

ORIGINAL STUDY



Patients with Heart Failure: the role of caregivers in self-care management

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Abstract - Informal carers of decompensated heart failure (DHF) patients play an important role in contributing to the self-care of their loved ones. Their contribution to self-care, in its three dimensions of maintenance, monitoring and management, is now recognised as a dyadic phenomenon in that it is mutually influenced by the carer and the patient. Consequently, support from a person close to the patient, such as an informal carer, can provide the so-called caregiver contribution to symptom management and improve patient outcomes and disease-related risks. The aim of this study is to investigate the caregiver contribution to self-care management in a sample of caregivers of patients with DHF in three central-south Italian provinces. The research is qualitative-descriptive and a deductive method will be used for content analysis obtained through semi-structured interviews using the CC-SCHFI 2 (Caregiver Contribution to Self-care of Heart Failure Index 2) and the CC-EHFSCB (Caregiver Contribution European Heart Failure Self-care Behaviour Scale). The caregivers identified for the study have a mean age of 53.45 years (SD 11.85), are predominantly female (77.27%) and married (22.72%). In general, the carer is their child (63.63%) who cares for the person for an average of 9.32 hours per day (range 2-24 hours/day). The patients cared for by caregivers are ambisexual (males= 45.45%; females= 54.54%) with a mean age of 78.2 years (SD 13.46) and mostly in NYHA class II (45.45%) and NYHA III (31.81%). Caregivers, even when not trained by experienced staff, can recognise DHF flares and often use non-evidence-based practices with risks for the patient. Healthcare professionals should therefore plan educational interventions and future research should investigate the relationship between the caregiver-patient dyad and DHF.

Key words: Self-care management, Caregivers, Decompensated Heart Failure, CC-SCHFI 2.

Key messages:

- Health education in caregivers would improve the management of decompensated heart failure symptoms.
- The implementation of andragogical courses can enhance appropriate self-care management actions, aimed at reducing hospitalisations, mortality, improving the quality of life of both patients and caregivers

Introduction

Informal caregivers are the people who, within or outside the family, provide most of the informal care for a person suffering from decompensated heart failure or another chronic degenerative disease (1). Furthermore, according to scientific literature, they are defined as "any person who, without being a professional or belonging to a social support network, regularly lives with the patient and, in some way, is directly involved in the patient's care or affected by the patient's health problem" (2).

Family care is a growing phenomenon in countries all over the world as the prevalence of chronic diseases and the frequency of shorter hospital stays increase (3). Informal support networks in Italy play a relevant role since the welfare model in our country continues to rely on the family, and in particular on women, to provide support to the most vulnerable (persons with disabilities, unemployed, elderly, children) (4).

Women are more involved in informal help networks than men are, and have great difficulty reconciling their role as caregivers with work (5).

The type of care provided by informal caregivers varies and has traditionally been divided into two categories: activi-

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ties of daily living (ADLs) and instrumental activities of daily living (IADLs). The former mainly refers to personal care or self-care activities such as bathing, washing, dressing, eating, etc. The latter, on the other hand, includes practical tasks, which may be considered non-vital, but enable people to live independently (6). This includes assisting with household chores, preparing meals and shopping.

In the context of chronic degenerative diseases, the duration of informal care often extends over years, starting with the diagnosis of the disease and continuing with treatment, until the death of the patient (7).

The role of the caregiver of persons with severe DHF includes managing drug therapy, daily weight monitoring, enforcing dietary requirements such as limiting salt intake and encouraging patient participation in physical activity (8). These tasks are both emotionally and physically intensive, creating a situation in which caregiver burden is common, where *burden* has been defined as the distress that informal caregivers experience as a result of providing care and is influenced by the characteristics of the patient, the individual caregiver and the environment (9).

Indeed, the caregiver's lifestyle is sometimes described as a constant state of anxiety caused by the need to closely monitor the patient for signs and symptoms of DHF, even during periods of disease stability (10). Since caregivers play a pivotal caring role, it is important to support their needs in health promotion and symptom management of people with advanced DHF (11). When caregivers' needs are not met, they are at increased risk of detrimental mental and physical health outcomes, creating a situation in which they find it difficult to fulfil their vital role (12).

Despite evidence supporting the benefits of carer input for DHF (13), some carers find it difficult to perform and it is often insufficient (14) (15) (16). Effective interventions require a supportive relationship, an individualised approach, efforts to promote self-efficacy, practical information on how to perform self-care and external support (e.g. informal caregivers) (17).

Various research shows that informal carers continue to have high and unmet needs for information and experience distress and anxiety due to poor communication with family, friends and health professionals (18).

Caregivers report a desire and need for understanding and support from family members (19), but communication difficulties occur, also because of previous conflicts (20). Thus, patient and caregiver disagreement about family involvement in health information and decisionmaking is associated with dysfunctional family communication (21).

Several factors have been theorised and/or demonstrated to influence how dyads cope with illness (22). These include demographic data such as age and gender (23); disease severity and symptoms (24); functional class and comorbid conditions (25); affective symptoms (26); patient introversion (e.g. when hiding worries) (27); care-related strain (28) and relational factors such as the quality of the relationship (29).

Given all these problems, the caregiver's contribution to self-care could play an important role in tackling DHF (30) (31).

Purpose

The aim of the study was to investigate the caregiver's contribution to self-care management by using the CC-SCHFI 2 scale, as an interview matrix, and CC-EHFSCB and assessing how this contribution can lead to a more careful and earlier recognition of symptoms with a subsequent improvement in disease management.

Materials and Methods

The study was performed using a qualitative-descriptive research design, with semi-structured interviews in which the questions were based on the items concerning self-care management of the CC-SCHFI 2 (Caregiver Contribution to self-care of heart failure index 2) and CC-EHFSCB (Caregiver contribution European Heart Failure Self-care Behaviour Scale) questionnaires. Convenience sampling was used to recruit participants (32). The inclusion criteria for enrolling caregivers in the study were:

- 1 Being an informal caregiver of a person diagnosed with DHF according to the guidelines of the European Society of Cardiology (33) for at least six months and classified according to the New York Heart Association (NYHA) scale;
- 2 Age > 18;
- 3 Self- and spatial-temporal orientation;
- 4 Consent to the study.

Twenty-two caregivers were enrolled in three different provinces in centralsouthern Italy (Salerno, Viterbo and Foggia) between August 2020 and February 2021.

Caregivers and patients were again informed about the purpose of the study and informed consent was obtained. Nine face-to-face interviews were then carried out and the remainder via VoIP system due to the limitations imposed by measures to contain the spread of infection caused by the SARS-CoV-2 virus



(34).

A content analysis was carried out using the methodology proposed by Mayring. The chosen analysis methodology, 'Structuring', was deductive, it involves establishing a structured system in defined categories based on theoretical constructs. The theoretical reference for the study was the Middle-range theory (35). This theory defines self-care in chronic diseases as the set of those behaviours that help to keep the disease stable (self-care maintenance), to monitor signs and symptoms (self-care monitoring) and to respond to signs and symptoms when they occur (self-care management) (36). The criteria of Lincoln & Guba (1986) (37) were used to ensure reliability of the results.

For the interviews, a content analysis was carried out using the methodology proposed by Marying. The chosen analysis methodology, 'Structuring', was deductive, it involves establishing a structured system in defined categories from theoretical constructs. The Atlas.ti software was used to analyse the interviews. The central tendency indices (mean, median and standard deviation) were analysed using SPSS v 21 software. It should be noted that the study was approved by the Lazio 2 Ethics Committee and was conducted in accordance with the principles of the Declaration of Helsinki and in compliance with current regulations on clinical trials. All data collected and analysed were processed in accordance with Legislative Decree no. 196/2023 and in compliance with the General Data Protection Regula-(European Regulation tion no. 679/2016)

Results

The mean age of the sample of caregivers

interviewed is 53.45 years (SD 11.85). The majority of the participants enrolled in the study were female (77.27%), married (22.72%) and stated that they lived with the patient (59.09%). The caregiver in most cases was their child (63.63%) and cared for the person for an average of 9.32 hours per day (range 2-24 hours/day). The most common educational qualification among the caregivers is the high school diploma (31.81%) and those engaged in a job equal the remaining part represented by the unemployed, pensioners and a housewife. (Tab. 1), (Tab. 2)

Tab. 1 - Social demographic of caregiver (n=22).

Among the caregivers enrolled, about one third have no children while the remainder have more than one child. The patients cared for by caregivers are of both sexes with a mean age of 78.22 years (SD 13.46). The aetiology of decompensated heart failure in most cases is of ischaemic origin (45.45%) and the patients belong mainly NYHA class II (45.45%) and NYHA class III (31.81%). The main comorbidities found in the patients using the integrated Charlson Comorbidity index are arterial hyperten-(77.27%), atrial fibrillation sion (68.18%), previous myocardial infarc-

AGE	Mean 53,45	(SD) (±11.85)		
SEX	N	(%)		
Man	5	(22.72)		
Woman	17	(77.27)		
GRADUATION				
Elementary School	3	(13.63)		
Middle School	6	(27.27)		
High School	7	(31.81)		
Professional	2	(9.09)		
Bacherol	4	(18.18)		
RELATIONSHIP				
Spouse	5	(22.72)		
Son/Daughter	14	(63.63)		
Daughter-in-law and son-in-law	1	(4.54)		
Nephew	1	(4.54)		
Other	1	(4.54)		
LIVING WITH PATIENT				
yes	13	(59.09)		
no	9	(40.90)		
JOB				
Freelance	2	(9.09)		
Employee	8	(36.36)		
Retired	3	(13.63)		
Other	5	(22.72)		
Unemployed	4	(18.18)		
SONS				
NO	6	(27.27)		
Just one	1	(4.54)		
More then one	15	(68.18)		
CARGIVING PER DAY	Mean 9.32	(SD) (±8.00)		



Tab. 2 - Social demographic of patient (n= 22).

AGE	Mean 78.22	(SD) (13.46)				
SEX	Ν	(%)				
Man	10	(45.45)				
Women	12	(54.54)				
STATUS						
Marriage	16	(72.72)				
Widower	6	(27.27)				
GRADUATION						
Elementary School	15	(68.18)				
Middle School	4	(18.18)				
High School	1	(4.54)				
Professional	1	(4.54)				
Illiterate	1	(4.54)				

Out of 22 interviews with the CGs, only in two cases the value of the sub-code was not counted, as it was not present. In the remaining 20 interviews, the CGs relied on the GP when they were not able to manage the presence of the exacerbations on their own; when their contribution was not sufficient to counteract the exacerbation of decompensated heart failure; or when it was necessary to perform an extra therapy, which was not present in the treatment plan. Following the first coding round where a verbal

tion (45.45%), COPD (40.90%), diabetes without complications (36.38%), anaemia (27.27%), peripheral vascular disease (31.81%). In a smaller number of cases, sleep apnoea (9.09%), hemiplegia (4.54%), chronic hepatitis (4.54%), kidney disease (9.09%) and connective tissue disease (9.09%) are present. *(Tab. 3)*

A first round coding (step 6 of Mayring's method) was carried out by extracting the assignments for sub-codes, previously defined with inclusion and exclusion criteria, and the corresponding calculation of the frequencies found in the interviews. We then moved on to step 7 of Mayring's method, where a second round coding was carried out following an analysis on the magnitude, i.e. the degree of contribution of the CG for the relevant sub-codes. Tab. 4 demonstrates the results obtained from the interviews conducted by extracting the number of times a certain aspect of care was expressed by the caregiver.

As can be seen from the calculation of total frequencies, the most frequently represented contribution was that of the sub-code 'Calling the doctor/nurse for symptom management', with a total frequency of 56 and an average of 2.54 per CG.

Tab. 3 - Clinical data patient (n=22)

Ischemic 10	(45.45)
Not ischomic 9	
NUC ISCHEIMIC 0	(36.36)
Idiopathic 2	(9.09)
Other 2	(9.09)
NYHA CLASS	
I 3	(13.63)
II 10	(45.45)
III 7	(31.81)
IV 2	(9.09)
COMORBILITY	
Hypertension 17	(77.27)
Atrial fibrillation 15	(68.18)
Previous myocardial infarction 10	(45.45)
COPD 9	(40.90)
Diabetes without complications 8	(36.38)
Peripheral vascular diseases 7	(31.81)
Anemia 6	(27.27)
Minor cerebrovascular disease without permanent damage 4	(18.18)
Sleep apnea 2	(9.09)
Kidney disease 2	(9.09)
Connective tissue diseases 2	(9.09)
Cancer without metastasis 2	(9.09)
Diabetes with complications 1	(4.54)
Hemiplegia/paraplegia 1	(4.54)
Peptic ulcer 1	(4.54)
Chronic hepatitis without portal hypertension and without esophageal variceal bleeding	(4.54)
PATIENT WITH HEART DEVICE	
No devices implanted 15	(68.18)
Defibrillator 4	(18.18)
Dual chamber pacemaker 3	(13.63)



Tab. 4 - Clinical aspects of caregiving.

	Average	Mean CG
Call your doctor/nurse for symptom management	56	2.54
Management of exacerbation and emotional impact on the caregiver	28	1.27
Request assistance from the health service	27	1.22
Limit physical activity if you have symptoms	24	1.09
Knowing how to manage flare-ups of heart failure	23	1.04
Reinforcement of dietary restrictions in relation to liquid intake	18	0.81
Administration of extra therapy	16	0.72
Reinforcement of dietary restrictions regarding salt in the diet	15	0.68
Seek advice from family or friends for managing symptoms	13	0.59

exchange was used to decode the text, a second coding round was carried out to qualitatively investigate the degree of the caregiver's contribution.

Magnitude coding (38) was used to assign a score ranging from M3 (highest degree of CG contribution) to M1 (low degree of CG contribution). The degree of CG contribution was then indicated in the interviews and it was seen that, due to the narrative and discursive character of the interviews, there were different degrees of magnitude for the same item. The results obtained are presented in Tab. 5.

As the calculation of the total frequency shows, 90.09% of the caregivers implemented the practice of calling the doctor/nurse when the symptomatic picture of decompensated heart failure was worsening. Only two CGs did not implement this activity. (68.18% of the CGs put in place a low contribution, 59.09% a medium contribution and 22.73% a high contribution). Going in descending order of frequencies we have 'Relapse management and emotional impact on the caregiver', where 86 36% of th cope mem Some

relaj of the CGs implemented this strategy to cope with the care of their family (M1 member (M1, 6; M2, 13; M3, 9). Some 22.73% of the CGs made a low Tab. 5 - Scores of Magnitude Coding Analisys.	pses' we had a , 4; M2, 6; M3, contribution, cribution and 4	total fr 13). 13 18.18 5.45%	requenc 3.64% 1 % a m a high	y of 23 made a nedium contri-
	Average	M1	M2	М3
Call your doctor/nurse for symptom management	56	34	16	6
Management of exacerbation and emotional impact on the caregiver	28	6	13	9
Request assistance from the health service	27	10	13	4
Limit physical activity if you have symptoms	24	10	9	5
Knowing how to manage flare-ups of heart failure	23	4	6	13
Reinforcement of dietary restrictions in relation to liquid intake	18	5	3	10
Administration of extra therapy	16	13	1	2
Reinforcement of dietary restrictions regarding salt in the diet	15	8	4	3
Seek advice from family or friends for managing symptoms	13	4	5	4

contribution, 50% a medium contribution and 36.36% a high contribution. 81.81% of the CGs restricted physical activity in the presence of symptoms (frequency 24): the most frequent contribution was low grade 10 (M1), medium grade 9 (M2) and high grade 5 (M3). 40.91% made a low contribution, 40.9% a medium contribution and 22.73% a high contribution). 72.72% of the CGs required assistance from the health service (frequency 27; M1, 10; M2, 13; M3, 4). 27.27% made a low contribution, 40.91% a medium contribution and 18.18% a high contribution.

The percentage of the sub-code 'Knowing how to manage decompensation flareups' (68.18%) was the same as that for 'Reinforcing dietary restrictions in relation to fluid intake' and 'Administering extra therapy'. In the sub-code 'Knowing how to manage decompensation



bution.

In 'Reinforcing dietary restrictions in relation to liquid intake' we had a frequency of 18 (M1, 5; M2, 3; M3, 10). 22.73% made a low contribution, 13.64% a medium contribution and 40.91% a high contribution).

In the sub-code 'Extra therapy administration' we had a frequency of 16 (M1, 13; M2, 1; M3, 2). 54.55% made a low contribution, 4.55% a medium contribution and 9.09% a high contribution. 59.09% of the CGs contributed to the sub-code 'Reinforcement of dietary restrictions regarding salt in the diet' with a total frequency of 15 (M1, 8; M2, 4; M3, 3). Some 36.36% had a low contribution, 18.18% a medium contribution and 13.64% a high contribution.

Analysing the data offered by the NYHA classes, it can be stated that the highest (III-IV) were diagnosed in patients with an average age of over 80 years (mean 81.33; SD 6.98) and the hours of care provided by caregivers averaged 14.11 (SD 9.52).

Spouses taking on the role of informal carers in this sample are 22.72%, providing care for an average of 5.8 hours (SD 3.03) while caring for patients with an average age of 64 years (SD 13.09). The children, who turn out to be the majority of the sample of caregivers (N 14), report providing on average 9.78 hours of care (SD 9.49). (*Tab. 6*)

Discussion

The aim of this study was to investigate the contribution of informal caregivers to self-care management in decompensated heart failure patients. As caregivers play a key role in improving the outcomes of decompensated heart failure patients (39), it is important to know the specific practices performed and how they

CAREGIVER	AGE	SEX	TYPEOF RELATIONS HIP	CARGIVING (HOURS perday)	PATIENT	AGE'	SEX	NYHA CLASS
CG_01_AT	30	М	Others	5	PZ_01_AT	58	F	Ι
CG_02_AT	30	F	Son/ daughter	2	PZ_02_AT	61	М	II
CG_03_AT	64	F	Spouse	4	PZ_03_AT	64	М	II
CG_04_AT	45	F	Son/ daughter	6	PZ_04_AT	88	F	IV
CG_05_AT	48	F	Son/ daughter	2	PZ_05_AT	95	F	II
CG_01_MP	68	F	Spouse	4	PZ_01_MP	71	М	III
CG_02_MP	42	М	Spouse	3	PZ_02_MP	43	F	Ι
CG_03_MP	68	М	Spouse	10	PZ_03_MP	64	F	II
CG_04_MP	57	F	Son/ daughter	2	PZ_04_MP	87	М	Ι
CG_05_MP	78	F	Spouse	8	PZ_05_MP	78	М	II
CG_06_MP	57	F	Son/ daughter	3	PZ_06_MP	86	М	II
CG_01_LA	42	М	Son/ daughter	24	PZ_01_LA	75	F	III
CG_02_LA	58	F	Son-in- law/ Daughter- in-law	24	PZ_02_LA	84	F	IV
CG_03_LA	64	F	Son/ daughter	24	PZ_03_LA	99	F	II
CG_04_LA	60	М	Son/ daughter	3	PZ_04_LA	85	М	II
CG_05_LA	59	F	Son/ daughter	24	PZ_05_LA	89	М	III
CG_06_LA	57	F	Son/ daughter	24	PZ_06_LA	87	F	III
CG_07_LA	48	F	Son/ daughter	6	PZ_07_LA	76	М	III
CG_08_LA	49	F	Nephew	10	PZ_08_LA	87	F	III
CG_09_LA	46	F	Son/ daughter	8	PZ_09_LA	83	F	II
CG_10_LA	53	F	Son/ daughter	5	PZ_10_LA	75	F	III
CG_11_LA	53	F	Son/ daughter	4	PZ_11_LA	86	М	II
MEDIA (DS)	53,45 (±11.85)			9.32 (±8.00)		78.22 (13.46)		

contribute to self-care. There is an urgent need to design culturally competent interventions that include patients and caregivers; such interventions are still rare in this region of the world (40). With regard to the caregiver's contribution to self-care management, almost all caregivers were able to recognise the symptoms of decompensated heart failure, but their practices towards these symptoms were not all correct and in some cases could even be dangerous for the patients. In fact, most caregivers were able to recognise the signs and symptoms of decompensated heart failure, but not all of them were able to manage the exacerbation of heart failure, perhaps by administering an extra diuretic. This shows what has been reported in the literature, i.e. that caregivers are afraid of taking on this "medical responsibility" and had low levels of confidence in the practice of self-care management, probably because they were not familiar with this strategy (40). This was demonstrated in the analvsis of the sub-codes in which the administration of an extra drug was implemented for the majority of caregivers to cope with the symptoms of decompensated heart failure. On the other hand, only a very small proportion administered extra therapy independently without notifying the GP. As far as symptom management is concerned, the caregivers are fairly well trained to deal with exacerbations of decompensation, although the study showed a high proportion of CGs who called the doctor/nurse by telephone as support not to make any mistakes as this was often related to a well-founded fear. In line with the literature (41) this study shows how the carer's contribution to self-care consisted of encouraging medication adherence, monitoring symptoms, arranging appointments, stimulating independence and taking action. This point to the importance of studying the practices of caregivers of decompensated heart failure patients at the population or country level, especially given the differences in health care systems and cultures.

It would be desirable for health care professionals or general practitioners to provide caregivers with adequate training to ensure proper management of signs and symptoms (42), reducing the burden (43), and thus responding adequately to self-care needs.

Limits of the study

The sample for this study is one of convenience. A population in the centre-south of Italy was identified that had the same criteria of accessibility to services. If we were to consider populations in Northern Italy or populations in which there is a different education and attention towards caregivers in the "discharge pathway", we would have likely obtained non-homogeneous data. Moreover, most of the interviews were conducted by telephone because of the COVID-19 pandemic.

Conclusions

As this study was conducted in centralsouthern Italy, practices related to the caregiver's contribution to self-care management could be used to implement sensitive interventions for caregivers living in this socio-cultural context. This would leverage prior knowledge to implement and ragogical didactics (44) in order to enhance appropriate self-care management actions, aimed at reducing hospitalisations, mortality, and improving the quality of life of both patients and caregivers, who are engaged in a care process with many complications.

Unfortunately, caregiver preparation has received little attention in decompensated heart failure. As suggested in the study by Vellone and colleagues (45), improving the preparation of caregivers would result in good management of decompensated heart failure symptoms and consequently in increased confidence. This could be a useful tool to be implemented through new professional figures that are being formed right now, such as the family nurse. Thanks to this new figure, the contribution of the CG could be enhanced in such a way as to reduce the demand for support to healthcare facilities and thus have greater autonomous management of decompensated heart failure.

Disclosures:

The Author declares that he has no relationships relevant to the contents of this paper to disclose.

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