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ORIGINAL RESEARCH

Dyadic symptom recognition in heart failure

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Aims

Patients with heart failure experience several symptoms that can be addressed through self-care, which both patients and caregivers in the dyad can contribute to. However, studies on dyadic symptom-recognition patterns in heart failure are scarce. We explored whether heart failure patients and their caregivers were concordant or discordant in their symptom-recognition behaviours, what characteristics concordant and discordant dyads had, and which variables predicted membership in the concordant or discordant symptom-recognition groups.

Methods and results

This is a secondary analysis of a randomized controlled trial (RCT) on 500 dyads. Dyads were classified as concordant or discordant according to their response to the symptom-recognition item of the Self-Care of Heart Failure Index and the Caregiver Contribution to Self-Care of Heart Failure Index. A multiple logistic regression model was adopted to identify predictors of membership in concordant or discordant dyads. Patients were typically male (58%), retired (77%, $n = 382$), with a median age of 75 years, belonging to New York Heart Association (NYHA) class II (62%); caregivers were typically female (76%), with a median age of 55 years, active workers (47%, $n = 235$), living with the patient (61%), and being patient's child (39%) or spouse (38%). Patient self-care and caregiver contribution to patient self-care were poor (i.e. SCHFI and CC-SCHFI scores <70). Most dyads (87%) showed concordant symptom recognition, meaning that both members agreed on the presence or absence of symptoms. Higher caregiver self-efficacy in contributing to patient self-care predicted membership in the discordant dyadic symptom-recognition group. Higher patient symptom burden and cognitive impairment, patient being retired, caregiver preparedness, and caregiver not being the patient's spouse predicted membership in the concordant dyadic symptom-recognition group.

Conclusion

Concordant dyadic symptom recognition was predominant and several variables differently predicted the membership to the dyadic symptom-recognition groups. This can help to further characterize dyads' attitudes toward symptom recognition, to better understand how to address symptom recognition and awareness of body changes at a patient, caregiver, and dyadic level, and ultimately to allow personalized symptom management strategies.

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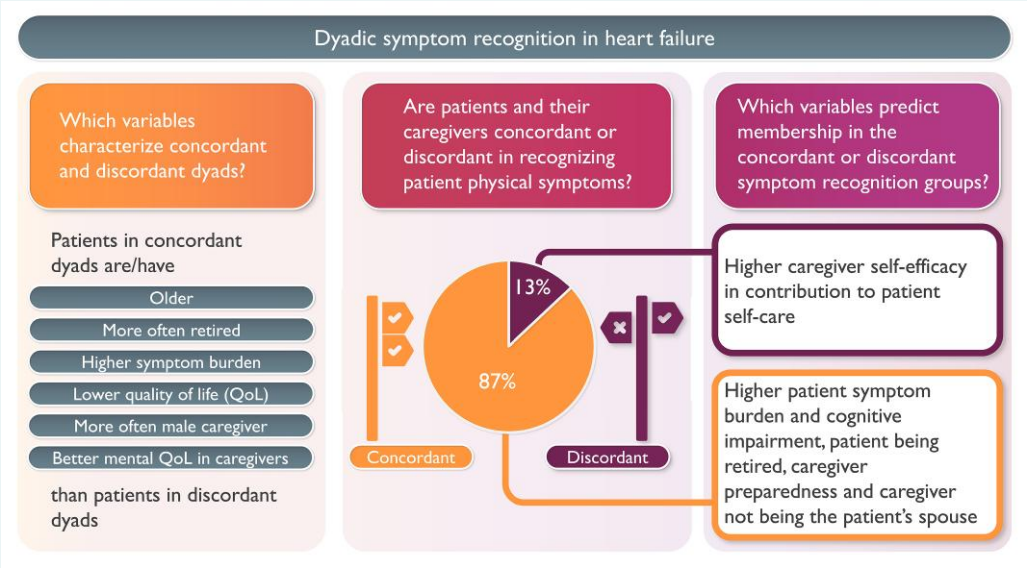
Graphical Abstract



Keywords Dyad • Heart Failure • Self-Care • Symptom Assessment • Symptom recognition

Novelty

- Concordant dyadic symptom recognition was predominant and several variables were able to differently predict the membership to the concordant vs. discordant dyadic symptom-recognition groups.
- The results of this study are particularly relevant as they can help to further characterize dyad's attitudes toward symptom recognition, to better understand how to address symptom recognition and awareness of bodily changes at both a patient, caregiver, and dyadic level, and ultimately to allow personalized symptom management strategies.

Introduction

Heart failure is a chronic disease with a prevalence of 56 million people worldwide that is continuously increasing because of aging populations, better treatment outcomes, and improved survival rates.[1] Patients with heart failure experience a multitude of physical symptoms, such as dyspnea, fatigue, and edema,[2,3] which contribute to lower quality of life[4] and increase hospitalization[2] and mortality rates.[5] Eventually, patients with heart failure experience high levels of symptom burden, which tend to increase as the disease progresses.[6]

If patients perform self-care,[7,8] symptoms can be managed and symptom burden can be alleviated. Specifically, self-care is a process of maintaining health, monitoring symptoms, and managing signs and symptoms when they arise.[9] Before even attempting to manage symptoms, it is essential that body signals are first perceived and accurately recognized as alterations of the normal physiological state.[10] However, patients often experience difficulties in accurately perceiving body signals for several reasons, including interoceptive deficits[11–13] that worsen with older age,[14] impaired decision-making, or weakened memory capacity.[13] Also, informal caregivers in the dyads can play an important role[7,8,15] in contributing to the recognition of patient body changes to ultimately improve patient outcomes,[16] as described in the Situation Specific Theory of Heart Failure Self-Care,[17] for instance, by nudging patients to listen to their body and, thus, foster symptom perception.[8] However, caregivers can contribute to patient recognition of their body changes to various extents, as several factors can affect such ability, including, for example, caregiver self-care self-efficacy, anxiety, depression,[18] gender, and mutuality.[19] As highlighted by the Theory of Dyadic Illness Management,[20] exploring how the dyad appraises illness as a unit is important because it can influence how the members of the dyad engage in subsequent illness management behaviours together, and eventually, it can influence the resulting individual and dyadic outcomes.[20] Studies on this aspect are lacking and, thus, warranted. Indeed, studies in HF commonly focus on either caregivers alone or together with patients but only examine their experiences and outcomes separately. Instead, fewer studies explore HF-related phenomena as they happen in the dyad, which is how patients and their caregivers live and manage the disease together as a team.[15]

Previous studies explored the dyadic patterns of the performed self-care behaviours in the dyad[21,22] by relying on the overall self-care scores to assess the concordance between patient and caregiver on their self-care behaviours. Other studies[23] explored dyadic types based on symptom-related behaviours in patients with multiple chronic

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conditions by relying on the Dyadic Symptom Management Type Scale, which classifies dyads as patient-oriented (both members of the dyad agree that the patient takes most of the responsibility in HF care), caregiver-oriented (both members of the dyad agree that the caregiver takes most of the responsibility in HF care), collaborative (both members of the dyad take the responsibility in HF care), and discordant dyads (the patient and the caregiver do not agree on which member of the dyad takes most of the responsibility in HF care). However, in heart failure, analyses of dyadic symptom-related patterns are scarce. One study[24] did explore dyadic types in heart failure based on symptom appraisal behaviours; however, only community-dwelling adults and their spousal/partnered caregivers were included in that study. Further exploring symptom-recognition behaviours at a dyadic level by relying on a specific symptom-recognition measurement could help to better characterize dyads' attitudes toward symptom recognition, to better understand how to address symptom recognition and awareness of body changes at a patient, caregiver, and dyadic level, and, ultimately, to improve symptom management.

Thus, in this study, we aimed to explore whether patients with heart failure and their informal caregivers were concordant or discordant in their symptom recognition, what characteristics concordant and discordant dyads have, and which variables predicted the membership in the concordant or discordant dyadic group of symptom recognition.

Methods

Study design

This is a secondary analysis of baseline data from the MOTIVATE-HF randomized controlled trial (RCT),[25] which primarily aimed at improving self-care through motivational interviewing in patients with heart failure. In the original study, several variables were collected over time before and after the delivery of the motivational interviewing intervention. For this cross-sectional analysis, we only relied on baseline data from the overall sample, and the variables used in this study are described below. Since we aimed to explore dyadic symptom recognition in heart failure, both the Situation Specific Theory of Heart Failure Self-Care[7,17] and the Theory of Dyadic Illness Management[20] informed this study, meaning that both theories were used as a reference to conceptualize the study and interpret the results.

Data collection and measurements

Since dyads in the original study were randomized into three arms and received different treatments over time (i.e. in arm 1, both patients and caregivers received a motivational interviewing intervention; in arm 2, only patients received the motivational interviewing intervention; in arm 3, dyads received standard care), for this study we only relied on baseline data. A total of 510 dyads of adults with heart failure and their primary informal caregivers (e.g. spouse or son) were recruited from a hospital, an outpatient, and a community setting in Italy between June 2014 and October 2018. Please note that, in the present study, we excluded 10 dyads because of the high missing values in the variables of interest for this analysis. For patients, inclusion criteria were a diagnosis of heart failure with New York Heart Association (NYHA) class II–III–IV and poor self-care (i.e. 0–2 on ≥2 items of the Self-Care of HF Index v.6.2),[26] while exclusion criteria included severe cognitive impairment (i.e. 0–4 on the Six-item Screener),[27] myocardial infarction in the previous 3 months, and living in residential facilities. For caregivers, inclusion criteria implied being identified by the patients as the person providing them with most of the informal care. More details can be found in the parent study.[28] Cognitive impairment was chosen as an eligibility criterion for patients because patients with HF often suffer from cognitive impairments,[29] which, in turn, has been shown to decrease self-care.[29–33] Thus, including patients with cognitive impairment in the study would have represented an important bias. We did not adopt this eligibility criterion for caregivers because, generally, caregivers do not have this problem when they take the responsibility to care for a patient with HF.

Patient self-care and caregiver contribution to patient self-care were measured with the Self-Care of HF Index v.6.2[26] and the Caregiver Contribution to Self-Care of HF Index,[34] respectively. To explore symptom-recognition behaviours in the dyads, in this study, we only relied on one single item of the Self-care of Heart Failure Index (patient version) which asks '*In the past month, have you had trouble breathing or ankle swelling?*' and the same single item in the caregiver version of the same index (i.e. Caregiver Contribution to Self-care of Heart Failure Index) asking '*In the past month, did the person you care for have trouble breathing or ankle swelling?*'. Participants could respond *yes* or *no*. Based on that, we could appraise if the patient and his/her caregiver were responding the same or not, giving us an understanding of their level of congruence in recognizing patient symptoms. Additionally, the item for symptom recognition in the Self-Care of Heart Failure Index[26] has been shown to be particularly relevant by acting as a mediator between self-care monitoring and self-care management in chronic illness.[10]

To describe the sample, other sociodemographic and clinical variables were measured with various instruments.[25] Briefly, besides sociodemographic and basic clinical characteristics (e.g. NYHA class), we measured several variables as follows. Symptom burden was measured with the HF somatic perception scale (HFSPS), which assesses four symptom domains and higher scores indicate higher symptom burden.[35] Quality of life was measured with the Short Form-12 (SF-12), which assesses both mental and physical quality of life, higher scores indicate better functioning.[36] HF-related quality of life was measured with the Kansas City Cardiomyopathy Questionnaire (KCCQ, where higher scores indicate better functioning).[37] Anxiety and depression were measured with the Hospital Anxiety and Depression Scale (HADS; higher scores indicate higher anxiety/depression).[38] Comorbidity was measured with the Charlson Comorbidity Index (CCI), which attributes a comorbidity risk category depending on the number and severity of the diseases a patient suffers from; higher scores indicate more severe conditions).[39] Mutuality refers to the perceived relationship between the members of the dyad and was measured with the Mutuality Scale (higher scores indicate greater mutuality).[40] Cognition was measured with the Montreal Cognitive Assessment (MoCA; higher scores indicate better cognitive functioning).[41] Sleep quality was measured with the Pittsburgh Sleep Quality Index (PSQI; higher scores indicate worse sleep quality).[42] Caregiver perceived preparedness in taking care of the patient was measured with the Caregiver Preparedness Scale (CPS; higher scores indicate greater perceived preparedness).[43] Perceived social support was measured with the Multidimensional Scale of Perceived Social Support (MSPSS), where higher scores indicate greater perceived social support.[44]

Data analysis

We initially found three groups (A: concordant dyads; B: discordant dyads, where patients recognized some symptoms but caregivers did not; C: discordant dyads, where caregivers recognized some symptoms but patients did not) and we detailly described the characteristics of each. Specifically, characteristics of both patients and caregivers were described using frequencies and percentages for categorical variables, and median and interquartile range (IQR) for continuous variables. Sample characteristics were presented overall and divided into three groups. Differences between groups were tested using Pearson's Chi-square test, Kruskal–Wallis rank sum test, or Fisher's exact test, as appropriate. Where significant differences were found, *post hoc* tests were performed using Bonferroni-adjusted Pearson's Chi-square test or Fisher's exact test for categorical variables and Dunn's *post hoc* test for continuous variables. The Bonferroni correction was implemented to control for type I errors due to multiple comparisons.

The next step we took was to create a model to explore the variables that could predict the membership to concordant or discordant dyad types. To do so, a logistic regression model was adopted. At this point, we decided to merge groups B and C to eventually have one group representing concordant dyads and another group representing discordant dyads. This was done to account for the small sample size of the two discordant groups (i.e. groups B and C) and the uneven distribution of the dyads in the three groups. Eventually, having two main groups to compare in the model, namely concordant dyads (group A) vs. discordant dyads (groups B + C), also allowed for a more balanced and robust model.

For variable selection, we adopted a two-fold approach. First, we included 22 variables that, based on the existing evidence, were mostly associated with the construct of symptom recognition (i.e. patient and caregiver gender, patient and caregiver age, patient and caregiver self-care self-efficacy, patient physical symptom burden, patient cognitive level, patient and caregiver quality of life, patient NYHA class, time since HF diagnosis, patient number of medications, patient and caregiver employment status,

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patient and caregiver perceived mutuality, caregiver preparedness, caregiver's relationship with the patient, patient and caregiver cohabitation, patient and caregiver sleep quality). Second, covariates were also tested for potential collinearity, considering a Variance inflation factor (VIF) ≥5 as a criterion to evaluate the exclusion of the variable and a VIF >10 as a criterion to exclude the variable from the model.[45] Results are reported as odds ratios (OR)s and 95% confidence intervals (CI)s.

Results

Our sample included 500 dyads and was characterized by patients being typically male (58%, $n = 290$) and retired (77%, $n = 382$), and caregivers being typically female (76%, $n = 380$) and active workers (47%, $n = 235$), with a median age of 75 (IQR: 65; 82) and 55 (IQR: 43; 65) years, respectively. Patients mostly belonged to NYHA Class II (62%) and had an ischemic HF (34%, $n = 167$) with a median time from diagnosis of 36 months (IQR: 20; 84). Caregivers were typically the patient's child (39%) or spouse (38%) and living with the patient (61%). Self-care and contribution to self-care scores were poor for both patients and caregivers, respectively. We identified three groups of dyads based on the concordance or discordance between patient and caregiver in their symptom recognition. Specifically, in group A (87%), patients and caregivers were concordant in recognizing patient symptoms (i.e. both agreed on the presence or absence of HF symptoms in the last month). Groups B and C represented discordant dyads. Specifically, in group B (8%), patients reported that they recognized HF symptoms in the last month while their caregivers reported they did not; in group C (5%), patients did not recognize any symptom in the last month while their caregivers did. By comparing the characteristics of the three groups, dyads belonging to group A (i.e. concordant symptom recognition) were characterized by caregivers being more often male and patients being older and with higher symptom burden (HFSPS) than those belonging to group B (i.e. discordant symptom recognition—patients: *yes*, caregivers: *no*). Furthermore, dyads belonging to group A were characterized by patients being more often retired, with higher symptom burden (HFSPS), and lower HF-specific quality of life (KCCQ) and caregivers having a higher mental quality of life (SF12-mental) than those belonging to the group C (i.e. discordant symptom recognition—patients: *no*, caregivers: *yes*). Instead, the only difference between groups B and C was in the higher mental quality of life (SF12-mental) of caregivers in group B compared to caregivers in group C. Sample characteristics, overall and divided into the three identified groups, are shown in *Table 1*, while detailed information on the scores of the administered tools is presented in *Table 2*.

According to the logistic regression model, several variables predicted the membership in the concordant or discordant dyad groups. Specifically, a 10-point increase in caregiver self-efficacy (CC-SCHFI) was associated with a 26% increase in the odds of belonging to the discordant group (OR_{10}: 1.26; 95% confidence interval [CI]: 1.05–1.52). Additionally, dyads in which the patient was an active worker were almost four times more likely to belong to the discordant group (OR: 3.85; 95% CI: 1.36–11.07). Instead, a 10-point increase in patient symptom burden (HFSPS) was associated with a 54% increase in the odds of belonging to the concordant group (OR_{10}: 1.54; 95% CI:1.20–2.01). Additionally, a 5-point increase in the MOCA scale, denoting decreasing cognitive impairment, was associated with a 35% increase in the odds of belonging to the concordant group (OR_5: 1.35; 95% CI:1.01–1.81). Furthermore, a 1-point increase in caregiver preparedness (CPS) was associated with a 79% increase in the odds of belonging to the concordant group (OR: 1.80; 95% CI:1.04–3.19). Lastly, dyads in which the caregiver was not the patient's spouse were more than three times likely to belong to the concordant group ('son/daughter' OR: 3.33; 95% CI: 1.16–9.95.00; 'other' OR: 3.42; 95% CI: 1.13–11.35). The results of the logistic regression model are presented in *Table 3*.

Discussion

In this study, we aimed to explore whether patients with heart failure and their caregivers were concordant or discordant in their symptom-recognition behaviours, what characteristics did concordant and discordant dyads have, and which variables predicted the membership to the concordant or discordant dyadic group of symptom recognition.

Dyadic behaviours of symptom recognition

We found that most dyads (87%) showed concordant symptom-recognition behaviours, meaning that both members agreed on the presence or absence of symptoms (i.e. trouble breathing and/or ankle swelling). These results align with the Situation Specific Theory of Heart Failure Self-Care[17] reporting that caregiver behaviours of contributing to patient's self-care mirror the self-care behaviours of the patients themselves. This is important because when both the patient and the caregiver are aligned and recognize the presence or absence of a symptom, a synergy arises, and the members of the dyad can better support each other in adopting self-care management behaviors[20,21,23] (e.g. by reducing fluid intake, taking an extra diuretic, or contacting the healthcare provider).

Furthermore, measuring symptoms by checking them at a dyadic level (i.e. asking the same information to both patient and caregivers) allows for more accurate validation of the presence or absence of a body change. When both dyad members agree on the body change they do or do not recognize, the symptom-recognition measurement can be even more solid. Although only an objective measurement can provide tangible information on the presence or absence of a body change, if only one member of the dyad reports the presence of a body change, it is difficult to understand if such body change has actually occurred. Instead, if both dyad members agree on the body change they report, this can increase the degree of confidence that such a body change has actually occurred.

As highlighted by the Theory of Dyadic Illness Management,[20] a dyadic perspective of symptom appraisal does not necessarily imply a correct respondent but, instead, the incongruence between patient and caregiver in their appraisal of the disease and its symptoms becomes the focus of understanding the phenomenon. The theory hypothesizes that, in heart failure, similar symptom recognition by patients and caregivers might lead to higher collaborative and concordant engagement in illness management (as we indeed noticed in our results) and, therefore, better outcomes for both patients and caregivers. However, studies on this aspect are lacking and, thus, warranted.

Individual factors and symptom recognition

Patient level

We found that patients in the concordant dyads were older, with higher symptom burden and higher self-care management, and were more often retired compared to those in the discordant dyads. This finding gives room to several interpretations: (i) older age together with higher symptom burden could indicate that older people tend to overestimate body signals because of declines in interoception[14,46] ultimately resulting in exaggerated symptom burden[3,47–49] resulting from inaccurate symptom recognition; (ii) older age and higher symptom burden occurring together with higher self-care management, like in our case, could indicate the actual necessity to address burdensome symptoms, and this is congruent with previous literature;[21] (iii) that the concordance between patient and caregiver in symptom recognition occurs because the symptoms are so evident: indeed, previous studies have highlighted that, for example, patient with HF and their caregivers tend to rate visible symptoms like edema most similarly.[15]

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Table 1 Sample characteristics overall and divided into three groups based on the response provided to symptom recognition

Variable	N	Overall N = 500[a]	A N = 433[a]	B N = 40[a]	C N = 27[a]	P-value[b]	Post-hoc adjusted P-value[c]
Patient sex	500					0.810	—
Male		290 (58%)	251 (58%)	22 (55%)	17 (63%)		
Female		210 (42%)	182 (42%)	18 (45%)	10 (37%)		
Caregiver sex	499					**0.037**	**A:B = 0.0384**
Male		121 (24%)	97 (22%)	16 (40%)	8 (30%)		A:C = 1.000
Female		378 (76%)	335 (78%)	24 (60%)	19 (70%)		B:C = 1.000
Patient age (years)	498	75 (65, 82)	75 (65, 83)	73 (62, 81)	68 (54, 76)	**0.020**	**A:B = 0.02920**
							A:C = 0.0156
							B:C = 0.3662
Caregiver age (years)	497	55 (43, 65)	55 (44, 65)	53 (41, 68)	51 (42, 64)	0.643	—
Patient employment status	498					**0.003**	A:B = 0.08490
Active worker		79 (16%)	60 (14%)	10 (25%)	9 (33%)		**A:C = 0.00543**
Retired		382 (77%)	343 (80%)	25 (63%)	14 (52%)		B:C = 0.69900
Other		37 (7.4%)	28 (6.5%)	5 (13%)	4 (15%)		
Caregiver employment status	498					0.834	—
Active worker		233 (47%)	198 (46%)	21 (53%)	14 (52%)		
Retired		133 (27%)	115 (27%)	11 (28%)	7 (26%)		
Other		132 (27%)	118 (27%)	8 (20%)	6 (22%)		
Caregiver relationship with the patient	499					0.685	—
Spouse		189 (38%)	159 (37%)	17 (43%)	13 (48%)		
Son/Daughter		193 (39%)	172 (40%)	13 (33%)	8 (30%)		
Other		117 (23%)	101 (23%)	10 (25%)	6 (22%)		
Patient and caregiver cohabitation	498					0.307	—
No		194 (39%)	165 (38%)	20 (50%)	9 (35%)		
Yes		304 (61%)	267 (62%)	20 (50%)	17 (65%)		
Patient NYHA class	499					0.436	—
II		308 (62%)	260 (60%)	28 (70%)	20 (74%)		
III		158 (32%)	143 (33%)	10 (25%)	5 (19%)		
IV		33 (6.6%)	29 (6.7%)	2 (5.0%)	2 (7.4%)		
Patient HF aetiology	492					0.099	—
Ischemic		167 (34%)	154 (36%)	9 (24%)	4 (15%)		
Idiopathic		130 (26%)	105 (25%)	14 (37%)	11 (41%)		
Non-ischemic		119 (24%)	102 (24%)	11 (29%)	6 (22%)		
Other		76 (15%)	66 (15%)	4 (11%)	6 (22%)		
Time since HF diagnosis (months)	494	36 (20, 84)	36 (24, 84)	46 (17, 80)	24 (18, 66)	0.851	—
Patient number of medications	493	6.0 (4.0, 9.0)	7.0 (5.0, 8.0)	6.0 (4.0, 9.0)	4.5 (3.0, 7.8)	0.060	—

For contingency table with frequencies <5, the *P*-value of the adjusted Fisher's exact test (Bonferroni) is reported. For continuous variables, the *P*-value of the Dunn *post hoc* test is reported. Group A = concordant; group B = patient: 'Yes' and caregiver: 'No'; group C = patient: 'No' and caregiver: 'Yes'. Numbers are presented as count (and percentage). Statistically significant data are reported in bold. HF, heart failure.

[a]*n* (%); Median (IQR).

[b]Pearson's Chi-squared test; Kruskal–Wallis rank sum test; Fisher's exact test.

[c]Multiple comparisons: For contingency table with frequencies ≥5, the *P*-value of the adjusted Pearson's Chi-squared test (Bonferroni) is reported.

However, more studies exploring these relationships should be conducted.

Instead, patients in the discordant dyads were more often younger, with less symptom burden, higher perceived health-related quality of life, lower self-care management, and were more often male and actively working compared to those in the concordant dyads. This differs from previous studies reporting that younger patients experience either equal[50] or higher symptom burden[51] than older patients. However, in our sample, the group of discordant dyads was characterized by younger patient age and higher patient quality of life. This could suggest that younger patients tend to be in better general health conditions compared to the elderly and, consequently, they report better

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Table 2 Scores in administered tools

	Variable	N	Overall, N = 500[a]	A, N = 433[a]	B, N = 40[a]	C, N = 27[a]	P-value[b]	Post-hoc adjusted P-value[c]
P	Morbidity (CCI)	500	2.00 (2.00, 4.00)	2.00 (2.00, 4.00)	2.50 (1.75, 4.25)	2.00 (1.00, 3.00)	0.108	—
P	Cognition (MOCA)	496	25 (19, 27)	25 (19, 27)	26 (18, 27)	25 (18, 29)	0.755	—
P	HF symptoms (HFSPS)	500	29 (16, 44)	31 (17, 47)	23 (13, 32)	22 (10, 36)	**0.004**	**A:B = 0.0128** **A:C = 0.0394** B:C = 1.000
P	Specific QOL-symptoms (KCCQTS)	500	58 (42, 75)	56 (40, 75)	60 (44, 76)	76 (62, 84)	**0.004**	A:B = 0.6010 **A:C = 0.0016** B:C = 0.0611
P	Specific QOL—total (KCCQOS)	500	47 (32, 67)	46 (32, 64)	50 (36, 68)	70 (49, 78)	**0.007**	A:B = 0.7611 **A:C = 0.0025** B:C = 0.0589
C	Caregiver preparedness (CPS)	499	2.00 (1.63, 2.63)	2.00 (1.63, 2.63)	2.00 (1.72, 2.50)	2.25 (1.69, 2.88)	0.722	—
C	Social support (MSPSS)	499	5.67 (4.96, 6.17)	5.67 (5.00, 6.17)	5.71 (5.15, 6.19)	5.50 (4.75, 5.75)	0.503	—
P	Mutuality (MS)	499	3.00 (2.47, 3.40)	3.00 (2.53, 3.40)	3.00 (2.45, 3.15)	3.20 (2.53, 3.57)	0.090	—
C	Mutuality (MS)	499	2.87 (2.33, 3.20)	2.80 (2.38, 3.20)	3.00 (2.33, 3.23)	2.73 (2.27, 3.33)	0.798	—
P	Anxiety (HADS)	500	8.0 (5.0, 11.0)	8.0 (5.0, 11.0)	7.5 (3.8, 11.0)	7.0 (6.0, 10.0)	0.892	—
C	Anxiety (HADS)	499	7.0 (4.0, 10.0)	7.0 (4.0, 11.0)	5.0 (3.0, 9.0)	8.0 (5.5, 9.5)	0.073	—
P	Depression (HADS)	500	8.0 (5.0, 11.0)	8.0 (5.0, 11.0)	9.0 (5.0, 11.0)	9.0 (8.0, 11.0)	0.714	—
C	Depression (HADS)	499	5.0 (3.0, 9.0)	5.0 (2.0, 9.0)	5.0 (3.0, 8.0)	8.0 (2.0, 9.0)	0.726	—
P	Generic QOL—physical (SF12)	500	34 (28, 42)	33 (28, 41)	35 (32, 45)	37 (31, 47)	0.089	—
C	Generic QOL—physical (SF12)	500	51 (45, 55)	51 (44, 55)	53 (47, 55)	52 (48, 56)	0.289	—
P	Generic QOL—mental (SF12)	500	44 (38, 53)	44 (38, 52)	45 (38, 54)	45 (41, 54)	0.351	—
C	Generic QOL—mental (SF12)	500	50 (42, 56)	50 (42, 56)	55 (46, 57)	45 (39, 49)	**0.003**	A:B = 0.1573 **A:C = 0.0067** **B:C = 0.0012**
P	Sleep quality (PSQI)	489	12.0 (9.0, 15.0)	12.0 (10.0, 15.0)	12.0 (9.0, 14.0)	11.0 (8.3, 13.0)	0.119	—
C	Sleep quality (PSQI)	491	9.0 (7.0, 12.0)	9.0 (7.0, 12.0)	9.0 (8.0, 11.0)	9.0 (7.3, 12.0)	0.924	—
P	Self-care maintenance (SCHFI)	500	47 (37, 57)	47 (37, 57)	42 (27, 50)	50 (35, 57)	0.050	—
C	CC to self-care maintenance (CC-SCHFI)	500	53 (40, 63)	53 (40, 63)	50 (36, 63)	47 (27, 63)	0.566	—
P	Self-care management (SCHFI)	350	40 (30, 50)	40 (30, 50)	30 (20, 43)	NA (NA, NA)[d]	**0.010**	—
C	CC to self-care management (CC-SCHFI)	332	50 (35, 60)	50 (35, 60)	NA (NA, NA)	50 (30, 75)	0.915	—
P	Self-care self-efficacy (SCHFI)	499	50 (33, 67)	50 (33, 67)	53 (33, 72)	50 (42, 64)	0.992	—
C	Caregiver self-efficacy (CC-SCHFI)	499	56 (44, 72)	56 (44, 72)	64 (44, 68)	61 (42, 75)	0.776	—

Numbers are presented as mean (and confidence interval). Statistically significant data are reported in bold.
P, tool administered to patients; C, tool administered to caregivers; CCI, Charlson Comorbidity Index; MOCA, Montreal Cognitive Assessment; HFSPS, Heart Failure Somatic Perception Scale; QOL, quality of life; KCCQTS, Kansas City Cardiomyopathy Questionnaire Total Symptoms score; KCCQOS, Kansas City Cardiomyopathy Questionnaire Overall score; CPS, Caregiver Preparedness Scale; MSPSS, Multidimensional Scale of Perceived Social Support; MS, Mutuality scale; HADS, Hospital Anxiety, and Depression Scale; SF-12= Short Form 12; PSQI, Pittsburgh Sleep Quality Index; SCHFI, Self-Care of Heart Failure Index; CC-SCHFI, Caregiver contribution to self-care of HF index; NA, non applicable.
[a]*n* (%); Median (IQR).
[b]Pearson's Chi-squared test; Kruskal–Wallis rank sum test; Fisher's exact test.
[c]Multiple comparisons: the *P*-value of the Dunn *post hoc* test is reported.
[d]NAs are here sometimes reported because the self-care management and the caregiver contribution to self-care management scales were only filled out when the presence of at least one symptom was reported.

quality of life,[3,52] but also that these patients might feel more autonomous, and thus, that their caregivers are included in the HF care at a minor extent. Previous studies also reported that patient quality of life can influence caregiver's management behaviours.[15] In that regard, our results might also suggest that the higher the patient perceives his/her quality of life, the lower the caregiver will perceive the need to engage in illness-management behaviours. Furthermore, our results could suggest that patients in the discordant dyads might experience some symptoms that they can, however, tolerate well and, thus, avoid negatively impacting their quality of life. At the same time, caregivers may notice the presence of such body changes and also that patients do not recognize or engage in managing them, and this can potentially involve some sort of struggle in the caregiver. In fact, caregivers in the discordant dyads in our sample reported lower mental quality of life than those in the concordant dyads, but this only held for discordant dyads where caregivers recognized

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Table 3 Logistic regression model on the membership in the group A (concordant—reference category) or B (discordant—after covariates selection)

Characteristic	N	Estimate	OR[a]	95% CI[a]	P-value
Patient gender (ref.: Male)					
Female		0.73	2.07	0.97; 4.53	0.0625
Caregiver gender (ref.: Male)					
Female		−0.36	0.70	0.34; 1.46	0.333
Patient age		−0.003	1.00	0.96; 1.04	0.863
Caregiver age		−0.004	1.00	0.97; 1.03	0.800
Patient self-care self-efficacy (SCHFI)		−0.01	0.98	0.97; 1.00	0.068
Caregiver self-efficacy (CC-SCHFI)		0.02	1.02	1.00; 1.04	**0.016**
Patient HF physical symptoms (HFSPS)		−0.04	0.96	0.93; 0.98	**0.001**
Patient cognitive level (MOCA)		−0.06	0.94	0.89; 1.00	**0.043**
Caregiver generic QOL—physical (SF12)		0.03	1.03	0.98; 1.08	0.218
Patient generic QOL—mental (SF12)		0.01	1.01	0.97; 1.05	0.604
Caregiver generic QOL—mental (SF12)		0.002	1.00	0.97; 1.04	0.926
Patient NYHA class (ref.: II)					
III		0.001	1.00	0.44; 2.20	0.998
IV		0.87	2.39	0.45; 10.05	0.256
Patient time since HF diagnosis (months)		0.001	1.00	1.00; 1.00	0.672
Patient employment status (ref: Retired)					
Active worker		1.35	3.85	1.36; 11.07	**0.011**
Other		0.83	2.30	0.69; 7.20	0.160
Caregiver employment status (ref.: Retired)					
Active worker		0.17	1.19	0.45; 3.17	0.730
Other		−0.31	0.73	0.27; 1.94	0.533
Patient mutuality (MS)		0.19	1.21	0.62; 2.40	0.571
Caregiver mutuality (MS)		−0.09	0.91	0.48; 1.75	0.785
Patient number of medications		−0.02	0.98	0.88; 1.10	0.779
Caregiver preparedness (CPS)		−0.59	0.55	0.31; 0.97	**0.040**
Caregiver relationship with the patient (ref.: Spouse)					
Other		−1.23	0.29	0.09; 0.89	**0.036**
Son/Daughter		−1.20	0.30	0.10; 0.86	**0.028**
Patient sleep quality		−0.04	0.96	0.86; 1.06	0.432
Caregiver sleep quality		0.06	1.07	0.96; 1.18	0.205
Patient and caregiver cohabitation (ref.: No)					
Yes		−0.49	0.61	0.28; 1.32	0.212

Statistically significant data are reported in bold. McFadden pseudo-R^2: 0.16.
[a]OR, odds ratio; CI, confidence interval.

symptoms and patients did not. This is congruent with previous studies reporting that higher caregiver contribution to patient self-care can negatively impact their quality of life and increase their burden.[18] However, more studies at a dyadic level are needed to better understand these patterns between dyadic symptom recognition and caregiver outcomes.

Caregiver level

We found that higher caregiver self-efficacy in contributing to patient self-care predicted the membership in the discordant dyadic group of symptom recognition: if caregivers are too confident, they may not accurately listen to patients' perceptions of their own body or not accurately observe patients and, instead, they may tend to over or

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underestimate patient symptoms only based on their own perceptions. When caregivers recognize a symptom, it means it has become so visible that they notice it. It might be that when the body change is relatively small, the too-confident caregiver will simply not notice it. In fact, in our analysis, we noticed that in the discordant dyads (specifically in the dyads where patients reported symptoms and caregivers did not), which were indeed characterized by lower patient symptom burden, the median value of caregiver self-care self-efficacy was higher compared to the concordant dyads. On the other hand, one could argue that confident caregivers feel so because they consider themselves very attentive and able to catch the smallest change that even the patient does not recognize. In fact, in our sample, patients in discordant dyads reported the lowest level of symptom burden, indicating that they only experience light symptoms (or symptoms they can tolerate well) that do not particularly burden them. However, their caregivers, who have high self-care self-efficacy, might have noticed even the smallest body change and, thus, reported having detected some symptoms. Caregiver self-efficacy in contributing to patient self-care has been proven to be associated with several positive outcomes, such as lower caregiver burden and depression,[53,54] and higher patient quality of life,[54] but there is scarce evidence on how it is associated with symptom recognition and consequent symptom management. Thus, considering these results, we believe that how caregiver self-efficacy affects symptom recognition and management processes needs further investigation.

Other individual factors within the dyad

We also found that higher symptom burden, higher patient cognitive impairment, patient being retired, caregiver being the daughter/son of the patient, and higher caregiver preparedness predicted the membership in the concordant dyadic group of symptom recognition (where concordant can indicate agreement on the presence or the absence of symptoms). This might be because caregivers who are sons/daughters of the patient are busier in their everyday life[55] and experience more difficulties in caring for their parent[56] that, being older, does not engage very much in self-care and body listening too: all that might eventually lead to concordant dyads where both members do not recognize any symptom, with ultimately higher perceived patient symptom burden. On the other side, a high symptom burden (observed in patients in the concordant dyads) implies that body changes are rather significant to become particularly burdensome and visible, not only to patients but also to their caregivers, and this can make both the members of the dyad concordant on appraising and recognizing them. In our sample, retired patients having a son/daughter as a caregiver were more likely to belong to the concordant dyads group. This might suggest that caregivers who are sons/daughters of the patient are more accurate in recognizing body changes in the parent, thus resulting in being concordant in recognizing emerging symptoms. Indeed, we also found that higher caregiver preparedness predicted membership in the concordant group, and this might similarly suggest an accurate ability of caregivers who are sons/daughters to notice body changes in the patient. Previous studies in other populations (e.g. cancer) found that spouses contributed more to caregiving than adult children and were more prepared.[55,57] However, there is a lack of knowledge in heart failure examining the contribution of caregivers to symptom recognition depending on their relationship to the patient. Thus, exploring caregiving across family relationships might reveal different processes and consequences of caregiving, which might be experienced differently depending on whether the caregiver is a spouse or an adult child.[58]

Ultimate relevance of dyadic appraisal of symptoms

Overall, these results are important because they further explain how both members of the dyad in heart failure recognize symptoms. If patients and caregivers recognize symptoms in a similar way, this might increase the validity of this subjective measurement and indicate coherence between the two members in their approach toward symptom recognition. Instead, if patients and caregivers recognize symptoms differently (e.g. one reports some symptoms while the other does not), this indicates a misalignment. Such misalignment could be due to over or underestimation of body changes because of, for example, interoceptive impairments, degree of preparedness in contributing to self-care, presence of anxiety or depression, or potential cognitive impairment. Ultimately, this could lead to different extents of contribution to self-care behaviours by patients and caregivers. Thus, the results of this study can aid in better characterizing dyadic behaviors towards symptom recognition, better understanding how to address symptom recognition at a patient, caregiver, and dyadic level, and eventually supporting the implementation of tailored strategies for symptom management.

Strengths and limitations

This study has some limitations. First, it is a secondary analysis of a mono-country study. Second, we relied on one item only to explore a complex phenomenon like symptom recognition. However, this item belongs to an instrument thoroughly tested for validity and reliability.[26,59] However, our sample size was rather large, and the dyads were recruited from different settings, facilitating the generalization of the results. Furthermore, considering the paucity of evidence on dyadic symptom recognition in heart failure, this study may represent an attempt to expand the knowledge in such an area and a spark for future studies.

Conclusion

Concordant dyadic symptom-recognition behaviors were the most prevalent in our sample. Sociodemographic and clinical variables in caregivers (i.e. self-care self-efficacy, being daughter/son of the patient) and patients (i.e. symptom burden, cognitive impairment, being retired) differently predicted dyadic symptom recognition. These results can help to further characterize dyads' attitudes toward symptom recognition, to better understand how to address symptom recognition and awareness of body changes at both a patient, caregiver, and dyadic level, and ultimately to facilitate personalized symptom management strategies. However, it would be relevant if future studies further investigate dyadic patterns related to symptom recognition: a better understanding of what dyadic variables affect symptom recognition and which are the outcomes of such processes could help design tailored symptom management strategies and improve dyadic outcomes.

Author contributions

Giulia Locatelli (Conceptualization, Methodology, Data curation, Writing—original draft, Writing—review & editing, Visualization, Supervision, Project administration), Diletta Fabrizi (Conceptualization, Methodology, Formal analysis, Data curation, Writing—original draft, Visualization), Davide Ausili (Conceptualization, Methodology, Writing—review & editing, Supervision), and Ercole Vellone (Conceptualization, Methodology, Resources, Writing—review & editing, Supervision)

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Data availability

Relevant data are presented in the manuscript and in the tables. Additional data might be requested by contacting the corresponding author.

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