ORIGINAL RESEARCH ARTICLE

Characteristics and health care utilization among patients with chronic heart failure: a longitudinal claim database analysis

Joost Johan Godert Wammes[1]*, Stefan Auener[1], Philip J. van der Wees[1], Marit A.C. Tanke[1], Louise Bellersen[2], Gert P. Westert[1], Femke Atsma[1] and Patrick P.T. Jeurissen[1]

[1]*Scientific Center for Quality of Healthcare, Radboud University Medical Center, PO Box 9101, 6500HBNijmegen, The Netherlands;* [2]*Department of Cardiology, Radboud University Medical Center, Nijmegen, The Netherlands*

Abstract

Aims   This study aimed to determine the characteristics of patients with heart failure and high costs (top 1% and top 2–5% highest costs in perspective of the general population) and to explore the longitudinal health care utilization and persistency of high costs.

Methods and results   Longitudinal observational study using claims data from 2006 to 2014 in the Netherlands. We identified all patients that received a hospital treatment for chronic heart failure between 1 January 2008 and 31 December 2010. Of each selected patient, all claims from the Dutch curative health system and with a starting date between 1 January 2006 and 31 December 2014 were extracted. Pharmaceutical and hospital claims were used to establish characteristics and indicators for health care utilization. Descriptive analyses and generalized estimating equation models were used to analyse characteristics, longitudinal health care utilization and to identify factors associated with high costs. Our findings revealed that the difference in costs between top 1%, top 2–5%, and bottom 95% patients with heart failure was mainly driven by hospital costs; and the top 1% group experienced a remarkable increase of mental health costs. Top 1% and top 2–5% patients with heart failure differed from lower cost patients in their higher rate of chronic conditions, excessive polypharmacy, hospital admissions, and heart-related surgeries. Heart-related surgeries contributed to the incidental high costs in 54% of top 1% patients, and the costs of the remaining top 1% patients were driven by mental health and pharmaceuticals use and rates of chronic conditions and multimorbidity. Top 1% patients were relatively young. Anaemia, dementia, diseases of arteries, veins and lymphatic vessels, influenza, and kidney failure were significantly associated with high costs. The end-of-life period was predictive of top 1% and top 5% costs. More than 90% of the population incurred at least one top 5% year during follow-up, and 31.8% incurred at least one top 1% year. Fifty-seven per cent incurred multiple top 5% years whereas only 8.6% incurred multiple top 1% years. Top 5% years were more frequently consecutive than top 1% years.

Conclusions   Top 1% utilization occurs predominantly incidentally and among less than a third of patients with heart failure, whereas almost all patients with heart failure experience at least one top 5% year, and more than half experience two or more top 5% years. Both medical and psychiatric/psychosocial needs contribute to high costs in heart failure patients. Comprehensive and integrated efforts are needed to further improve quality of care and reduce unnecessary costs.

Introduction

It is known that health care costs are concentrated among the so-called high-cost patients.[1] Although they receive substantial care from multiple sources, it is widely believed that many of these patients have critical unmet health care needs and many receive unnecessary and ineffective care. In the USA, ~40% of high-cost patients suffer from congestive heart failure (heart failure onwards).[2,3] In earlier work, we found heart failure affected 12% of Dutch high-cost patients.[1] Repeated hospitalizations contribute to the high costs of patients with heart failure, and it is known that non-cardiovascular co-morbidities, a lack of multidisciplinary treatment, a lack of advance care planning, and a lack of guideline recommended care contribute to (preventable) hospitalizations.[4,5] Patients with heart failure may thus be exemplary for high-cost patients and may be an interesting target population to seek for possible quality improvement and cost reduction.

A variety of interventions and programmes have been developed to improve the quality and efficiency of care for patients with heart failure.[6] Heart failure clinics with specialized nurses have shown to improve clinical outcomes and reduce all cause and heart failure-related readmissions.[7] For high-cost patients, studies have shown that the effectiveness and efficiency dramatically increase when interventions are targeted at the patients that are most likely to benefit.[8] It is thus of utmost important to acquire an in-depth understanding of the characteristics and health care utilization of patients with heart failure and those with high longitudinal utilization in particular.

Little is known about the variety in characteristics and longitudinal health care utilization of patients with heart failure. Studies focusing on the costs of heart failure are scarce, and the few that are available do not focus on high-cost patients within this population.[9,10] Furthermore, previous studies have focused on the prediction and prevention of hospital readmissions, the predominant cost driver of heart failure, and such studies are often limited by a short time horizon.[11,12]

The overall objective of this study was to explore the characteristics and longitudinal health care utilization of patients with heart failure and high costs. We aimed to describe the characteristics of patients with heart failure and high costs and to identify drivers of high costs. Furthermore, we aimed to study the longitudinal health care utilization of patients with heart failure and to identify the persistency of high costs over time.

Methods

Design and context

The study was designed as a longitudinal observational study in routinely collected claims data. The study was situated in the curative health system in the Netherlands—a health insurance scheme based on the principles of managed competition that is governed by the Health Insurance Act. The system provides a wide range of services, including care provided by general practitioners, hospitals, and specialists; dental care through age 18; prescription drugs; physiotherapy through age 18; most mental care; medical aids and devices; maternity care; transportation; and others. Voluntary complementary insurance benefits were excluded from analysis, as were long-term care benefits that are covered under a separate scheme.[13] This study complies with the Declaration of Helsinki. No ethical approval is needed for this type of research in the Netherlands according to current legislation.

High-cost patients

Top 1% and top 5% of annual care utilization in perspective of the total population are widely used indicators for intensive utilization of health resources. We used the total beneficiary population (including beneficiaries without heart failure) to establish this characteristic per patient per year. The data were not available for the years before 2009. Therefore, the cut-off values for the top 1% and top 2–5% classes were extrapolated from subsequent years and used to determine top 1% and top 2–5% utilization.

Patient selection and data source

Data were drawn from the claims database of Zilveren Kruis, a health insurer currently covering 4.5 million beneficiaries who are primarily living in the central, eastern, and western parts of the Netherlands. Detailed information about (a predecessor of) this database has been published in an earlier study.[14]

We identified all patients that received an inpatient or outpatient hospital treatment for chronic heart failure between 1 January 2008 and 31 December 2010. We selected all patients with a claim containing specialism code 320 (cardiology) and diagnostic code 302 (chronic heart failure), and limited inclusion to patients with long duration, slowly developing heart failure, rather than patients with rapid onset of the disease. We verified the correctness of this selection criterion with a cardiologist in our hospital. Analyses were limited to patients that were insured at the insurer during the entire study period or until death. Patients younger than 18 and patients who already received hospital treatment for heart failure before January 1 2008 were excluded. The study population thus represented all incident chronic heart failure patients that had one or more admissions or visits to the outpatient clinics. Patients were included irrespective of acute heart failure claims, and patients may have incurred claims for both chronic as well as acute heart failure.

Since our inclusion period covered a time horizon of 3 years, some patients received initial hospital treatment for heart failure in 2008 while others started heart failure treatment in 2009 or 2010. Therefore, years were recoded relative to the initial hospital treatment for heart failure. This enabled analysis of data relative to the first presentation of heart failure in hospitals (see *Figure 1*).

Of each selected patient, all claims with a starting date between 1 January 2006 and 31 December 2014 were extracted. Pharmaceutical claims contained Anatomical Therapeutic Chemical (ATC) class codes, which were aggregated to ATC level 2. In addition, several beneficiary characteristics were obtained from the insurer's databases, including gender, date of birth, and date of death. Zip codes (first four digits) were obtained to subsequently derive socio-economic status based on income estimates (*Appendix S2*).

Variables

Literature was searched to identify factors known to affect the progression, prognosis, and health care utilization of patients with heart failure.[10,15,16] *Appendix S1* shows which variables were identified and how the variables were operationalized in the present study. Polypharmacy was defined as receiving five or more prescription medications (ATC level 2) within a period of 3 months. We averaged this over a 1-year period to account for incidental medication.[17] Excessive polypharmacy was defined similarly for receiving at least 10 prescription medicines.

We developed two measures to establish multimorbidity. Hospital DRGs (diagnostic related groups, in Dutch: DBCs; refer to hospital payments) in the Netherlands contain specialism and diagnosis codes, and we used these to categorize the claims according to ICD-10 (sub)chapters (e.g. ICD-10 chapter IX: diseases of the circulatory system; and ICD-10 subchapter I60–I69 cerebrovascular diseases). We summed all ICD-10 subchapters to establish a hospital DRG-based multimorbidity measure. Second, we used pharmaceutical claims to establish chronic conditions based on a validated set of ATC codes.[18] We summed all chronic conditions to establish a drug-based multimorbidity measure.

We used hospital claims to create dichotomous variables for heart-related admissions and surgical interventions. Time since first hospital treatment for heart failure, previous health care expenditures, and end-of-life period have all been identified as important cost drivers[19–21] and were included as well.

We combined chronic conditions derived from pharmaceutical claims and ICD-10 subchapters derived from hospital claims to establish dichotomous variables for specific conditions. Hospital claims and claims from specialized mental health institutions were combined to establish indicators for mental health care use.

Analyses

For each year, we determined the percentage of patients that incurred top 1% or top 2–5% costs. Descriptive analyses were performed to describe the characteristics of our study population at the index year ($t = 0$). The analyses were performed separately for the hierarchical spending groups (top 1%, top 2–5%, and bottom 95% patients).
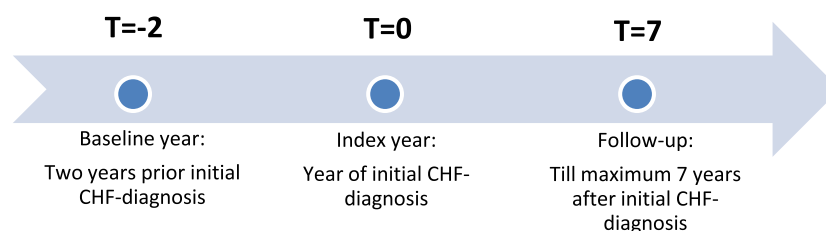
Longitudinal health care utilization and persistency of high costs

Descriptive analyses were used to analyse the longitudinal health care utilization per health care domain for the entire cohort and per hierarchical spending group. The level of health care utilization during the index year ($t = 0$) determined whether a patient was categorized to the top 1%, top 2–5%, or the bottom 95% subgroup for this analysis. In the following analyses, all repeated measurements ($t \geq 0$) were our unit of analysis. We determined the percentage of top 1% and top 5% high-cost years and identified the percentage of high-cost years that occurred consecutively.

Drivers of high costs

We used logistic generalized estimating equation (GEE) models to determine which factors were associated with high costs, while taking into account the clustering of repeated

Figure 1 Timeline used to recode time relative to initial heart failure treatment.

T=-2
Baseline year:
Two years prior initial CHF-diagnosis

T=0
Index year:
Year of initial CHF-diagnosis

T=7
Follow-up:
Till maximum 7 years after initial CHF-diagnosis

measurements within patients. We used GEE models with an exchangeable working correlation structure to account for this clustering.[22] In these analyses, repeated measurements (per year) were our unit of analysis; all follow-up years ($t \geq 0$) were analysed. Our aim was to identify all factors significantly associated with high costs. Two types of dichotomous outcomes were analysed in separate models: (i) the top 1% as opposed to the lowest 99% cost years and (ii) the top 5% high-cost years as opposed to the lowest 95% cost years. As independent variables, we used all predictors, including demographics, disease specific variables, excessive polypharmacy, previous top 1%/top 2–5% health care utilization, heart-related admission, heart-related surgery, times since initial heart failure treatment in years, and quarter of dying. All continuous variables were tested for the assumption of linearity and categorized if linearity could not be assumed. Backward selection was performed manually on the basis of the type 3 significance tests ($P < 0.05$), which is based on likelihood ratio statistics (PROC GENMOD in SAS). Associations were expressed as odds ratios (ORs) and 95% confidence intervals. To determine the performance of the models, area under the curve was assessed.

All analyses were performed using SAS 9.4.

Results

Table 1 gives an overview of the repeated measurements (years) in our study. There were 25.372 unique patients with heart failure in our study. The percentage of patients that incurred top 1% or top 2–5% costs steadily increased until the index year ($t = 0$). In the index year, the percentage incurring high costs was highest. From $t = 2$ and onwards, the percentage that incurred high costs levelled: 7% incurred top 1% costs, and 20% incurred top 2–5% costs.

Characteristics during the index year

Table 2 shows the characteristics for the three spending groups during the index year ($t = 0$). More than half of the cohort incurred top 1% or top 2–5% costs. Top 1% patients were younger, and the top 2–5% patients were older than those in the bottom 95%. Despite the difference (5.2

years) in age between the top 1% and top 2–5% groups, survival rates were similar. The rate of excessive polypharmacy was three times higher in the top 1% and top 2–5% groups than in the low-cost group. Most variability was observed in our multimorbidity measure based on hospital services: top 1%, top 2–5%, and bottom 95% patients were treated for, respectively, 6.6, 4.9, and 2.9 ICD-10 subchapters. In addition, the three groups differed in their use of heart-related surgeries and admissions. The percentage admitted to the hospitals was four times higher in the top 1% group than in the bottom 95% group. Heart-related surgeries were performed in 54% of top 1% patients. Not shown in the table: remaining top 1% patients differed in many aspects, most notably in their rate and intensity of mental health and pharmaceuticals use, and rates of chronic conditions and multimorbidity. They incurred 15.5% lower average costs.

Longitudinal health care utilization

Figure 2 shows the average total costs over time for the full cohort of patients and separately for survivors (those alive at the latest year with cost data). The overall patterns of utilization were similar. Highest average costs were found during the index year. The average cost per patient increased between $t = -2$ and $t = 0$, and this increase was mainly driven by increasing hospital costs. After the year of initial heart failure treatment, costs quickly declined and stabilized at a level that was significantly higher than in the years prior initial heart failure treatment. Hospital costs were the predominant cost drivers in all years, followed by pharmaceutical costs. Not shown in the figure is that at any individual year, decedents incurred 90% higher costs than remaining patients in that year. The overall average costs in *Figure 2* are similar because in each year ≈10% of patients die.

Appendix S2 shows the same health care utilization patterns but for the three hierarchical spending groups separately. Groups were based on health care utilization during the index year. During the index year, average costs in the top 1% group (€ 48.120) were 10 times as high compared with the bottom 95% group (€ 4.627). Top 1% incurred higher costs in each health care domain at any moment. This

**Table 1** The percentage of top 1% and top 2–5% patients in each of the study years

Year[a]	−4	−3	−2	−1	0	1	2	3	4	5	6
Total number of patients	8976	17 327	25 372	25 372	25 372	23 714	21 792	20 133	18 368	10 859	4747
Top 1%	3%	4%	5%	7%	16%	9%	7%	7%	7%	7%	7%
Top 2–5%	13%	14%	16%	19%	34%	23%	22%	21%	20%	21%	20%
Bottom 95%	84%	82%	80%	74%	49%	68%	71%	72%	73%	72%	73%

[a]Since our inclusion period covered a time horizon of 3 years, some patients received initial hospital treatment for heart failure in 2008 while others started heart failure treatment in 2009 or 2010. Therefore, years were recoded relative to the initial hospital treatment for heart failure.

Table 2 Characteristics of patients in hierarchical spending groups in the index year and survival after initial heart failure treatment

		Bottom 95%	Top 2–5%	Top 1%
Demographics				
Percentage of total cohort		49.2%	34.5%	16.3%
Mean age in years		73.5	75.8	70.6
Gender = male		50%	48%	60%
Socio-economic status = low		48%	51%	49%
Generic indicators of care needs				
Mean number of chronic conditions		3.1	4.2	4.4
Mean number of ICD-10 subchapters		2.9	4.9	6.6
Percentage polypharmacy (≥5 medications)		71%	90%	91%
Percentage excessive polypharmacy (≥10 medications)		11%	32%	36%
Percentage surgery (heart-related)		0.2%	10%	54%
Percentage admission (heart-related)		20%	65%	82%
Prevalence of conditions				
Anaemia		6%	15%	20%
Cardiac arrest and arrhythmias		12%	20%	29%
Chronic lung disease		28%	41%	38%
Dementia		1%	4%	5%
Depression, anxiety, and sleep disorders		12%	22%	25%
Diabetes		19%	30%	32%
Diseases of arteries, veins, and lymphatic vessels		6%	12%	20%
Gout		5%	9%	10%
Hyperlipidaemia		47%	51%	63%
Influenza, pneumonia, or use of antibacterials		24%	46%	51%
Ischaemic heart disease		9%	21%	36%
Kidney failure		2%	7%	13%
Neoplasms		14%	23%	25%
Pain		12%	24%	29%
Psychosis		2%	6%	7%
Thyroid disorders		7%	9%	8%
Valve disorders		4%	7%	12%
Adjustment and management of devices, cardiac rehabilitation, and others		1%	3%	12%
Follow-up services after surgery		6%	12%	41%
Survival in years after the day of initial heart failure treatment	1	94%	85%	84%
	2	90%	76%	75%
	3	84%	67%	69%
	4	78%	59%	62%
	5	72%	51%	54%

Figure 2 Average costs for survivors and the total cohort.
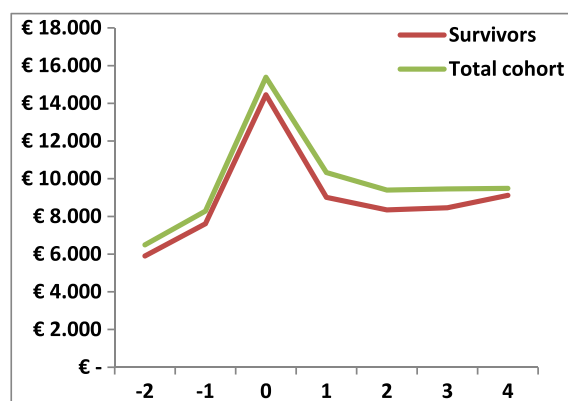
difference in total costs between the hierarchical spending groups was mainly driven by differences in hospital costs. The top 1% group experienced a remarkable increase of mental health care costs during the index year.

Persistency of high costs

Figure 3A and *B* shows the persistency of high costs after first heart failure treatment ($t \geq 0$) for top 5% and top 1% utilization, respectively. The height of the bars (*y*-axis) indicates the percentage of the cohort incurring a certain number of high-cost years (*x*-axis). Colour saturation shows the proportion of high-cost years that occurred consecutively. While >90% of the population incurred at least one top 5% year during follow-up, only 31.8% incurred at least one top 1% year. Furthermore, 57.0% incurred multiple top 5% years whereas only 8.6% incurred multiple top 1% years. In addition, top 5% years were more frequently consecutive than top 1% years.

Drivers of high costs

GEEs were performed for top 1% or top 5% high-cost years compared with bottom 99% and bottom 95% years, respectively. As explained above, all repeated measurements ($t \geq 0$) were our unit of analysis. Of the 125.166 follow-up

Figure 3 Frequency and persistency of high-cost years during follow-up period ($t \geq 0$). For example, (A) shows that 22% of the cohort had two top 5% years: 12% experienced two consecutive top 5% years, and 10% experienced two non-consecutive top 5% years.
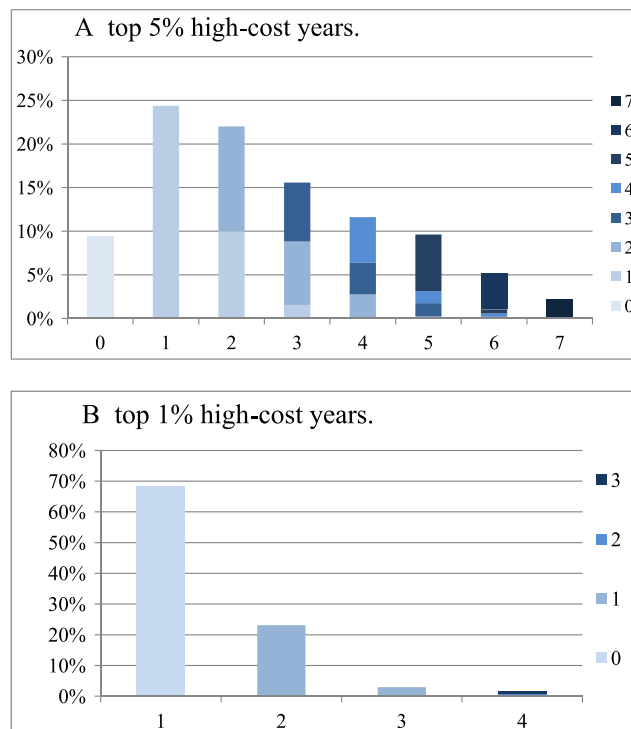
years included in this study, 11.483 (9.2%) and 30.056 (24.0%) were top 1% and top 2–5% high-cost years, respectively.

Table 3 shows the estimated ORs for our final models. Younger groups were more likely to incur top 1% costs. Excessive polypharmacy, high costs in the previous year, and end-of-life periods were all predictive of top 1% and top 5% costs. Heart-related surgeries and heart-related admissions showed highest ORs. In years 1 and 2 after initial heart failure treatment, the odds of high costs were decreased, and in the following years, the odds of high costs increased. Influenza was a specific disease with a high OR for high costs as well as a high prevalence among high-cost patients (see *Table 2*).

top 1% year. Top 5% years were more frequently consecutive than top 1% years. Top 1% and top 2–5% patients with heart failure differed from lower cost patients in their higher rate of chronic conditions, excessive polypharmacy, hospital admissions, and heart-related surgeries. Besides, top 1% patients were relatively young, and elder patients were less likely to incur a top 1% year. Several of the disease specific variables showed significant ORs for high costs, including anaemia, dementia, diseases of arteries, veins and lymphatic vessels, influenza, and kidney failure. The end-of-life period was also predictive of top 1% and top 5% costs. These results provide necessary information for further increasing quality of care and reducing costs for patients with heart failure.

Discussion

In this study, we explored the longitudinal health care utilization and the persistency of high costs in patients with heart failure. Furthermore, we determined the characteristics of patients with heart failure and high costs and identified drivers of high costs. Our findings revealed that the difference in costs between the three groups was mainly driven by hospital costs. In addition, the top 1% group experienced a remarkable increase of mental health costs during the index year. More than 90% of the population incurred at least one top 5% year during follow-up, and 31.8% incurred at least one

Strengths and limitations

To our knowledge, this is the first longitudinal study focusing on high-cost patients within a population of patients with heart failure. By using administrative data from our country's largest health insurer, we created a large set of variables that covered demographic characteristics, chronic conditions, hospital treatments, and mental health utilization. This allowed us to assess which characteristics were particularly associated with high costs. Because of having data of multiple consecutive years, we were also able to explore the longitudinal health care utilization and persistency of high costs. One limitation

Table 3 Odds ratios for high-cost years derived from GEE estimates: disease-specific model

Variables		Top 1% year OR (95% CI)	Top 5% year OR (95% CI)
Gender male ref = female		1.17 (1.11–1.24)	NS
Age	60–69	0.86 (0.78–0.94)	1.00 (0.93–1.07)
Ref = 18–59	70–79	0.71 (0.65–0.78)	1.05 (0.98–1.12)
	80–89	0.41 (0.38–0.46)	0.93 (0.87–0.99)
	≥90	0.23 (0.20–0.27)	0.73 (0.67–0.79)
Socio-economic status	Average	NS	0.93 (0.89–0.98)
Ref = high	Low	NS	0.99 (0.95–1.03)
Excessive polypharmacy		1.56 (1.47–1.66)	1.95 (1.88–2.03)
Heart-related surgery		22.00 (20.08–24.09)	65.08 (51.16–82.80)
Heart-related admission		2.38 (2.22–2.55)	6.77 (6.45–7.11)
Time since heart failure treatment in years	1	0.57 (0.52–0.61)	0.56 (0.52–0.59)
Ref = 0 (year of initial hospital treatment)	2	0.80 (0.75–0.87)	0.79 (0.75–0.83)
	3	1.16 (1.07–1.25)	0.97 (0.92–1.01)
	4	1.63 (1.50–1.77)	1.15 (1.09–1.21)
	5	1.62 (1.47–1.78)	1.19 (1.12–1.27)
Quarter of dying	1	0.37 (0.28–0.48)	0.41 (0.36–0.47)
Ref = 0 (survived entire year)	2	0.98 (0.83–1.16)	1.23 (1.10–1.38)
	3	1.83 (1.59–2.10)	2.33 (2.08–2.60)
	4	2.82 (2.52–3.15)	3.93 (3.55–4.35)
Top 1% in the previous year		3.51 (3.21–3.84)	3.04 (2.87–3.22)
Top 2–5% in the previous year		1.76 (1.67–1.86)	1.74 (1.67–1.81)
Disease-specific variables			
Anaemia		1.66 (1.55–1.77)	1.94 (1.85–2.04)
Cardiac arrest and arrhythmias		0.91 (0.85–0.98)	NS
Chronic lung disease		NS	1.38 (1.33–1.43)
Dementia		1.90 (1.66–2.18)	2.27 (2.03–2.52)
Depression, anxiety, and sleep disorders		1.34 (1.25–1.43)	1.44 (1.37–1.51)
Diabetes		1.13 (1.07–1.20)	1.40 (1.35–1.45)
Diseases of arteries, veins, and lymphatic vessels		2.26 (1.09–2.46)	1.93 (1.80–2.06)
Gout		1.15 (1.06–1.24)	1.21 (1.15–1.28)
Influenza, pneumonia, or use of antibacterials		1.81 (1.72–1.90)	2.04 (1.97–2.10)
Ischaemic heart disease		0.74 (0.68–0.81)	NS
Kidney failure		2.11 (1.90–2.34)	2.10 (1.93–2.28)
Neoplasms		1.70 (1.59–1.82)	2.00 (1.91–2.10)
Pain		1.60 (1.51–1.69)	1.87 (1.80–1.94)
Psychosis		1.32 (1.19–1.47)	1.41 (1.31–1.53)
Valve disorders		1.44 (1.31–1.60)	NS
Adjustment and management of devices, cardiac rehabilitation, and others		1.26 (1.10–1.44)	1.33 (1.12–1.58)
Follow-up services after surgery		NS	0.71 (0.67–0.76)
AUC		0.87	0.85

AUC, area under the curve; CI, confidence interval; GEE, generalized estimating equation; OR, odds ratio.
NS: Some variables were excluded in the backward selection process in the model for top 1% and not for the top 5% and vice versa.

was our lack of clinical data, data of long-term care (which covers most spending for cerebrovascular disease—an important co-morbidity in patients with heart failure), and individual patient data of quality of care. Such data could facilitate a deeper understanding of health care utilization, care needs, and opportunities to intervene in patients with heart failure. For example, future research may consider to include information of severity of illness, type of heart failure (with reduced or preserved ejection fraction), and aetiology (ischaemic vs idiopathic). More detailed inpatient utilization measures—what services are used during admissions?—might further improve the actionability of findings. Besides, analyses were limited to the Netherlands, which may limit the generalizability of our findings. In addition, our study dated until end 2014, and may not represent current cost of treatment, because of recent entry of new medications and treatments. Finally, patient inclusion was based on chronic heart failure claims in order to maintain homogeneity of the study population. However, the distinction between chronic and acute heart failure coding may be accidental and subjective, because of the vague delineation between both types of heart failure.

Reflection on our findings

Our findings generally align with prior research, which supports the generalizability of our findings. The prevalence of most co-morbid conditions such as chronic lung diseases, diabetes, anaemia, and depression were similar to previous studies,[15,16,23–25] as was rate of mortality.[26] We found that the odds of high costs decreased in the 2 years following initial heart failure treatment and increased in the years thereafter. This corresponds with the progressive nature of heart failure and associated increase of health care

needs.[10,21] The relatively high costs at initial diagnosis are surprising and may reflect extensive diagnostic trajectories or time for the treatment to take effect. In addition, we found that the number of hospitalizations was high. One reason for this high number of hospitalizations might be our broad definition, which includes hospitalizations for all types of diseases in cardiology, and it is widely known that multiple cardiovascular morbidity is common in chronic heart failure patients.

We were the first to explore the frequency and persistency of high costs in patients with heart failure. Our findings indicate that top 1% utilization predominantly occurs incidentally and among less than a third of patients with heart failure, whereas almost all patients with heart failure experience at least one top 5% year, and more than half experience two or more top 5% years. Our breakdown of characteristics and cost drivers revealed the most important cost drivers in patients with heart failure. Heart-related surgeries contributed to the incidental high costs in 54% of top 1% patients, and the costs of the remaining top 1% patients were driven by mental health and pharmaceuticals use and rates of chronic conditions and multimorbidity. The high frequency and persistency of top 5% utilization point to the well-known fact that heart failure is a devastating disease with severe symptoms, which is often accompanied by many co-morbidities and low quality of life, which requires intensive medical treatment.

Our work contributes to existing literature because of our extensive inclusion of potential drivers for high costs. Wammes *et al.* and Joynt *et al.* argued that expensive procedures may be a more significant cost driver in high-cost patients than avoidable hospitalizations.[1,3] Our results confirm that procedures are important cost drivers in patients with heart failure. Besides, our findings point to a select set of key cost drivers. Such drivers include chronic conditions and multimorbidity, excessive polypharmacy, and mental health care needs. Furthermore, we found that decedents incurred 90% higher costs in the year they died. Reducing end-of-life expenditures are important targets for intervention. However, the benefits of interventions aimed at longer term drivers of high costs may be of more importance if one seeks for additional value and efficiency for these patients.

Policy and research implications

Many initiatives to stimulate value and efficiency of care among patients with heart failure primarily concern reducing heart failure-related readmissions. For example, disease management programmes at heart failure clinics have shown to improve patient well-being, reduce both hospitalizations and mortality, and may even save costs. Key ingredients of such programmes are guideline adherence and the integration and coordination of multidisciplinary heart failure treatment across the continuum of care, which includes treatment by specialized heart failure cardiologists and specialized heart failure nurses, adequate post-discharge planning, and advance care planning in advanced heart failure.[27]

Our findings revealed a range of drivers for high costs that may be beyond the scope of such initiatives. The scope of care improvement programmes may be widened to include also the treatment of common co-morbidities. Moreover, it is widely known that mental care needs are underestimated in heart failure patients and may be underserved in current health systems, and timed treatment, or tailored treatment for heart failure induced depression, might have prevented the high mental care expenditures we observed.

Furthermore, identified indicators may reflect overuse of care. The optimal indication criteria for surgical interventions tend to evolve in time, and in the Netherlands, there is a nascent trend towards operating less in (frail) elderly. *Unnecessary* transaortic valve replacements were reduced through a multidisciplinary approach.[28] Research of medical practice variation has identified unwarranted variation in a range of services.[29] Especially near the end of life, patient preferences vary substantially and shared decision-making is warranted.[30]

This study used administrative data from the perspective of patients with heart failure and high costs, in order to inform policy and practice. Inclusion of clinical data, patient-reported outcome measures, and of quality of care might further improve the validity and actionability of our findings, for example, through identification of organizational characteristics (at hospital or health system level) or processes that are associated with costs, outcomes of care, and/or unwarranted variation of care. In addition, further research may be needed to discern *preventable* spending from high-value spending in patients with heart failure, and further research is needed to study the effects of organizational factors and medical practice variation towards high costs in patients with heart failure.

In conclusion, our study has addressed persistently high costs and drivers of high costs in patients with heart failure. Comprehensive and integrated efforts are needed to further improve quality of care and reduce unnecessary costs.

Conflict of interest

None declared.

Funding

Supporting information

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

Appendix S1. Definition of variables.
Appendix S2. Cost trajectories per healthcare sector per hierarchical spending group. Costs in € (y-axis) over time (x-axis).

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