






EMPIRICAL RESEARCH QUANTITATIVE

Generic and disease-specific caregiver contribution to self-care in a population with multiple chronic conditions: A comparative study

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Abstract

Aim: Describe and compare generic and disease-specific caregiver contribution (CC) to self-care behaviours in the dimensions of self-care maintenance, self-care monitoring and self-care management in multiple chronic conditions (MCCs).

Design: Multicentre cross-sectional study.

Methods: We enrolled caregivers of patients with MCC, from April 2017 to November 2022, if they were (a) 18 years of age or older and (b) identified by the patient as the principal unpaid informal caregiver. The Caregiver Contribution to Self-Care of Chronic Illness Inventory, Caregiver Contribution to Self-Care of Heart Failure Index, Caregiver Contribution to Self-Care of COPD Inventory and Caregiver Contribution to Self-care of Diabetes Inventory were used to measure generic and disease-specific contribution to patient self-care. Descriptive statistics, Student's *t*-tests and Pearson's correlation coefficients were used.

Results: We found adequate generic CC for self-care monitoring but inadequate CC in self-care maintenance and management. All CC to disease-specific self-care maintenance, monitoring and management scales' scores were inadequate, except for caregivers of diabetic patients in which we observed an adequate score in the CC to self-care maintenance and self-care management scales in those practice insulin therapy.

Conclusion: Caregivers experience difficulties in performing behaviours of contribution to their patients affected by chronic conditions. Caregivers of patients with MCCs contribute more to self-care in aspects related to provider prescriptions and less to lifestyle changes.

Implications for the Profession and/or Patient Care: Healthcare professionals have to know in which behaviours caregivers show gaps and reflect on the reasons for poor CC to self-care to develop interventions to enhance these behaviours.

Impact: This study underlines the importance of choosing the most appropriate instrument for measuring CC to self-care, considering the caregiver's characteristics.

Reporting Method: We adhered to STROBE guidelines.

Patient or Public Contribution: Caregivers of patients affected by MCCs were enrolled.

KEYWORDS

caregiver contribution, chronic conditions, self-care behaviours

1 | INTRODUCTION

Chronic conditions are becoming a relevant health problem in developed countries. In Europe, people ≥ 65 years of age are about 20% of the general population and those with ≥ 85 years are projected to increase from 12.5 million in 2019 to 26.8 million in 2050 (Eurostat, 2021).

Not only chronic conditions are highly prevalent in the older adult population, but they can also coexist in the same individuals at the same time; this is defined as a situation of multiple chronic conditions (MCCs) (Dattalo et al., 2017). The prevalence of MCCs ranges between 55% and 98% in people ≥ 65 years (Lochner et al., 2013). MCCs are associated with a higher risk of disability, hospitalization, mortality, and higher healthcare costs (Vetrano et al., 2019).

To counteract the burden of chronic conditions, self-care behaviours adopted by patients (i.e. the daily management of the diseases) are essential to improve patient outcomes (De Maria et al., 2021; Riegel et al., 2012), but several studies have shown consistently that patients with MCCs perform self-care insufficiently (Jaarsma et al., 2017; Vellone et al., 2015). In these cases, the support or help from an informal caregiver, called caregiver contribution (CC) to patient self-care, has a crucial role (Trivedi et al., 2012; Vellone et al., 2019).

Caregiver contribution to patient self-care entails a series of recommendations (or actions to replace) that informal caregivers (in general family members or close friends) give to patients: (i) to maintain stable their health conditions (CC to self-care maintenance; e.g. recommending patients to perform physical activity); (ii) to monitor signs and symptoms (CC to self-care monitoring; e.g. helping the patients to monitor medication side effects) and (iii) to manage signs and symptoms of exacerbation when they occur (CC to self-care management; e.g. call the healthcare provider for the patients in case of symptoms) (Vellone et al., 2019; Vellone, Lorini, et al., 2020). Several studies report that when caregivers contribute more to patient self-care, patients report better outcomes such as greater adherence to medication (Bouldin et al., 2017), reduction of hospital readmissions, length of hospital stay and healthcare costs (Ruppar et al., 2016), improvement of healthy patients' behaviours (Iovino et al., 2021) and quality of life (Bryant et al., 2016).

2 | BACKGROUND

Considering the importance of CC to self-care, several generic and disease-specific instruments have been developed to measure this

What does this paper contribute to the wider global community?

- Regarding caregiver contribution (CC) to generic self-care, caregivers are adequate in the dimension of self-care monitoring. Regarding CC to disease-specific self-care of patients affected by chronic obstructive pulmonary disease and heart failure, caregivers performed inadequate contribution in all dimensions.
- Regarding disease-specific self-care, only caregivers caring for diabetes mellitus patients contribute adequately to self-care maintenance and self-care management when patients are treated with insulin.
- Is important for healthcare professionals to choose the most appropriate instrument for measuring CC to self-care considering caregiver's characteristics to develop tailored interventions for them.

contribution. The Caregiver Contribution to Self-care of Chronic Illness Inventory (CC-SC-CII) (Vellone, Lorini, et al., 2020) was developed to measure generic CC to patient self-care and can be used in all chronic conditions. In fact, this instrument asks caregivers to report how often they recommend patients to perform those self-care behaviours that are useful for all chronic conditions.

Investigators have also developed disease-specific measures of CC such as the Caregiver Contribution to Self-Care of Heart Failure Index (CC-SCHF) (Vellone et al., 2013), the Caregiver Contribution to Self-Care of Chronic Obstructive Pulmonary Disease Inventory (CC-SCCOPDI) (Matarese et al., 2022) and the Caregiver Contribution to Self-Care of Diabetes Inventory (CC-SCODI) (Fabrizi et al., n.d.). These instruments have been specifically designed to evaluate how often caregivers contribute to patient self-care behaviours that are important in specific conditions. Generic and disease-specific instruments are both important because the generic instrument measures behaviours that are appropriate for all different chronic conditions, while disease-specific instruments measure particular behaviours that are important only for an explicit condition.

So far, investigators have used generic or disease-specific CC to patient self-care measures. To our knowledge, they have never used both (generic + diseases specific) instrument typologies in the same population. However, the combined use of generic and disease-specific CC to self-care instruments could be useful in understanding

better and in a comprehensive way how caregivers contribute to MCCs patient self-care.

The Self-Care of patient and caregiver Dyads in MCCs: A Longitudinal sTudY (SODALITY) is an observational, longitudinal and multicentric study aimed to describe patient self-care and CC to self-care in MCCs (De Maria et al., 2019). In this study, we enrolled patients affected by MCCs, specifically with heart failure (HF) and/or chronic obstructive pulmonary disease (COPD) and/or diabetes mellitus (DM) and other chronic conditions and their caregivers (De Maria et al., 2019, 2022, 2023; Iovino et al., 2021). A novelty of the SODALITY study is that we used both generic and disease-specific instruments to evaluate MCCs patient self-care and CC to self-care. In previous studies, we explored the CC to generic self-care and factors influencing generic self-care and CC to generic self-care without studying the disease-specific behaviours. Previous studies, using the SC-CII and the CC-SC-CII, (i) described patient self-care and CCs to self-care and identified determinants of patient self-care and CCs to self-care at the patient and caregiver level (Iovino et al., 2021), (ii) compared self-care and CCs to patients' self-care in different care type and identified the patient and caregiver characteristics associated with each care type (De Maria et al., 2023) and (iii) explored the existence of a dyadic construct in self-care maintenance, monitoring and management in patients affected by chronic conditions and their caregivers (De Maria et al., 2022).

In the study reported in this article, differently from the prior published papers, we have simultaneously analysed generic and disease-specific CC to self-care.

3 | THE STUDY

3.1 | Aims

The aims of this study were (i) to describe simultaneously generic and disease-specific CC to self-care behaviours in MCCs and (ii) to compare and correlate generic and disease-specific CC to patient self-care behaviours in the dimensions of self-care maintenance, self-care monitoring and self-care management.

4 | METHODS

4.1 | Design

We perform a secondary analysis on the baseline data from the ongoing SODALITY study.

4.2 | Participants and setting

For this analysis, we used caregiver data from SODALITY study. In this study, caregivers of patients with MCCs were enrolled in outpatient and community settings in Italy, from April 2017 to November

2022, if they met the following inclusion criteria: (a) 18 years of age or older and (b) identified by the patient as the principal unpaid informal caregiver, inside or outside the family, providing most of the informal care. According to the sample size estimated for the parent study (De Maria et al., 2019) in which we planned to recruit a sample of 1000 patient-caregiver dyads at time 0 to obtain at least a sample of 500 chronically ill patient-caregiver dyads at time 2 (after 1 year), after estimating an attrition rate of 50%, all patient enrolled at the time of the analysis were used. A post hoc power analysis was performed on all subsamples (DM, HF and COPD), using Cohen's table (Lipsey, 1990); the significance level at .05, a medium effect size, the power reached up to 95% which indicated adequacy of all subsamples size for this study including the smallest one of 150 subjects.

4.3 | Instruments

Several instruments are used in the SODALITY Study, but for the aims of this study, we considered the following:

The CC-SC-CII is a 19-item valid and reliable instrument developed to measure generic CC to self-care behaviours of chronically ill patients (Vellone, Lorini, et al., 2020). It includes three separate scales, which measure CC to self-care maintenance (seven items) (e.g. how often do you recommend the patient to take prescribed medicines without missing a dose?), CC to self-care monitoring (five items) (e.g. how often do you recommend the patient to monitor the health condition?) and CC to self-care management (six items) (e.g. how often do you recommend the patient to call the healthcare provider to get guidance on symptoms?). The CC-SC-CII items use a five-point Likert scale for responses from 1 (never) to 5 (always) for CC to self-care maintenance and monitoring and from 1 (not likely) to 5 (very likely) for CC to self-care management. Each scale has a standardized score from 0 to 100 with higher scores meaning better CC to self-care. The CC-SCHF version 6.2 was used to measure the disease-specific CC to self-care in HF. It is a valid and reliable instrument, including 22 items (Vellone et al., 2013) which are divided into three scales: CC to self-care maintenance (10 items) (e.g. how often do you recommend the patient to eat low-salt diet?), CC to self-care management (six items) (e.g. how often do you recommend the patient to monitor weight daily?) and Caregiver Confidence (six items) (e.g. how do you feel confident in doing something to relieve patient symptoms?). The caregiver confidence scale was not used in this analysis. To make a comparison with the CC-SC-CII scales, the two items of the CC to self-care maintenance measuring daily weighing and ankle swelling were separated from the above scale to form the CC to self-care monitoring scale. Indeed, these two items are in the same factor at the factor analysis (Vellone, Lorini, et al., 2020) and were moved to the CC to self-care monitoring scale in the CC-SCHF version 2 (Vellone, Barbaranelli, et al., 2020). Respondents to CC-SCHF items are asked to report how often they recommend

to HF patients to follow specific HF self-care behaviours. The CC-SCHFI items use a 5-point Likert scale for responses from 1 (never) to 5 (always) for CC to self-care maintenance and monitoring and from 1 (not likely) to 5 (very likely) for CC to self-care management. Each scale has a standardized score from 0 to 100 and a higher score means better CC to self-care.

The 32-item CC-SCCOPDI was used to measure the CC to self-care of patients with COPD (Matarese et al., 2022). It is composed of three different scales that measure CC to self-care maintenance (10 items) (e.g. how often do you recommend the patient to use abdominal breathing or pursed lips breathing to regulate my breath?), CC to self-care monitoring (nine items) (e.g. how often do you recommend patients to monitor if breathlessness increases?) and CC to self-care management (10 items, e.g. how likely are you to recommend patients to call the doctor if the amount of sputum increases?). The CC-SCCOPDI items use a 5-point Likert scale for responses from 1 (never) to 5 (always) for CC to self-care maintenance and monitoring and from 1 (not likely) to 5 (very likely) for CC to self-care management. Each scale's scores are standardized from 0 to 100, and higher scores mean better CC to patient self-care.

The CC-SCODI was used to measure disease-specific CC to self-care in Type 1 and Type 2 DM. CC-SCODI is composed of 40 items divided into three scales reflecting the dimension of CC to self-care maintenance (12 items) (e.g. how often do you recommend the patient to take care of your feet—wash and dry the skin, apply moisture, use correct socks?), CC to self-care monitoring (eight items) (e.g. how often do you recommend the patient to monitor blood sugar regularly?) and CC to self-care management (nine items) (e.g. how often do you recommend the patient to check blood sugar when he feels symptoms, such as thirst, frequent urination, weakness, perspiration, anxiety?). Also for this instrument, the self-care confidence scale was not adopted in this study. The CC-SCODI items use a 5-point Likert scale for responses from 1 (never) to 5 (always) for CC to self-care maintenance and monitoring and from 1 (not likely) to 5 (very likely) for CC to self-care management. Each scale has a standardized score from 0 to 100. A higher score means better CC to self-care.

For all the above CC instruments, CC to self-care management scales of both generic and disease-specific instruments were only completed by a caregiver of the patient with symptoms. A score ≥ 70 is the cut-off point for CC to patient self-care adequacy (Vellone et al., 2013; Vellone, Lorini, et al., 2020) for all the scales.

We also used an ad-hoc structured questionnaire, developed by the research team, to collect caregivers' sociodemographic variables such as age, sex, marital status, education level, socioeconomic status, perceived income adequacy, cohabitation with patients, and the characteristics of caregiving such as years and hours of caregiving and the presence of a second caregiver. We also collected data about patient's chronic conditions such as the number of comorbidities, severity of diseases, New York Heart Association (NYHA) for patients affected by HF, the Modified British Medical Research

Council Questionnaire (mMRC) for patients affected by COPD and type of complications for patients affected by DM.

4.4 | Validity and reliability

The generic and disease-specific instruments have all been developed and tested for validity and reliability in previous studies in the Italian language. The factorial validity of CC-SC-CII was tested through Confirmatory Factor Analysis (CFA) (Comparative Fit Index [CFI] ranging from 0.97 to 0.99 and Root Mean Square Error of Approximation [RMSEA] ranging from 0.05 to 0.06 across the three scales) and the reliability through Cronbach's alpha, ranging from .76 and .90 (Vellone, Lorini, et al., 2020). CC-SCHFI validity was tested through CFA (CFI is 0.95 and RMSEA ranging from 0.051 to 0.071 across the three scales) and also reliability of the three scales was confirmed (coefficients ranging between 0.65 and 0.90 for the three scales) (Vellone et al., 2013). Also, CC-SCCOPDI showed good factorial validity (CFI ranging from 0.95 to 0.99 and RMSEA ranging from 0.025 to 0.076) and reliability (global reliability indices ranged from 0.75 to 0.88) (Matarese et al., 2022). Finally, CC-SCODI showed good factorial validity (CFI ranging from 0.99 to 1.00 and RMSEA ranging from 0.026 to 0.069) and reliability (global reliability indices ranged from 0.78 to 0.87) (Fabrizi et al., n.d.).

4.5 | Data collection

After examining eligibility criteria, trained nursing research assistants administered the instruments to caregivers through face-to-face interviews that lasted about 30min. The current analysis includes all data collected from April 2017 to November 2022, in 12 Italian regions.

4.6 | Data analysis

No missing data were present in the study dataset. Sociodemographic data regarding caregivers (e.g. sex, age) and CC-SC-CII, CC-SCHFI, CC-SCCOPDI and CC-SCODI item scores were analysed with descriptive statistics such as frequency, percentage, mean and standard deviation (SD). Skewness and kurtosis were used to evaluate the normality of the items' scores. To compare generic (CC-SC-CII) and disease-specific CC to self-care behaviours (CC-SCHFI, CC-SCCOPDI and CC-SCODI) in all subsamples (DM, HF and COPD), we used paired Student's *t*-tests. To correlate generic and disease-specific CC to self-care, we used Pearson's correlation coefficients (*r*). To perform the post hoc power analysis, G*Power software was used (Faul et al., 2007). We used SPSS 22.0 software (IBM Corp.) to analyse data. A *p*-value of $\leq .05$ was considered statistically significant. The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) checklist was used to describe our study (Cuschieri, 2019).

4.7 | Ethical consideration

The SODALITY study received the approval of the ethical committee of a regional healthcare system (ComEt ASReM #128-07/25/17). All data were treated confidentially, participation was voluntary, and all caregivers provided written informed consent. Participants were identified with alphanumeric codes to assure privacy. The participants could drop out of the study at any time without providing a reason.

5 | RESULTS

5.1 | Participants characteristic

We enrolled 896 caregivers of patients affected by MCCs. Table 1 shows the sociodemographic characteristics of study participants. Caregivers were mostly female (73.44%) with a mean age of 52.34 (SD 15.45) years; 65.18% had more than 9 years of education and 96.21% perceived to have enough or more than necessary for living. More than half of caregivers (53.46%) were sons or daughters of patients, lived with patients (47.32%) and did not receive help from other caregivers (64.84%). Caregivers reported a mean of 9.34 years of caregiving and 39.62% took care of their loved ones until 10h per week. Caregivers primarily cared for patients affected by DM and other chronic conditions (66.29%), followed by caregivers taking care of patients with HF (41.18%) and COPD (16.74%). The mean number of chronic conditions per patient was 3.25 (SD 1.31) with a median of 3.00 [2–4] (Table 2).

5.2 | Generic CC to self-care

Table 3 reports the item's description of CC-SC-CII scales. Regarding the CC to self-care maintenance scale, the mean score was 68.91 (SD 21.61) and, considering the cut-off point of 70, in 44.30% of caregivers the contribution to self-care was inadequate. The item with the highest score was recommended to 'Take prescribed medicines without missing a dose' (4.16, SD 1.29), while the item with the lowest score was recommended to 'Do physical activity' (3.28, SD 1.36). Regarding CC to self-care monitoring scale, the mean score was 77.53 (SD 21.84) and in 29.13% of caregivers, the contribution to self-care was inadequate. The item with the highest score was recommended to 'monitor for symptoms' (4.14, SD 1.00), while the item with the lowest score was recommended to 'monitor for medication side-effects' (3.89, SD 1.16). In the CC to self-care management scale, the mean score was 68.02 (SD 20.22) and caregivers with inadequate contribution to self-care were 49.66%. The highest score was obtained by the item recommending the patient to or tell healthcare providers about the symptom at the next office visit (4.42, SD 0.90), while the item with the lowest score was 'Did the treatment you used [last time] make the patient feel better?' (3.14, SD 1.28).

TABLE 1 Sociodemographic characteristics of caregivers (N=896 caregivers).

	N	%
Gender		
Female	658	73.44
Male	238	26.66
Education level		
≤8 Years	312	34.82
>9 Years	584	65.18
Living with		
Alone	52	5.80
1 Person	297	33.15
2 People	189	21.09
≥3 People	358	39.96
Perceived income		
Lower than necessary to live	34	3.79
Enough/more than necessary to live	862	96.21
Years of caregiving		
0–≤5	356	39.73
6–≤10	308	34.38
≥11	231	25.78
Caregiving hours per week		
0–10	355	39.62
11–20	260	29.02
21–30	143	15.96
>30	138	15.40
Another caregiver		
No	581	64.84
Yes	315	35.16
Cohabitation with patient		
No	463	51.67
Yes	424	47.32
Relationship patient–caregiver		
Son/daughter	479	53.46
Spouse/partner	232	25.89
Brother/Sister	11	1.23
Other	174	19.42
	Mean (range)	SD
Age	52.34 (19–86)	15.45

Abbreviations: N, number; SD, standard deviation.

5.3 | Disease-specific CC to self-care in HF, COPD and DM

Table 4 reports item scores of CC to self-care in HF. Regarding the CC to self-care maintenance scale, the mean score was 67.57 (SD 19.42) and 51.50% of caregivers presented inadequate contribution to self-care. The item with the highest score was recommended patients to 'See health care provider for routine health care' (4.49, SD

TABLE 2 Sociodemographic and clinical characteristics of patients (N=896 patients).

	N	%
Patient's multiple chronic conditions		
DM+other chronic diseases	594	66.29
HF+other chronic diseases	369	41.18
COPD + other chronic diseases	150	16.74
HF+DM+other chronic diseases	129	14.39
HF+COPD + other chronic diseases	63	7.03
DM+COPD + other chronic diseases	46	5.13
DM+COPD + HF	21	2.34
Patient's HF severity (Class NYHA) (N=369)		
1	73	19.78
2	189	51.22
3	89	24.12
4	18	4.88
Patient's COPD severity (mMRC) (N=147)		
0	20	13.61
1	41	27.89
2	37	25.17
3	30	20.41
4	19	12.3
Patient's DM severity (N=594)		
Without complications	441	49.2
With complications	153	26.3
Minor complications	115	12.8
Major complications	38	6.4
	Mean (range)	SD
Number of chronic conditions	3.25 (2-9)	1.31
	Median 3.00	

Abbreviations: COPD, chronic obstructive pulmonary disease; DM, diabetes mellitus; HF, heart failure; mMRC, Modified British Medical Research Council Questionnaire; N, number; NYHA, New York Heart Association; SD, standard deviation.

0.90), while the item with the lowest score was recommended to 'Get some exercises for 30min daily' (2.52, SD 1.34). Regarding the CC to self-care monitoring scale, the mean scale score was 56.75 (SD 24.96) and 78.04% of caregivers reported inadequate contribution to self-care. The item with the highest score was recommended to 'Check ankles for swelling' (3.71, SD 1.17), while the item with the lowest score was recommended to 'Monitor weight daily' (2.49, SD 1.18). Regarding CC to self-care management scale, the mean score was 66.61 (SD 16.60) and 50.30% of caregivers had inadequate contribution to self-care. The item with the highest score was recommended 'To call the doctor or nurse for guidance' (4.30, SD 1.06), while the item with the lowest score was recommended to 'reduce fluid intake' (2.92, SD 1.40).

Table 5 shows specific CC to self-care in COPD. The self-care maintenance scale's mean score was 66.14 (\pm 18.62) and the

TABLE 3 Generic caregiver contribution to self-care of chronic illness (N=896 caregivers).

Caregiver Contribution to Self-Care of Chronic Illness Inventory (CC-SC-CII)			
		Mean	SD
CC to self-care maintenance (N=896)			
How often did you recommend the persons you care for the following behaviours			
1. Make sure to get enough sleep		3.56	1.36
2. Try to avoid getting sick (e.g. flu shot, wash your hands)		4.08	1.14
3. Do physical activity (e.g. take a brisk walk, use the stairs)?		3.28	1.36
4. Eat special food or avoid certain food		3.90	1.20
5. Keep appointments for routine or regular health care		4.00	1.16
6. Take prescribed medicines without missing a dose		4.16	1.29
7. Do you avoid tobacco smoke?		3.81	1.78
8. Do something to relieve stress (e.g. mindfulness, yoga, music)?		3.31	1.39
<i>Scale total score</i>		68.91	21.61
CC to self-care monitoring (N=896)			
How often did you recommend to the persons you care for to do the following things			
9. Monitor your condition		4.13	1.00
10. Pay attention to changes in how you feel		4.24	0.93
11. Monitor for medication side effects		3.89	1.16
12. Monitor whether you tire more than usual doing normal activities		4.11	1.00
13. Monitor for symptoms		4.14	1.00
<i>Scale total score</i>		77.53	21.84
CC to self-care management (N=896)			
When the person you care for has symptoms, how likely are you to recommend performing the following behaviours (or you perform these behaviours if the person you care for is unable to do so)			
16. Change what you eat or drink to make the symptoms decrease or go away		3.77	1.16
17. Change your activity level (e.g. slow down, rest)		3.68	1.19
18. Take a medicine to make the symptoms decrease or go away		3.69	1.26
19. Tell your healthcare provider about the symptoms at the next office visit		4.42	0.90
20. Call your healthcare provider for guidance		4.22	1.09
21. Think of a treatment you used the last time you had symptoms. Did the treatment you used make you feel better		3.14	1.28
<i>Scale total score</i>		68.02	20.22

Abbreviations: CC, caregiver contribution; SD, standard deviation.

TABLE 4 Caregiver contribution to self-care of patients with heart failure and other chronic conditions (N=369 caregivers).

Caregiver Contribution to Self-Care of Heart Failure Index (CC-SCHFI)		
	Mean	SD
CC to self-care maintenance behaviours (N=369)		
How often did you recommend these things to the person you care for		
3. Try to avoid getting sick (e.g. wash your hands)	4.24	0.96
4. Get some exercise (e.g. take a brisk walk, use the stairs)	3.03	1.29
5. See your healthcare provider for routine health care	4.49	0.90
6. Eat a low-salt diet	3.82	1.20
7. Get some exercises for 30min daily	2.52	1.34
8. Take prescribed medicine	4.46	1.06
9. Ask for low-salt food when visiting family and friends	3.37	1.41
10. Use a system or method to help you remember to take your medicines	3.68	1.43
<i>Scale total score</i>	67.57	19.42
CC to self-care monitoring behaviours (N=369)		
How often did you recommend to the person you care for to do the following things?		
1. Monitor weight daily	2.49	1.18
2. Check ankles for swelling	3.71	1.17
<i>Scale total score</i>	56.75	24.96
CC to self-care management behaviours (N=167)		
If the person you care for has trouble breathing or ankle swelling, how likely are you to recommend (or do) one of these remedies		
12. In the past month, if the person you care for had trouble breathing or ankle swelling, how quickly did you recognize it as a symptom of heart failure?	3.28	1.17
13. To reduce the salt in the diet	3.85	1.23
14. To reduce fluid intake	2.92	1.40
15. To take an extra water pill	3.28	1.51
16. To call the doctor or nurse for guidance	4.30	1.06
Think of a remedy you tried the last time the person you care for had trouble breathing or ankle swelling		
How sure were you that the remedy helped or did not help?	3.66	1.05
<i>Scale total score</i>	66.61	16.60

Abbreviations: CC, caregiver contribution; SD, standard deviation.

caregivers' inadequate self-care contribution was 50.66%. The item with the highest score was recommended patients 'Make regular visits to healthcare provider for checks-ups of chronic lung disease' (4.65, SD 0.76), while the item with the lowest score was recommended to 'Exercise with the arms at least three times a week' (2.11, SD 1.27). The CC to self-care monitoring scale mean score was

TABLE 5 Caregiver contribution to self-care of patients with COPD and other chronic conditions (N=150 caregivers).

Caregiver Contribution to Self-Care of Chronic Obstructive Pulmonary Disease Inventory (CC-SC-COPDI)		
	Mean	SD
CC to self-care maintenance (N=150)		
Indicate how often you recommend the follower behaviours you care for		
1. Avoid people with colds or flu	4.03	1.17
2. Move away from the room/place where someone is smoking	3.99	1.41
3. Avoid contact with sprays, paints, solvents and dust	3.73	1.43
4. Keep my lungs free by coughing or with deep breathing if needed	3.55	1.28
5. Pause during my daily activities to rest	4.07	1.16
6. Use abdominal breathing or pursed lips breathing to regulate my breath	2.58	1.40
8. Regularly do some form of exercise (walking, cycling, swimming, etc.)	3.02	1.43
10. Exercise with my arms at least three times a week?	2.11	1.27
13. Engage in social activities with other people at least once a week	2.81	1.36
14. Get a flu vaccination every year	4.36	1.14
16. Take the medicines as prescribed by my healthcare provider	4.63	0.91
23. Protect my mouth/nose when I walk outdoors and the air is cold	3.89	1.39
24. Make regular visits to my healthcare provider for check-ups of my chronic lung disease	4.65	0.76
<i>Scale total score</i>	66.14	18.62
CC to self-care monitoring (N=150)		
Indicate how you often recommend, or perform in place, of the person you assist, the follower behaviours		
25. Monitor for an increase in sputum quantity	3.52	1.36
26. Monitor for a change in sputum colour	3.59	1.43
27. Monitor for an increase of coughing	4.23	1.00
28. Monitor for an increase in breathlessness or whistles	4.29	1.00
29. Monitor whether I wake up during the night with trouble breathing	3.62	1.48
30. Check whether I struggle to fall asleep due to trouble breathing	3.40	1.43
31. Monitor whether I get tired more than usual when I do something	4.09	1.08
32. Check for palpitations, tremors, insomnia, dry mouth and difficulty urinating after taking inhaled medications	3.16	1.45
<i>Scale total score</i>	63.24	24.44

(Continues)

TABLE 5 (Continued)

Caregiver Contribution to Self-Care of Chronic Obstructive Pulmonary Disease Inventory (CC-SC-COPDI)		
	Mean	SD
CC to self-care management (N = 143)		
Indicate how likely you are to recommend the follower behaviours when your person has symptoms		
34. Talk to my healthcare provider if I have problems with prescriptions for my chronic lung disease	4.27	0.99
35. Go to my healthcare provider if I have any health problem that lasts for more than a few days	4.34	1.01
36. Speak to my healthcare provider if I feel that the breathlessness has increased	4.42	0.92
37. Speak to my healthcare provider if I feel that the cough has increased	4.30	1.02
38. Speak to my healthcare provider if the sputum changes colour	4.08	1.26
39. Speak to my healthcare provider if the amount of sputum increases	4.07	1.26
41. Speak to my healthcare provider if I get side effects from my inhaled medicines (e.g. tremors, insomnia, dry mouth, difficulty urinating)	3.33	1.38
42. When the symptoms of my illness worsen, I modify prescribed therapy as my healthcare provider told me to do (e.g. take cortisone and/or an antibiotic)	4.11	1.24
43. Sit doing housework when I have breathlessness	3.86	1.28
44. When I have breathlessness, sit on a chair or on another support when I shower or use the bathtub	3.71	1.43
<i>Scale total score</i>	68.67	20.98

Abbreviations: CC, caregiver contribution; SD, standard deviation.

63.24 (SD 24.44) and 48.66% of caregivers contributed to self-care inadequately. The item with the highest score was recommended to 'Monitor for an increase in breathlessness or whistles' (4.29, SD 1.00), while the item with the lowest score was recommended to 'Check for side effects of inhaled medications, such as palpitations, tremor, insomnia, dry mouth and difficulty at urinating' (3.16, SD 1.45). The CC to self-care management scale mean score was 68.67 (SD 20.98) and caregivers with inadequate contribution to self-care were 45.45%. The item with the highest score was recommended to 'Speak to healthcare provider if breathlessness has increased' (4.42, SD 0.92), while the item with the lowest score was 'Speak to the healthcare provider if patient get side effects from inhaled medicines (e.g. tremor, insomnia, dry mouth, difficulty urinating)' (3.33, SD 1.38).

Table 6 reports specific CC to self-care in DM. Regarding the CC to self-care maintenance scale, the total score was 71.29 (SD

TABLE 6 Caregiver contribution to self-care of patients with DM and other chronic conditions (N = 594 caregivers).

Caregiver Contribution to Self-Care of Diabetes Inventory (CC-SCODI)		
	Mean	SD
CC to self-care maintenance (N = 594)		
How often do you recommend the following things to the person you care for?		
1. Maintain an active lifestyle (e.g. walking, going out, doing activities)?	3.57	1.29
2. Perform physical exercise for 2 h and 30 min each week? (e.g. swimming, going to the gym, cycling, walking)	2.59	1.45
3. Eat a balanced diet of carbohydrates (pasta, rice, sugars and bread), proteins (meat, fish, legumes), fruits and vegetables?	4.16	1.01
4. Avoid eating salt and fats (e.g. cheese, cured meats, sweets, red meat)?	4.05	1.08
5. Limit alcohol intake (no more than one glass of wine/day for women and two glasses/day for men)?	3.77	1.57
6. Try to avoid getting sick (e.g. wash your hands, get recommended vaccinations)?	4.13	1.13
7. Avoid cigarettes and tobacco smoke?	3.97	1.69
8. Take care of your feet (wash and dry the skin, apply moisture, use correct socks)?	3.62	1.41
9. Maintain good oral hygiene (brush your teeth at least twice/day, use mouthwash, use dental floss)?	3.49	1.45
10. Keep appointments with your healthcare provider?	4.39	0.99
11. Have your health check-ups on time? (e.g. blood tests, urine tests, ultrasound, eye exams)?	4.37	0.99
12. Many people have problems taking all their prescribed medicines. Do you take all your medicines as your health care provider prescribed (please also consider insulin if your doctor prescribed it for you)?	4.08	1.27
<i>Scale total score</i>	71.29	21.18
CC to self-care monitoring (N = 594)		
How often do you recommend the following things to the person you care for?		
13. Monitor blood sugar regularly?	3.86	1.30
14. Monitor weight?	3.24	1.29
15. Monitor blood pressure?	3.64	1.25
16. Keep a record of blood sugars in a diary or notebook?	3.09	1.58
17. Monitor the condition of feet daily to see if there are wounds, redness or blisters?	3.23	1.47
18. Pay attention to symptoms of high blood sugar (thirst, frequent urination) and low blood sugar (weakness, perspiration, anxiety)?	3.85	1.23

TABLE 6 (Continued)

Caregiver Contribution to Self-Care of Diabetes Inventory (CC-SCODI)		
	Mean	SD
The last time the person you care for had symptoms		
19. How quickly did you recognize that he or she was having symptoms?	3.04	1.50
20. How quickly did you know that the symptoms were due to diabetes?	3.09	1.57
<i>Scale total score</i>	61.82	24.60
CC to self-care management		
How often do you recommend the following things to the person you care for? (Or, how often do you do these activities because the person you care for is not able to do them?)		
21. To check blood sugar when the person you care for feels symptoms (such as thirst, frequent urination, weakness, perspiration, anxiety).	3.82	1.30
22. When the person you care for has abnormal blood sugar levels, take notes about the events that could have caused it and actions he or she took.	3.24	1.45
23. When the person you care for has abnormal blood sugar levels, to ask a family member or friend for advice.	3.06	1.46
24. When the person you care for has symptoms and discovers that blood sugar is low, to eat or drink something with sugar to solve the problem.	3.84	1.20
25. If the person you care for finds out that blood sugar is high, to adjust the diet to fix it.	3.89	1.16
26. If the person you care for finds out that blood sugar is high, to adjust physical activity to fix it?	2.98	1.37
27. After taking actions to adjust an abnormal blood sugar level, to recheck blood sugar to assess if the actions were effective.	3.79	1.29
28. If the person you care for finds out that blood sugar is very low or very high, to call your healthcare provider for advice.	3.96	1.23
If your person takes insulin, please answer the following question (N=203)		
29. If the person you care for finds out that blood sugar is too high or too low, to adjust the insulin dosage in the way your healthcare provider suggested	4.28	1.16
<i>Scale total score</i>		
- Insulin (N=203)	72.45	22.31
- No insulin (N=373)	63.57	22.33

Abbreviations: CC, caregiver contribution; SD, standard deviation.

21.18) and caregivers with inadequate contribution to self-care were 39.22%. The item with the highest score was recommended to 'Keep appointments with health care provider' (4.39, SD 0.99),

while the behaviour with the lowest score was recommended to 'Perform physical exercise for 2h and 30min each week' (2.59, SD 1.45). Regarding the CC to self-care monitoring scale, the mean score was 61.82 (SD 24.60) and caregivers with inadequate contribution to self-care were 54.71%. The item with the highest score was recommended to 'Monitor blood sugar regularly?' (3.86, SD 1.30), while the behaviour with the lowest score was 'How quickly did you recognize that he or she was having symptoms?' (3.04, SD 1.50). Regarding CC to self-care management scale, two scores were calculated depending on whether the patients were in therapy with insulin (N=203) or not (N=373). For the first group, the mean score was 72.45 (SD 22.31) and caregivers with inadequate contribution to self-care were 14.31%, while in the second group, the mean score was 63.57 (SD 22.33) and caregivers with inadequate contribution to self-care were 36.19%. The item with the highest score was recommended to 'call health care provider for advice if the person you care for find out that blood sugar is very low or very high' (3.96, SD 1.23), while the item with the lowest score was 'If the person you care for find out that blood sugar is high, to adjust physical activity to fix it' (2.98, SD 1.37).

5.4 | Comparison and correlations between generic and disease-specific CC to self-care

Table 7 and Figure 1 report the comparison and correlations between generic and disease-specific CC to self-care behaviour scales in the same participants. Regarding the comparison between CC-SC-CII and CC-SCHF1, all comparisons were statistically significant, with the CC-SCHF1 scores that were lower than CC-SC-CII scores (56.75 vs. 81.47, respectively). Regarding the comparison between the CC-SC-CII and the CC-SC-COPDI, we found that only in the dimension of CC to self-care monitoring, the CC-SC-COPDI scales' scores were statistically lower than CC-SC-CII scale scores ($p < .0001$) with a difference of $\Delta = 16.58$. In the comparison between CC-SC-CII and the CC-SCODI scales, scores were statistically different in the dimensions of CC to self-care maintenance and monitoring. Specifically, we found that the CC-SCODI scores were higher than those of the CC-SC-CII in self-care management but lower in self-care monitoring. The correlations between generic and disease-specific CC to self-care were all significant with coefficients ranging between .44 and .65 (Table 7). The weakest and strongest correlations were found between CC-SC-CII and the CC-SCHF1 for the self-care management and the self-care maintenance scales' scores respectively.

6 | DISCUSSION

This study aimed to describe generic and disease-specific CC to self-care behaviours in MCCs and to compare and correlate generic and disease-specific caregiver behaviours. To our knowledge, this is the first study in which generic and disease-specific CC to self-care have been measured simultaneously on the same participants, and it is

TABLE 7 Description, comparison and correlations between caregiver contribution to generic and disease-specific self-care ($N=896$ caregivers).

	Mean (SD)	Mean (SD)	Δ CC to self-care	<i>t</i>	<i>r</i>
	Range	Range		<i>p</i> -Value	<i>p</i> -Value
<i>N</i> = 369	CC-SC-CII	CC-SCHFI			
CC-self-care maintenance	70.57 (21.61) 0-100	67.57 (19.42) 6.25-100	+3.00	3.28 .001	0.64 <.001
CC-self-care monitoring	81.47 (20.13) 0-100	56.75 (24.96) 6.22-100	+24.72	20.80 .001	0.50 <.001
CC-self-care management (<i>N</i> = 167)	72.77 (17.82) 0-100	66.61 (16.60) 23.1-100	+6.16	4.38 <.001	0.44 <.001
<i>N</i> = 150	CC-SC-CII	CC-SCCOPDI			
CC self-care maintenance	69.04 (19.80) 0-100	66.14 (18.62) 11,54-100	+2.90	1.78 .077	0.46 <.001
CC self-care monitoring	79.82 (20.25) 25-100	63.24 (24.44) 0-100	+16.58	8.11 <.001	0.43 <.001
CC-self-care management (<i>N</i> = 139)	68.87 (19.36) 0-100	68.67 (20.98) 10-100	+0.20	0.115 .908	0.40 <.001
<i>N</i> = 594	CC-SC-CII	CC-SCODI			
CC-self-care maintenance	69.18 (21.33) 0-100	71.29 (21.18) 6.26-100	-2.11	-2.86 .004	0.65 <.001
CC-self-care monitoring	76.29 (22.42) 0-100	61.82 (24.61) 0-100	+14.47	17.07 <.001	0.62 <.001
CC-self-care management					
Insulin (<i>N</i> = 373)	69.74 (19.40) 0-100	72.45 (22.31) 2.79-100	-2.71	-1.88 .061	0.52 <.001
No insulin (<i>N</i> = 203)	65.29 (20.70) 0-100	63.57 (22.33) 9.37-100	+1.72	1.507 .133	0.57 <.001

Note: A statistical analysis to evaluate the statistical differences in means of caregiver contribution to generic and specific patient's self-care scores. The Student's *t*-test was used. Delta (Δ) self-care represents the difference between caregiver contribution to generic and specific patient's self-care scores (CC-SC-CII and CC-SCHFI, CC-SC-CII and CC-SCCOPDI and CC-SC-CII and CC-SCODI). The bold values are the significant ones.

Abbreviations: CC, caregiver contribution; CC-SC-CII, Caregiver Contribution to Self-Care of Chronic Illness Inventory; CC-SCHFI, Caregiver Contribution to Self-Care of Heart Failure Index; CC-SCCOPDI, Caregiver Contribution to Self-Care of Chronic Obstructive Pulmonary Disease Inventory; CC-SCODI, Caregiver Contribution to Self-Care of Diabetes Inventory; *N*, number; *r*, Pearson's correlation coefficients; *t*, Student's *t*-test.

also the first study in which comparisons and correlations between these two types of behaviours have been made. These findings are important because they give new insights on how informal caregivers of patients affected by MCCs contribute to generic and disease-specific self-care behaviours.

Regarding CC to generic self-care, on average, we found that our sample performed adequate self-care monitoring but inadequate self-care maintenance and management as the scores of these two scales were below 70 points. Regarding CC to disease-specific self-care, all self-care maintenance, monitoring and management scales' scores were inadequate, with the only exception for the CC-SCODI in which we observed a score >70 in the self-care maintenance and self-care management scales in those practicing insulin therapy. No studies using CC-SC-CII have been conducted so far, consequently, we could not make any comparisons with the literature, but the scores of the CC instruments used in this study are consistent with the scores of the generic and disease-specific patient self-care (Ausili et al., 2018; Durante, Greco, et al., 2019; Durante, Paturzo, et al., 2019; Iovino et al., 2021). This confirms that patients

and caregivers are interdependent in the self-care processes; when patients perform lower self-care, caregivers also perform lower CC to self-care and vice versa.

Regarding single CC-SC-CII, CC-SCHFI, CC-SCOPDI and CC-SCODI items, we observed several consistencies among the scales. Regarding CC to self-care maintenance scales, taking medications as prescribed and keeping regular check-ups were the behaviours that caregivers mostly recommended to their patients, while performing physical activities was the behaviour less recommended. The scores of the CC to self-care monitoring scales were higher for those items related 'typical' symptoms of the diseases (e.g. ankle swelling for HF, breathlessness for COPD and blood sugar for diabetes) but were lower for more 'sophisticated' behaviours, such as monitoring medication side effects (in the CC-SC-CII and CC-SCOPDI) and symptom recognition (in CC-SCODI). Finally, the scores of the CC to self-care management items were higher for those behaviours measuring how likely caregivers were to call the healthcare providers in case of symptoms (for all the CC to self-care management scales) but lower for those behaviours related to the symptom management due to

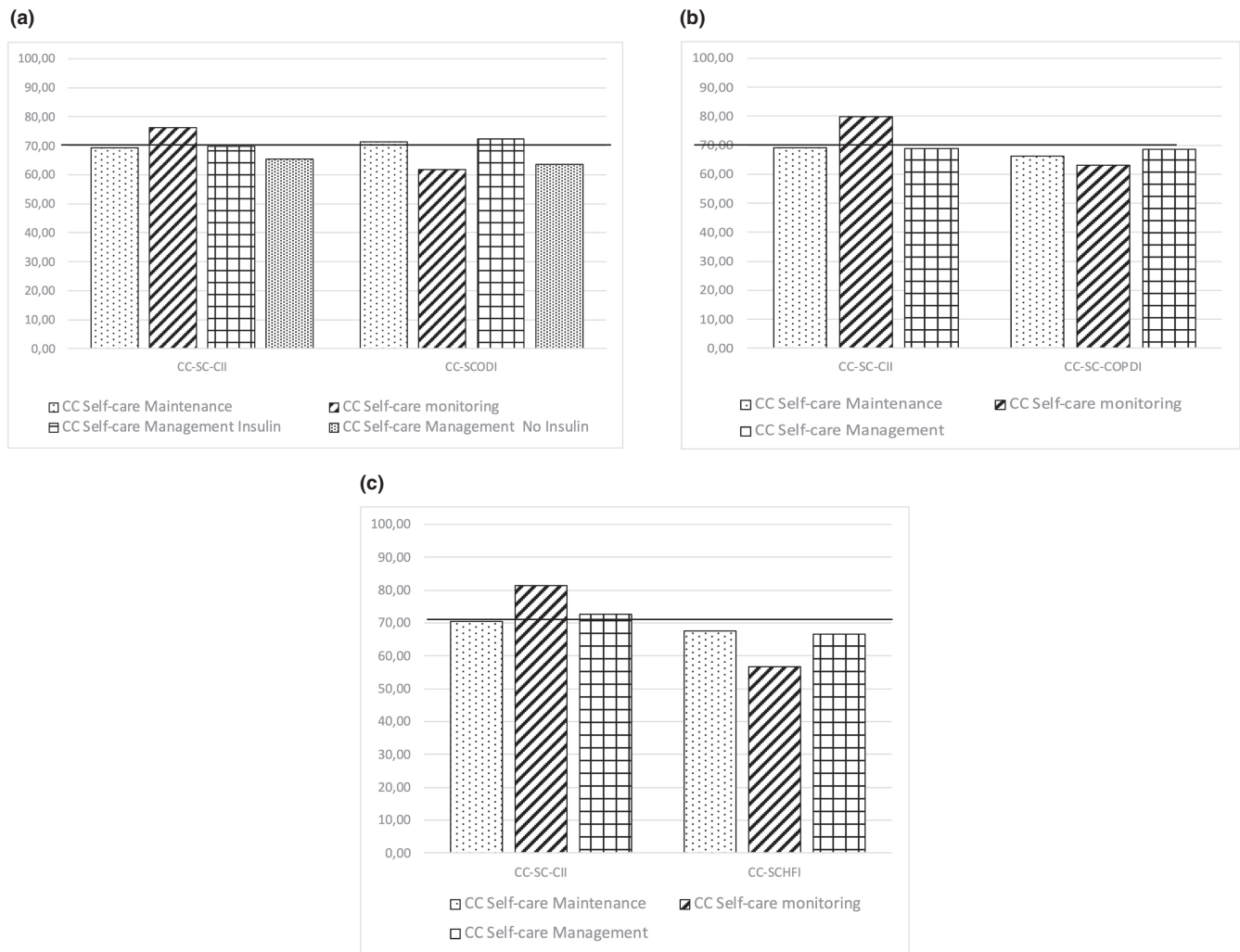


FIGURE 1 Comparison between caregiver contribution to generic and disease-specific self-care in heart failure, diabetes mellitus and chronic obstructive pulmonary disease. Comparison between (a) Caregiver Contribution to Self-Care of Chronic Illness Inventory (CC-SC-CII) and Caregiver Contribution to Self-Care of Diabetes Inventory (CC-SCODI), (b) Caregiver Contribution to Self-Care of Chronic Illness Inventory (CC-SC-CII) and Caregiver Contribution to Self-Care of Chronic Obstructive Pulmonary Disease (CC-SCCOPDI), and (c) Caregiver Contribution to Self-Care of Chronic Illness Inventory (CC-SC-CII) and Caregiver Contribution to Self-Care of Heart Failure Index (CC-SCHF). The 70 value is the cut-point for the adequacy of the Caregiver's Contribution to generic and disease-specific self-care. It is signed in the histogram with a continuous line.

the disease or the side effects of medications. The scores of these items depict a caregiving pattern characterized by recommending patients follow more healthcare provider prescriptions than to advise lifestyle changes and non-pharmacological approaches to manage the diseases. These findings are not surprising as also previous studies conducted on individual chronic conditions have found similar patterns associated with a low level of caregiver preparedness in managing the diseases (Aggarwal et al., 2013; Buck et al., 2015; Durante, Greco, et al., 2019; Durante, Paturzo, et al., 2019). These findings could be a sign either that caregivers of patients affected by chronic conditions are not sufficiently educated and trained by healthcare providers, or that caregivers experience difficulties applying the knowledge they receive to their patients. This aspect might also be a sign that our caregivers do not see themselves as agents of the healthcare system but as supporters of someone they

love (as a family member or friend). This aspect requires further studies to understand better how caregivers of patients affected by chronic conditions perceive their role.

In the comparison between generic and disease-specific CC to self-care, we found statistical differences but only the differences between CC to self-care monitoring scales have a real clinical meaning with higher scores in the CC-SC-CII compared with the other scales. Our interpretation is that generic CC to self-care includes very 'generic' recommendations (e.g. monitor one's own condition or pay attention to changes in health) that every caregiver who cares for a loved one recommends. Instead, when caregivers take care of patients affected by specific diseases, they should know specific behaviours that require advanced knowledge—such as checking for ankle swelling in HF, monitoring for sputum colour changes in COPD and monitoring blood sugar in diabetes. The lack of clinically

significant differences between generic and disease-specific CC to self-care maintenance and management behaviours could be due to the adoption of similar items (e.g. physical activity and calling the provider in case of symptoms) in all the CC measures we used. As we found similar scores among the generic and the disease-specific measures of CC to self-care, we expected stronger correlations but we did not. This could be a sign that caregivers are not consistent in generic and disease-specific behaviours.

6.1 | Implication for practice and research

The results of our study have important clinical and scientific implications, even though, to our knowledge, this is the first study comparing generic and disease-specific CC to self-care. As we found that in the dimensions of maintenance and management, there are no clinical differences between generic and disease-specific self-care, it seems that the generic and disease-specific instruments can give a consistent estimation of the CC to self-care. In other words, it seems that CC to self-care maintenance and management have consistent scores and, consequently, the score of generic CC to self-care might be a good estimation of disease-specific CC and vice-versa. However, we also found no strong correlations between the generic and disease-specific CC to self-care. This implies that both generic and disease-specific measurements of CC to self-care are needed for clinicians.

Several aspects remain still unknown and deserve further studies. We need to know better how generic and specific CC to self-care interrelate and if important outcomes such as patient quality of life and patient hospitalizations and mortality are predicted better from generic or specific CC to self-care. Also, it would be important to investigate if some items, which are redundant in generic and disease-specific CC to self-care instruments, can be omitted during the administration.

6.2 | Limitation and strength

Our study has some limitations. First, although this was a multicenter study, it used a convenience sample, thus limiting the generalizability of the results. Second, our study was conducted in only one country, so our results are cautiously generalizable to other cultural contexts. However, this is the first study that describes the CC to generic and disease-specific self-care in the context of MCC using a large sample of caregivers of MCC's patients.

7 | CONCLUSION

In conclusion, in this study, we found that caregivers of patients with MCCs contribute more to self-care in aspects related to provider prescriptions and less to lifestyle changes. Regarding CC to generic self-care, caregivers are adequate to the dimension of self-care

monitoring. Regarding disease-specific self-care, only caregivers caring for DM patients contribute adequately in the dimension of self-care maintenance and self-care management when patients are treated with insulin. Regarding CC to disease-specific self-care of patients affected by COPD and HF, caregivers performed inadequate contributions in all dimensions. As generic and disease-specific behaviours are important in managing MCC, healthcare professionals have to reflect on the reasons for the poor contribution of caregivers to self-care and design future interventions to enhance these behaviours. This study also underlines the importance of choosing the most appropriate instrument for measuring CC to self-care considering the caregiver's characteristics.

AUTHOR CONTRIBUTIONS

All the authors are entitled to authorship and meet the criteria for authorship: Maria Matarese, Davide Ausili, Ercole Vellone and Maddalena De Maria were responsible for the conception and design of the study and interpretation of data. Ilaria Erba, Ercole Vellone and Maddalena De Maria were involved in drafting the manuscript or revising it critically for important intellectual content; Maddalena De Maria, Manuela Saurini and Ilaria Erba contributed to data acquisition; Maddalena De Maria contributed to data analysis. All the authors approved the final version of the manuscript.

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CONFLICT OF INTEREST STATEMENT

No conflict of interest has been declared by all the authors.

DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request.

AUTHORS STATEMENT

The authors have checked to make sure that our submission conforms as applicable to the Journal's statistical guidelines described here. There is an expert in data analysis on the author team (Maddalena De Maria). The authors affirm that the methods used in the data analyses are suitably applied to their data within their study design and context, and the statistical findings have been implemented and interpreted correctly. The authors agree to take responsibility for ensuring that the choice of statistical approach is appropriate and is conducted and interpreted correctly as a condition to submit to the Journal.

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SUPPORTING INFORMATION

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

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