical cost per PPPY according to NYHA class. (*B*) Broad cost categories per PPPY according to NYHA class. *Costs in other sectors refer to productivity losses caused by lost leisure time e.g. voluntary work, housework, caring for children, gardening, etc.

obstructive HCM reported much higher annual medical expenditures of $19 525 and $26 929.[10,11] This cost difference might be explainable due the focus on a different disease in a more advanced disease stage as well as the different healthcare system, making the transferability of their results to our study or a European setting in general difficult. Specifically for more symptomatic DCM patients (NYHA class ≥3), we also estimated vastly higher total DCM costs of €31 233 PPPY (€10 033 PPPY for medical care only). A Spanish study that used a similar bottom-up approach to estimate medical and informal care costs in symptomatic chronic heart failure patients reported total annual costs per patient ranging from €12 995 to €18 220.[33] This is comparable to our findings in the symptomatic DCM subgroup with costs of €15 909 (€10 033 PPPY for medical care and €5876 for patient and family costs). Finally, patient and family costs and costs in other sectors made up the least amount of the total DCM costs, while costs in other sectors varied considerably depending on the methodology used for its calculation. Without stopping the calculation after 12 weeks, costs in other sectors would increase to the second highest cost component of the total yearly DCM costs (€5 132 PPPY), even higher than costs for medical care. This would still be a reasonable cost estimate given the findings of the QoL assessment. Under this scenario, most of the problems occurred in the dimension of usual activities, which, similarly to the category of costs in other sectors, deals with problems related to voluntary work, housework or leisure activities.

As typical for DCM, our cohort was diverse regarding age, disease severity and comorbidities, which emphasizes the need for performing subgroup analyses. Notable differences in costs and QoL were observed between NYHA subgroups. This is in accordance with previous research, indicating that a reduction in QoL and increase in costs are often associated with clinical parameters and the symptomatology of patients.[6,11,33] Yet LVEF did not appear to be significantly associated with QoL or costs. This could be caused due to the overall relatively high LVEF values of our cohort, and the fact that LVEF is not per se associated with symptoms and limitations of a patient in contrast to the NYHA class.

This BoD study has several strengths. First, the study measured DCM costs from a societal perspective, which means that not only medical expenditures but also time losses for relatives and work-related productivity losses for society were included. Hence, this study explored the full economic impact of DCM, which is unique so far. Information about broader cost types beyond medical care are often neglected as those are usually not available in aggregated data sources or claims databases.[8] Importantly, our study included patient and family costs, which is essential given the familial nature of DCM. Thus, valuable insights into the perspective of patients and relatives about the additional burden and care effort were gained. Second, data were collected with standardised and pre-validated questionnaires. Those questionnaires have been frequently used in various disease areas with constantly increasing registration numbers.[17,34–37] Third, our cohort

included patients from different disease stages and revealed substantial differences between severity stages. Lastly, our results have shown to be very robust to different modelling techniques. Bootstrapping did not affect the utility or costs results, nor the regression coefficients compared to those based on the sample data, suggesting a limited impact of the violation of normality assumptions on the study results. Only 'costs in other sectors' were most sensitive to some changes. Currently, no clear guidance on whether to apply the friction cost method for these costs exists, nor similar studies in inheritable cardiomyopathies are available to compare our results.

Some limitations need to be addressed. First, the data collection on resource utilisation and productivity losses was based on patient answers. Hence, our cost estimates rely on patient reported outcomes, which are prone to recall bias. To minimise the risk of bias, we used standardised questionnaires with a recall period of 3 months and 4 weeks, which is often considered suitable. Further, patient reported outcomes are regarded as highly valuable to get information on health issues from the patients directly and, in our case, the use was necessary to measure costs other than for medical care.[38] Second, we only captured all-cause expenditures, as it is impractical to ask patients to solely report resource utilisation caused by DCM. We addressed this by reporting the results for all cost items separately and by distinguishing cardiovascular care and non-cardiovascular care separately whenever possible. Third, our cohort is relatively healthy, which may lead to an underestimation of the total DCM costs. We checked for selection bias by comparing the differences in baseline characteristics, and, with the exception of two comorbidities, found no difference in patients who participated in the study and those who did not. However, due to the time gap between the start of the patient recruitment (patients enrolled between January 2004 and December 2021) and the sending of the questionnaires (sent December 2021), only patients who did not die (due to DCM) were included. Hence, a selection bias might still be at hand necessitating the analysis via prospective and longitudinal studies. Lastly, QoL was measured with a generic instrument; however, small nuances or more in-depth insights might not be captured within our study.

This BoD study provided novel insight into a rather unexplored area of DCM. Future research in different cohorts and settings are needed to confirm these results. Particularly, the mixed findings when comparing QoL in different age subgroups to the general population and the relation between age and QoL in DCM patients would need more attention in future studies. Further, studies using disease-specific instruments for the measurement of QoL could reveal further details about the DCM burden. Due to the heterogeneity of DCM patients, it is necessary to look more closely at selected patient profiles and different types of DCM as the burden is very likely to vary between subgroups, e.g. genetic DCM vs. cardiotoxic chemotherapy-induced DCM. Further, longitudinal studies are needed to analyse and describe potential changes and trends in QoL and costs over a longer time period. This might be useful to study the impact of the progression of DCM and to fully understand the impact of the disease on patients and society.

# Conclusion

This cross-sectional analysis on QoL and societal costs of DCM provides novel data on the economic and societal disease impact, which has not been described before within a European setting. Our study showed that DCM is associated with high societal costs, which increase with the severity of DCM, and reduced QoL compared to the national average, and has pointed to DCM as a public health burden. These results may inform the design and conduct of future cost-effectiveness studies to allow the comparison between different interventions in DCM. More research on the economic burden of DCM is needed to confirm these results as well as more in-depth analyses within selected patient subgroups to optimise the disease management of DCM and to improve patient-centred care.

# Supplementary material

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

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**Conflict of interest:** S.H., FESC, FHFA, is professor of Cardiomyopathies, Head of Heart Failure Research (www.hfresearch.eu), Chair of Study Group of Inherited Cardiomyopathies and Heart failure, HFA of the ESC. Nucleus member of the Committee of Translational Research & the committee of HFPEF, of the HFA of the ESC. The other authors declare to have no conflict of interest.

## Data availability

The data underlying this article will be shared on reasonable request to the corresponding author.

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