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**ORIGINAL RESEARCH:  
EMPIRICAL RESEARCH - MIXED METHODS**

# Needs and problems related to sociodemographic factors of informal caregiving of people with heart failure: A mixed methods study in three European countries

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**Abstract**

**Aims:** To explore caregivers' needs and problems in three European countries and associate the clusters of caregivers' needs with their sociodemographic characteristics.

**Design:** A qualitative focused mixed methods design was used.

**Methods:** In total, 52 caregivers of heart failure (HF) people were interviewed in three European countries between March 2017 and December 2018. Transcripts were analysed using the seven-phase method of the exploratory multidimensional analysis according to Fraire with Reinert lexical classes findings were organized in dendrograms. Mayring's content analysis was also performed.

**Results:** Three clusters of caregivers were identified: spouses, adult children and non-family members. Caregivers not only provide HF patients with vital unpaid support for their physical and emotional needs, but they are continually trying to cope with their social isolation and deteriorating health.

**Conclusions:** Informal caregiving emerged as a complex process influenced by various sociodemographic factors. Gender, relationship type and economic status are the important factors to be considered planning to develop approaches to address the needs of caregivers serving people with heart failure.

**Impact:** A comprehensive understanding of the nature of informal caregiving of individuals with heart failure, the complexity of the real-world sociodemographic and cultural factors is warranted. The use of the EMDA method gave us the possibility of processing large masses of qualitative data through rapid, complex calculations. In detail, AATD allowed us to study in deep the significant fuzziness of what caregivers expressed and to analyse the content of the entire interviews and to produce global knowledge by using multi-dimensional statistical methods to grasp the fundamental sense of the interviews, beyond the simple words.

Institutions where the work was performed: University of Rome "Tor Vergata", Rome, Italy; Hospital Lozano Blesa, Zaragoza, Spain and Maastricht University Medical Center, MUMC, Patiënt & Zorg, Maastricht, The Netherlands.

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Three clusters were identified in the samples, including spouses, adult children and non-family members. This study demonstrated that some sociodemographic characteristics could lead to everyday needs. Therefore, these demographic characteristics should be considered in developing targeted interventions. The research was conducted in Europe, but the technique shown can be replicated everywhere. The findings not only impact nursing but can be extended to all those stakeholders who concur with a public health educational mission.

**Patient or Public Contribution:** Carers were involved in this study after the discharge of their loved ones or at the time of the outpatient visit. They were involved after they had been observed in their dynamics of involvement in caring of the familiars or friends with heart failure.

#### KEYWORDS

caregiving, chronic illness, cross-cultural, family care, heart failure, nursing, public health nursing, sociodemographic characteristics

## 1 | INTRODUCTION

Heart failure (HF) is considered a highly prevalent disease, with prevalence rates between 0.5% and 2% in the general population (Savarese & Lund, 2017). The incidence of HF is increasing quickly, mainly because of the ageing population, and the number of people with HF between 2012 and 2030 is predicted to increase from 25% to 46% (Gerber et al., 2015). HF is often associated with poor quality of life (QOL) (Nieminen et al., 2015), and with physical and psychological symptoms and burdens that are comparable to cancer (Bekelman et al., 2009). People affected by HF require a high level of care and should undertake self-care behaviours to avoid the disease worsening. Worsening HF is burdensome for patients (Gallacher et al., 2011) and caregivers who make an important contribution to the care of their relatives (Bidwell et al., 2018). Nevertheless, sociodemographic factors (social, cultural, economic and demographic features) can impact the caregiving process (Grant & Graven, 2018).

An informal caregiver is an unpaid individual, either inside or outside the family, who provides most of the care for a patient (Hounsell et al., 2014). This care can include assistance with personal needs, household chores, personal finance management, arrangements for outside services, or regular visits to the care receiver. Being an informal caregiver of an individual with HF is complex and stressful, and this may have a profound effect on the lives of both patient and caregiver (Grant & Graven, 2018). The way that dyads appraise illness as a unit affects the ways in which they engage in behaviours to manage the full course of illness together (Lyons & Lee, 2018).

## 2 | BACKGROUND

Caregivers are a key resource for people with heart failure, monitoring the health status of their loved ones, assisting them in their daily care and providing emotional support. Grant and Graven (2018)

outlined that caregivers normally face four key problems when providing care: (a) performing multifaceted activities and roles that revolve around daily heart failure demands, (b) maintaining physical, emotional, social, spiritual and financial well-being, (c) receiving insufficient caregiver support and (d) performing caregiving with uncertainty and inadequate knowledge (Grant & Graven, 2018). Although all these findings are important, the authors concluded that knowledge of caregiver needs (physical, psychological, social, economic and environmental) is still minimal; even if it is well known how much important listen to families' stories of illness to become aware of what believes can support and encourage family wellness and recovery (Årestedt et al., 2015).

Caregiver stress can lead to multiple adverse outcomes, including a decline in physical health, increased mental health concerns and decreased quality of life. Caregiver stress also leads to increased financial costs to the person, family and healthcare systems, making it a public health issue (Broxson & Feliciano, 2020). A recent meta-ethnographic review (Kim et al., 2020) included 12 qualitative studies and identified three major themes: 'shouldering the entire burden', 'starting a new life' and 'balancing caregiving and everyday life'. These three themes illustrate how family caregivers fulfil caregiving roles, what helped them juggle their multiple responsibilities and how they struck a balance between life as a caregiver and as an individual. This review explains how family caregivers need timely counselling and adequate coping strategies and that their needs require regular assessment.

Caregivers who experienced burden spent a considerable amount of time providing daily support to patients with HF, with disruption to daily life, work productivity and experience of stress, consequentially increasing anxiety and depression and reduced HRQoL (Lahoz et al., 2021). We already know that patient's disease severity is not the primary issue related to caregiver burden. A previous study in HF showed that caregiver characteristics predict a higher total caregiver burden score. The specific caregiver burden

dimensions were: caregivers' older age and female gender, hours of caregiving provided per day and social support. Older caregivers' age was associated with higher time-dependence, physical, social and the total burden; female caregiver gender was associated with only higher time-dependence burden; more time spent in caregiving was associated with a lower social and emotional burden and finally, higher social support was associated with a lower social burden (Durante et al., 2019).

Beyond sociodemographic characteristics, we know that culture is a factor that influences the caregivers' experience (Grant & Graven, 2018; Vellone et al., 2021). Despite this, research on caregiving is still necessary to help healthcare professionals fully understand the relationship between demographic variables and caregiver needs and problems. The health of both members of the dyad is assumed to co-vary inherently (Lyons & Lee, 2018). To obtain better outcomes for caregivers and prevent burdensome situations, it is crucial to understand these relationships so that healthcare professionals can access personalized interventions rather than a one-size-fits-all program (Bos-Touwen et al., 2015).

### 3 | AIMS

The aim of this study was twofold: (a) to explore the needs and problems of caregivers for patients with HF (qualitative) and (b) to link clusters of caregiver needs with their sociodemographic characteristics (quantitative). The mixed methods purpose was to develop a comprehensive understanding and cluster the needs and problems of informal caregivers regarding their sociodemographic characteristics.

## 4 | METHODS

### 4.1 | Design

Both quantitative (QUAN) and qualitative (QUAL), research approaches were used, (Creswell & Plano Clark, 2018). The quantitative approach was based on computer-analysed statistics as represented by the Automatic Analysis of Textual Data (AATD) approach, which extracted the underlying real-world lexical corpora that are constituted of entire documents (e.g., interviews, monologues, debates) (Piervisani et al., 2021). This approach was chosen to deeply capture the richness of the language, specific to each country, as a cultural component.

AATD allowed us to study in deep the significant fuzziness of what caregivers expressed and analyse the content of a 'context unit' (entire interviews) and produce global knowledge by using multi-dimensional statistical methods (e.g., cluster analysis of what caregivers said) to grasp the fundamental sense of the interviews, beyond the simple words. A descriptive qualitative approach driven the interpretation of the whole cluster by conducting a content analysis according to Mayring (2014).

### 4.2 | Sampling and settings

A convenience sampling approach was used to enrol HF caregivers from Italy, Spain and the Netherlands between March 2017 and December 2018. A minimum of 10 caregivers from each country were invited to participate, and then recruitment continued until data saturation was achieved (i.e., the point at which no new relevant information tends to be forthcoming, even if more people are interviewed). Caregivers were recruited at the hospital when the patient was discharged or while they were with the patient at the outpatient follow-up visit. This allowed us to collect the experience of caregivers both in the acute phase in the hospital and in the daily management of the disease through outpatient follow-ups. Qualitative enrolling was suspended until reaching data saturation. The interviews were stopped when the argument became redundant and repetitive according to categories extracted from the theory of Vellone et al. 'A Situation-Specific Theory of Caregiver Contributions to Heart Failure Self-care' (Vellone et al., 2019).

All caregivers of persons diagnosed with HF were enrolled. Still, those who were minors, unable to provide written consent, or had an illness that significantly affected their cognitive capacity and independent decision-making (e.g., dementia, Alzheimer's, psychiatric disorders, etc.) were excluded. Caregivers were enrolled from different settings, hospitals or outpatient clinics, according to the local ethical committee authorization received. Before the inclusion, the researcher who had to conduct the interview explained the research goals.

### 4.3 | Data collection

The data were collected through individual semi-structured interviews, audio-recorded and stored on a digital device. The interview guide contained 21 open-ended questions that were constructed based on previous literature (Grant & Graven, 2018), and the professional experience of the researchers involved (Durante et al., 2019). The guide was used to support the interviewers, researchers trained by the principal investigator, all with the nursing background, during the participant's storytelling. The first questions were designed to allow the caregivers to range in their answers and start talking about their experiences in a general way. For example, we asked, "*Can you tell me about the effects of caregiving on your life?*". Subsequently, the questions were more specific and aimed to explore problems they might have related to their experience. For example: "*Do you experience any problems in the care for... and what kind of problems are they?*". Finally, we introduced an open-ended question "*Do you have anything else you would tell me about your experience as a caregiver?*" to allow us to talk about their experience freely beyond subject previously requested.

Each country test in on two people before using it (not included in the study). The core of the guide was used to inquire about the caregivers' experiences from the physical, psychological and social points of view (Appendix S1). Caregivers were interviewed

face-to-face in their preferred location (e.g., their homes). During the interviews, a narrative approach was adopted to gain deeper insights into the caregivers' experiences. The interviewer's welcoming behaviour encouraged the respondents to share their experiences spontaneously using an inductive process, characterized by probing questions and reflections on the participant's lived experiences. The GRAMMS criteria for reporting mixed methods studies in health services research (GRAMMS) checklist were used for complete reporting (O'Cathain et al., 2008).

#### 4.4 | Ethical considerations

This study complied with the Declaration of Helsinki. The ethics committee of each centre approved the research protocol, and both patients and caregivers signed the informed consent forms before data collection. Participation in this study was voluntary and unpaid, and the participants had the right to withdraw from the study at any time they wished without any consequences. The collection, analysis and storage of all the data complied with international ethical and scientific quality standards (ICH, 1996; D. Min Salute 14/7/97), and European data regulations (UE, 2016/679). Data sets were stored in a secure archive of the participating universities. The Excel data sets, linking the study identification code number to the patients' identities, were encrypted and stored by the principal investigator.

#### 4.5 | Data analysis

All interviews were recorded in their original languages to preserve and analyse the typical expressions of the three different context languages (Italian, Spanish and Dutch).

All interviews were transcribed verbatim before data analysis into the original language and checked for accuracy. Interviews were not translated but coded into English by a team member, one from each country, who had an adequate background in English of at least level B2. In addition to the interviews, the researchers used a brief questionnaire to collect the participant's sociodemographic data and patients' clinical characteristics, abstracted from their medical records. In each of the three countries, the interviews were conducted in the participant's native language by three trained Ph.D. students, one per country involved. No drop-out was reported. Codes, sub-categories and categories were developed in English. Interviews and field notes were analysed by two independent researchers (AD and AC). The outcome of the analysis is given by themes describing the phenomenon (Elo & Kyngäs, 2008).

We analysed quantitative data (e.g., participant age) using descriptive statistics such as mean and standard deviation, or median and interquartile range. To ensure quantitative saturation, a preliminary analysis of lexical balance was undertaken to verify the consistency of text and its statistics reliability as Bolasco criteria (Bolasco, 2012). The three text corpora, one for each country were

considered stable and consistent because they reached a minimum of 25,000 occurrences, the limit minimum which allows the analysis (Bolasco, 2012). Transcripts were analysed in original language except for the Dutch interviews translated in English for a limit of the IraMuTeQ 'dictionary'.

The transcripts were analysed using the seven-phase method of the exploratory multidimensional analysis (EMDA) described by (Fraire, 2009) to organize the findings in dendrograms. The data analysis employed was from previous healthcare and social sciences (Piervisani et al., 2021; Robieux et al., 2018). These analyses, known as lexicometry, are statistical analyses based on vocabulary which reorganize words as data to summarize them and make them meaningful. Analyses were performed using IraMuTeQ open-source software.

In Fraire's model, the first four steps (see Figures 1 and 2) are the 'preliminary phases', which are crucial to the entire process because they are determined by specific statistical choices, driven by the research aim. After the first round of reading the raw material, the corpus of the text was algebraically structured in 'a priori coding', dividing the text of each interview according to the main domains of the interview. Transcripts were divided into eight main domains: (a) role-taking (as a caregiver), (b) the general experience, (c) the problems of caring, (d) specific problems related to the physical or psychosocial areas, (e) the need for help, (f) time management, (g) the idea of the future and (h) free expression. 'Posteriori coding' was then performed, which involved selecting the units for the lexicometry analysis. This was done according to Bolasco's procedure (2013, pp. 88–89), in which the text is organized into sentences (segments) made of a minimum of three occurrences and word frequencies, to a maximum of 10 (Bolasco, 2012). We chose segments between a minimum of four and a maximum of 30 words. It is a lexicometric approach based on the main standard criteria: frequency, co-occurrences and the proximity of the words.

The overall pre-processed text was cleaned of irrelevant text forms (e.g., articles, digits, conjunctions, onomatopoeias, prepositions). A data matrix was constructed with tables of the results based on the frequencies of the segments. The next step, the fifth phase known as the 'choice of measure', is very similar to quantitative multidimensional analysis, but adapted to the type of data table (contingency in this case). A chi-squared test was used for contingency tables. The sixth phase consisted of developing exploratory multidimensional data analysis (EDMA): classificatory cluster analysis followed by principal component analysis (PCA)—graphically represented with a Cartesian coordinate system with a factorial analysis (FA)—and a multiple correspondence analysis (MCA). The final (seventh) phase involved the output of the synthesis of the results, both numerical (e.g., factorial weights, factorial scoring) and graphical (e.g., plots of factorial planes and dendrograms) (Fraire, 2009). This paper presents the classification cluster analysis results using dendrograms in consideration of the distribution of the cluster on the Cartesian coordinate system (as a result of PCA and FA), determined by the sociodemographic variables. The quantitative sociodemographic variables selected to drive the analysis included the ages

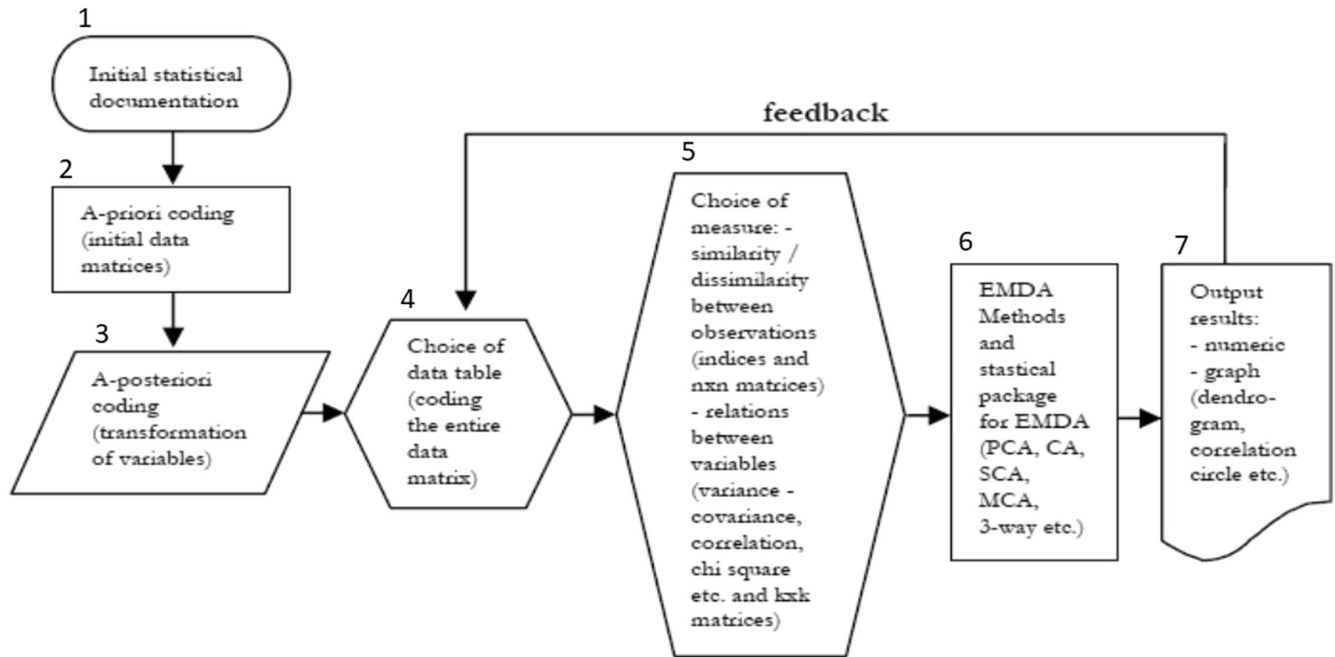


FIGURE 1 Seven phases of EMDA from Fraire (2009)-authorized image.

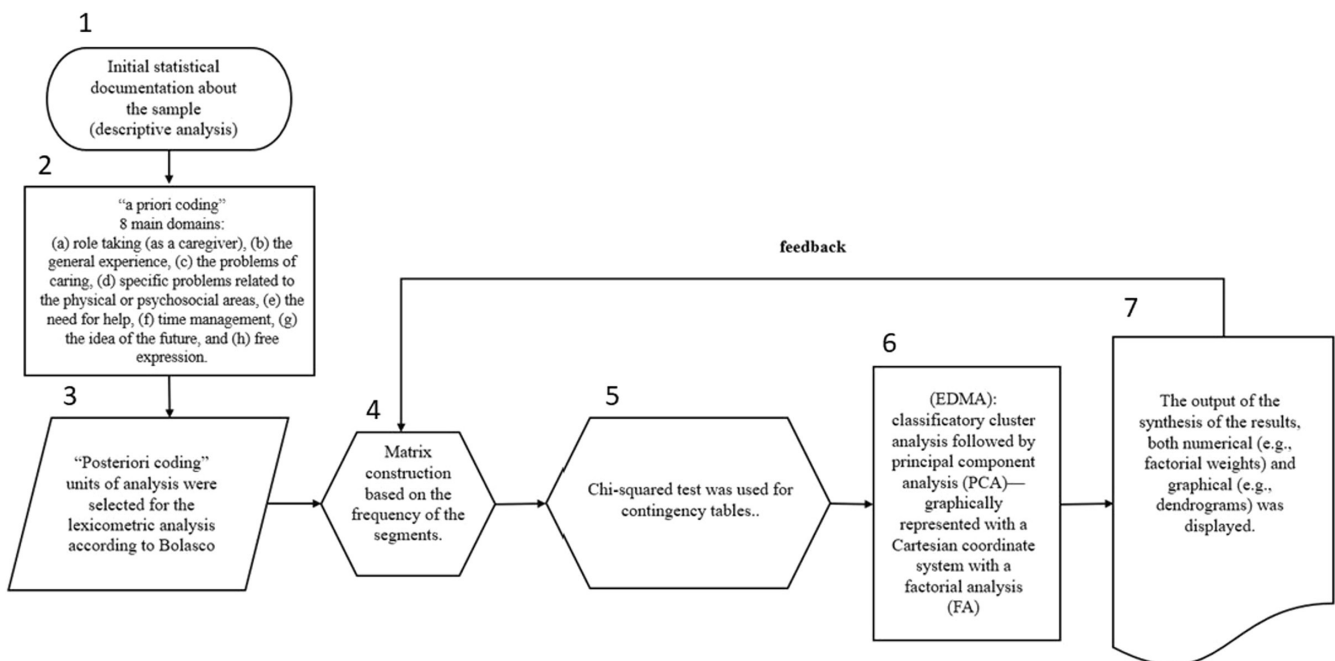


FIGURE 2 Seven phases of EMDA adapted to authors' choice according to Fraire (2009).

of patients and caregivers, their gender, type of relationship (e.g., father and son) and the economic status declared by the caregivers.

#### 4.6 | Validity and reliability/rigour

Transcriptions were randomly checked before analysing to ensure accuracy (10% of the total interviews). A preliminary descriptive-exploratory analysis of the corpus was performed using IramuTeQ

open-source software, to verify the reliability and the consistency of the necessary occurrences within the text. The strictness of the statistical analysis technique chosen, according to Fraire, and the use of the software limited the variable manipulation just to the choice of them; selected according to literature.

The trustworthiness of qualitative findings was ensured in several ways. To achieve rigour and credibility in the results, each interview was independently analysed by two researchers (researchers triangulation) up to reach an agreement about the findings. Both

researchers were required to be able to speak English (minimum B2 certified level) and the language in which the interviews were conducted, with the strict condition that one of them must have been a native speaker. The accuracy of the data, the preliminary and the final findings was performed by an expert cardiovascular researcher nurse, not involved in the analysis process, to assess the adequacy and ensure dependability. Credibility was reached discussing within the research team about the interpretation of the contents of the clusters and its justifications, till reach the agreement. The translation and linguistic adaptation of the scientific report were performed focusing on conceptual content avoiding literal equivalent sentences or terms.

## 5 | RESULTS

A sample of 52 caregiver and patient dyads were enrolled in the study: 21 in Spain, 20 in Italy and 11 in the Netherlands). The sociodemographic data reported below are summarized in [Table 1](#).

The transcription of the interviews generated 131 pages; audio recordings lasted from a minimum of 17 min to a maximum of 120 min. The caregiver's thoughts in each country were reported in clusters according to their distribution on the Cartesian coordinate system generated for each country. For any has been reported: the variance covered by the cluster, the most recurrent words, the predominant themes and needs, with the sociodemographic characteristics of the speakers. This information is given in dendrograms in [Figures 2, 3 and 4](#). The analysis performed led to the extraction of three clusters per country, into which the caregiver narrations were distributed. Furthermore, we reported the quotations identified with the qualitative content analysis for each cluster.

### 5.1 | Results from Spain ([Figure 3](#))

#### 5.1.1 | Cluster 1%–47% of the variance

The first cluster of Spanish samples covered 47% of the variance. This cluster was composed mostly of women, young caregivers (<65 years old) and older patients (mostly aged 85–92); they were the second or the third generation of caregivers (adult children or nephews). Some refused to declare their financial status; others said that they earned enough to cover the necessities.

The predominant themes that emerged as problems were uncertainty, worry about the future and doubt about the trajectory of the illness. They strongly felt the need to talk to someone and share their experiences to find a sense of 'new' normality also wished they could receive help from the healthcare system and informal sources (e.g., other family members, the patient's friends).

We reported below the caregiver's quotations from the themes that emerged from the qualitative content analysis:

"[referring to illness trajectory] About that I don't know. Even the doctor said he can't answer me; I don't know. I don't know, and that's

what it is...that you go to the doctors, and you expect that they can answer you, but they don't know either." (Spanish daughter, 52 age, from Spanish Cluster 1).

"[referring to the need to be helped] What can help me? I don't know, a lot of times I think I'm the one who's wrong, I didn't know how to organize, because what I should have done is to have looked for someone to help me from the beginning and I didn't do that. Well, maybe an informal help, like an assistant who can accompany her to places... and leave me freer, to go out maybe, to go shopping more calmly or something like that but at least not always running." (Spanish woman, 65 age, from Spanish Cluster 1).

#### 5.1.2 | Cluster 2%–13.7% of the variance

The second Spanish cluster derived from the same arm of extraction as Cluster 1, which means that these two clusters were very close in terms of occurrences. The second cluster included 13.7% of the variance.

This second Spanish cluster comprised caregivers who had recently retired and were distantly related to the patients (e.g., daughters-in-law). The patients they cared for were older women (aged over 90). The caregivers of this cluster declared an optimal financial status, with more than enough to live on.

The emergent themes in this cluster, which they explained in-depth, were the positive and negative aspects of being a caregiver felt as problems, and their focus on the personal experiences of caring. The caregivers in this cluster were found to be very social and keen and have a need to share and compare their experiences and ask for solutions to their everyday caregiving challenges; for example, they needed information and practical advice about how to manage difficult life situations such as architectural barriers (e.g., stairs).

We reported below the caregiver's quotations from the themes that emerged from the qualitative content analysis:

"Yesterday my husband went to buy her a wheelchair, because we are more than ten minutes away from the outpatient on foot with our house and she has to come for a kidney examination today, so we had to find a way to make her come and go. This decision is not good for the other son because he lives in a terraced house with the stairs, which is a problem for him." (Spanish woman, 66 age, from Spanish cluster 2).

"I live my life as best I can, after all, what can I aspire to? I would like to have a coffee on a terrace at the bar, sit down and talk to someone about it, not bad, but no. I can't I just drink it at home. I just drink it at home." (Spanish woman, 74 age, from Spanish cluster 2).

#### 5.1.3 | Cluster 3%–39.2% of the variance

The final cluster derived from an independent arm of extraction, which means that it had no connection on the Cartesian representation and explained 39.2% of the variance. This cluster was composed of female caregivers, primarily wives, who had a slight age difference (nearly 5 years) with their partners. They declared poor financial status. The themes on which they mostly focused were

TABLE 1 Sociodemographic characteristics of dyads

Country	Spain		Italy		Netherlands	
	Patients (N = 21)	Caregivers (N = 21)	Patients (N = 20)	Caregivers (N = 20)	Patients (N = 11)	Caregivers (N = 11)
Age	Mean 84.10 SD 8.34	Mean 57.86 SD 13.44	Mean 73.75 SD 10.33	Mean 64 SD 12.18	Mean 77.64 SD 9.22	Mean 69.09 SD 8.57
Gender (%)						
Male	66.7	19	65	15	63.6	18.2
Female	33.3	81	35	85	36.4	81.8
Marital status (%)						
Married	38.1	71.4	75	90	81.8	90.9
Widow/er	61.9		20		18.2	9.1
Separate/divorced		9.5	5	5		
Single		19		5		
Relationship (%)						
Son/daughter		60				18.2
Groom/bride		25		75		81.8
Son/daughter in law		5		20		
Brother/sister				5		
Education (%)						
Primary school	90.5	30	30	20	27.3	9.1
Secondary school	9.5	25	5	5	45.5	45.5
High school		25	55	60	18.2	18.2
Degree			5	15	9.1	27.3
Professional training		20	5			
Employment (%)						
Employee		40	21	40		
Retired	100	25	63.2	25	100	100
Unemployed		10	10.5	35		
Unemployed because of illness/caring		25	5.3			
Cohabitation (%)						
Yes		70		80		63.3
No		30		20		36.4
N° of cohabitants (%)						
Living alone	10				18.2	
One	50		70			
More than one	35		30		81.8	
Economic status (%)						
Serious financial problems				5.6	9.1	
Having the necessities to live	90	85	94.4	94.4	54.5	72.7
Having more than enough to live well	10	15	5.6		36.4	27.3

awareness of the role of a caregiver, and the emotional, social and physical problems they had already experienced (e.g., sleep disorders, low moods). They needed free time for themselves, and they expressed the need to relax or have spare time for go on a trip, read

a book, and so on. The results from the Spanish dendrogram are presented below (Figure 3).

We reported below the caregiver's quotations from the themes that emerged from the content qualitative analysis:



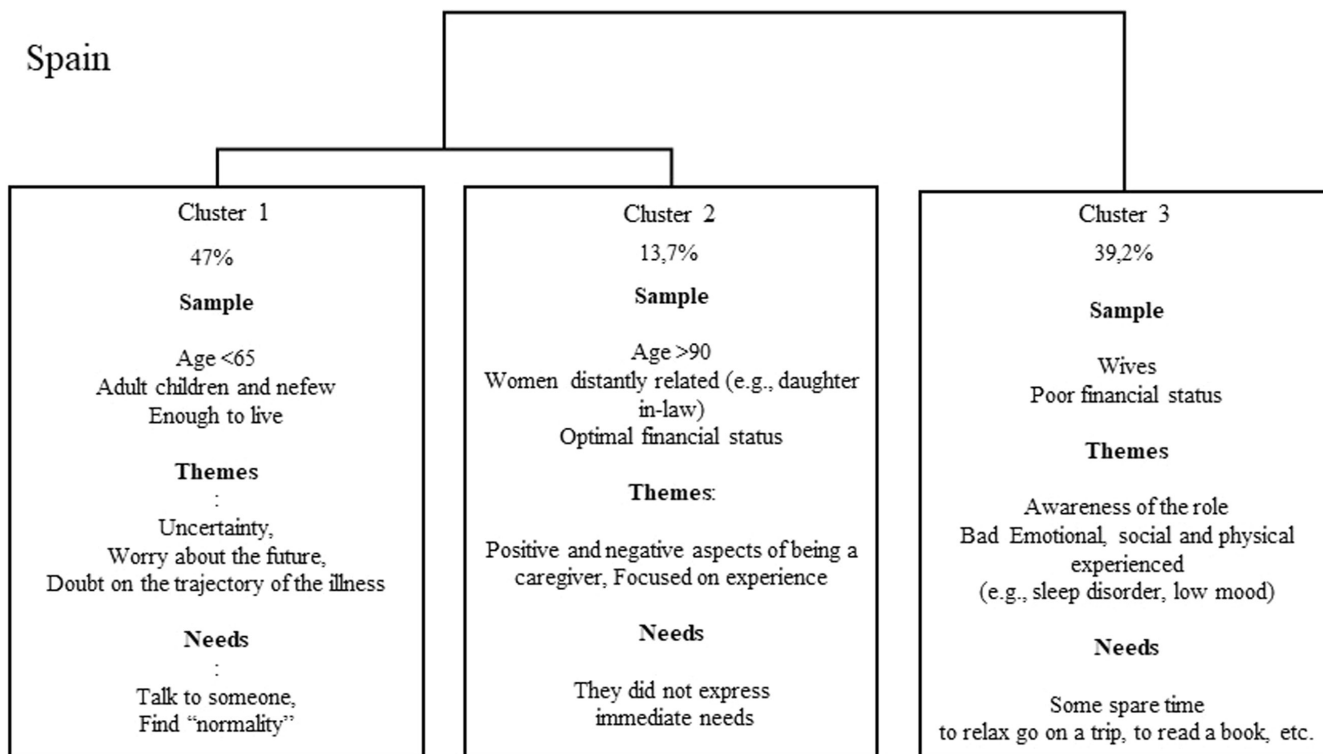


FIGURE 3 Spanish clusters

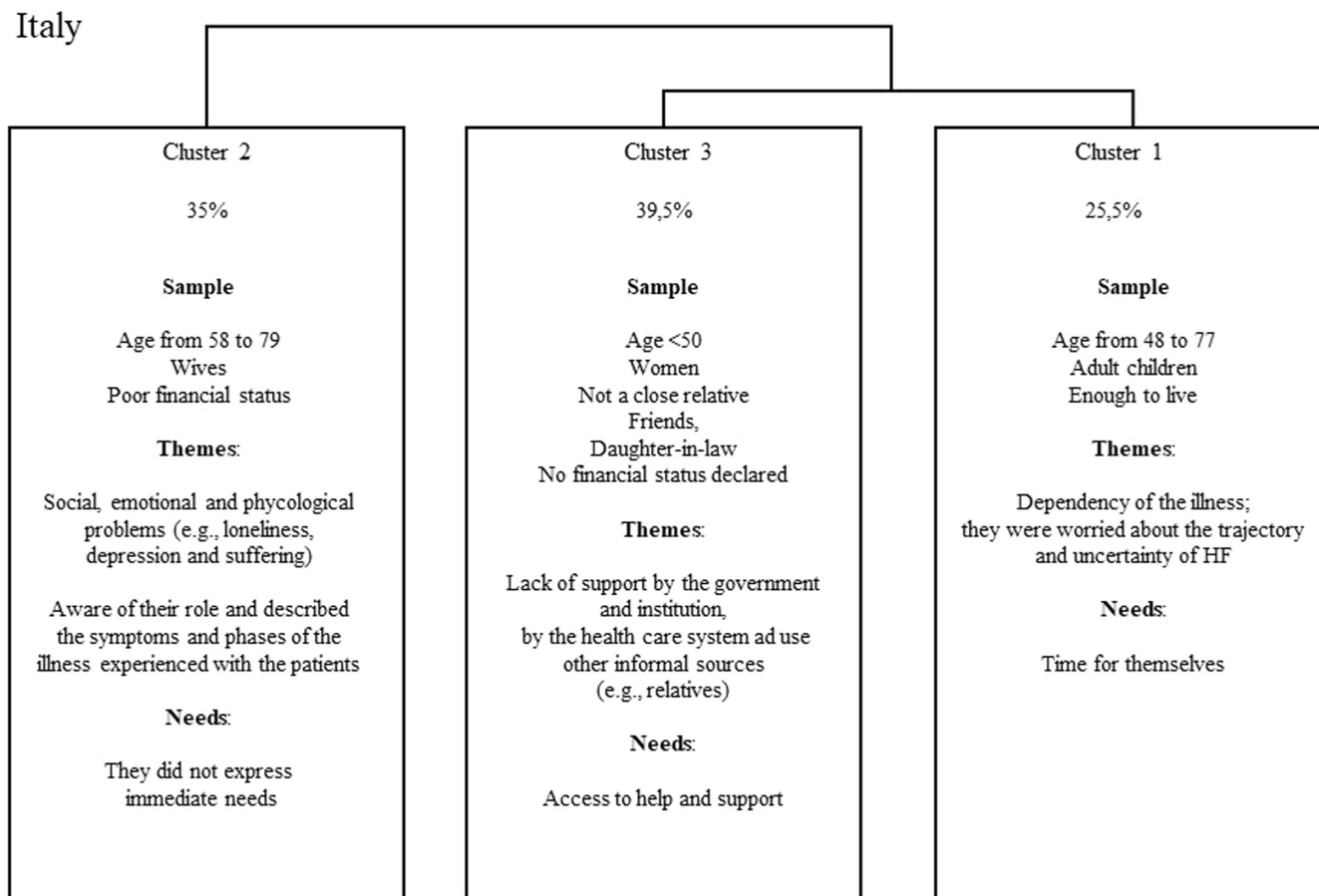


FIGURE 4 Italian clusters

"You have to have some time to yourself every day, even if it's just to relax. And you can't spend twenty-four hours out of twenty-four in this way...because what happens to you...that's what happened to me, I fell into a deep depression, I had a stress that...didn't make me go on. In other words, you have to have even if it's only half an hour, an hour, you have to have some relaxation to be able to disconnect, **to come back** and start again." (Spanish woman, 56 age, from Spanish cluster 3).

"I do it because I did it with my father. He died, I was very close to my father, and when he died... what remained was the thought that I could have done more... and I was with him until the last moment, and then with my mother, well, the same thing happened... I think that the day she will leave us, I will be happy to have done what I did for her, because she is my mother, and she helped me many times" (Spanish woman, 52 age, from Spanish Cluster 3).

## 5.2 | Results from Italy (Figure 4)

### 5.2.1 | Cluster 3%–39.5% of the variance

Most of the variance was represented by the arm made up of Cluster 3 (39.5%). This cluster sample was composed of young women caregivers (aged <50) who were not biologically related (e.g., friends) or were distant family (e.g., daughters-in-law). This meant that the age of the patients in this cluster was very varied. This group of caregivers did not declare their financial status.

The themes mostly stressed by the caregivers in this cluster experienced problems of lack of support from government institutions, complaints about the healthcare system and needed for other informal sources of help (e.g., relatives).

We reported below the caregiver's quotations from the themes emerged from the content qualitative analysis:

"I go shopping with my **friend**, I put her in a wheelchair, and we go to the shops in the cooler months and not in the hot hours. If I like something I ask her for advice. I don't have a social life. I've never seen a gym, even from the outside. I read and watch movies. But the day of rest does not exist." (Italian woman, 40 age, from Italian Cluster 3).

"It might be **helpful** to have someone to look after him when I'm not around, for example when I go to work, it would be good to have someone to look after him because he can hardly do anything on his own." (Italian woman, 49 age, from Italian Cluster 3).

### 5.2.2 | Cluster 1%–25.5% of the variance

Cluster 1 was from the same arm of extraction as Cluster 3, so that in the Cartesian representation the clusters had points in common. It represented 25.5% of the variance. This cluster was mostly composed of chiefly female caregivers who were the patient's adult children and were aged between 48 and 77; the patients were older,

from a minimum of 56 to a maximum of 86. They declared that their financial status was enough to cover the necessities.

The problems that strongly emerged among the caregivers were expressed by the themes: the length of the illness and the increasing dependency level of the patients and the apprehension about the trajectory and uncertainty of HF. In fact, caregivers were also worried about the high demands of caring due to the illness and needed having time for themselves.

We reported below the caregiver's quotations from the themes that emerged from the content qualitative analysis:

"I describe this experience negatively because although I try to stay calm, unfortunately, it is not completely possible. I am always worried, and I try not to be away for a long time so as not to leave him alone. I always **live** with the fear that he might feel bad. There is always this thought that used to leave us free." (Italian woman, 61 age, from Italian Cluster 1).

"My mother came to live with me after she stayed for six **years** in her flat on the second floor because she has deforming coxarthrosis. Like mothers of a certain culture, she never wanted to live with me. She couldn't go out, she couldn't walk, she couldn't go down the stairs, and for six years she just looked out of the window...but then when she couldn't take it anymore, because she **needed** care, she had to come and **live** with me. Her room is in the lounge on the ground floor of my house now, so she can come and go whenever she wants." (Italian man, 60 age, from Italian Cluster 1).

"[Answering the question: "What are your thoughts about the trajectory of the disease? Do you think your needs will change during the time?"] I hope my life will be like now. I hope to be healthy, and I hope to continue doing what I am doing for my husband. But I also realize that some things happen suddenly. You wake up one morning and everything can change. But I hope everything goes well because hope is the last to die." (Italian woman, 70 age, from Italian Cluster 1).

### 5.2.3 | Cluster 2%–35% of the variance

Cluster 2, which represented 35% of the variance, was totally independent of the other arms of extraction. This cluster was composed of spouses, mostly wives. The caregivers' ages ranged from 58 to 79, and the patients from 63 to 84, with nearly 5 years of age difference between caregivers and patients. The caregivers in this cluster declared poor financial status. The problems that caregivers mostly spoke on emerged by themes related to their social, emotional and psychological problems (e.g., loneliness, depression and suffering). These caregivers were aware of their roles, and described the symptoms and phases of the illness they had experienced with the patients with accuracy. They did not express any immediate needs.

We reported below the caregiver's quotations from the themes emerged from the content qualitative analysis:

"I have **problems** with hypertension maybe because of agitation, that's why I'm here at the doctor's (laughs).

Without realizing it, I can see what my husband's experience has done to my health. I suffer from insomnia at night and over time all these factors accumulate to the extent that my organism is failing (sighs)." (Italian woman, 72 age, from Italian Cluster 2).

"**Depression**...no because I think that being **depressed** at certain times is a luxury. I can't allow myself to be assailed by **depression**. Undoubtedly, had moments of discouragement, of personal discomfort, but I but did not let them **limit** me, I always did everything..." (Italian woman, 63 age, from Italian Cluster 2).

### 5.3 | Results from the Netherlands

The three clusters derived by the Dutch interviews text corpus are shown in [Figure 5](#).

#### 5.3.1 | Cluster 1%–57.8% of the variance

The arm represented almost all the variance (57.8%) made up of Cluster 1. Cluster 1 in the Dutch sample comprised the caregivers, primarily female, of HF patients over 70, who were predominantly in a spousal relationship, or were daughters. The ages of the caregivers ranged from 60 to 80 years old, and the patients were all over 70. All caregivers reported that their financial status met what was necessary to live, and only one declared having more than necessary.

The predominant problems mentioned were physical, psychological and social issues, and their patient's increasing dependency due to concurrent patient illnesses. They presumed that their physical, psychological and social problems originated from the stress arising from their role as caregivers. They expressed the need to relax.

We reported below the caregiver's quotations from the themes emerged from the content qualitative analysis:

"Sometimes I read some things, I look up some things on the internet, I'm making a file of the problems I can encounter in **stoma** care, in the area of nutrition, the **problems**, why it hurts, and you call it, but I make my file, a kind of diary." (Dutchman, 72 age, from Dutch cluster 1).

"When we really need help from the people, it doesn't always happen optimally, I have **problems** with that. Not with the fact that he is sick. I don't **feel** heard, as a partner, I don't **feel** heard, I am not considered as a partner" (Dutch woman, 63 age, from Dutch Cluster 1).

#### 5.3.2 | Cluster 2%–26.5% of the variance

The second cluster of the Dutch sample was derived from the same arm of extraction as Cluster 1. Cluster 2 covered 26.5% of the variance. This cluster was mainly composed of wives. The caregivers and patients were peers, and over 70 years old. They did not report financial problems and instead reported that they had more than necessary to live. The predominant problems were the irregular trajectory of the illness and uncertainty. These patients and caregivers had a remarkably close relationship, with the patients having a medium-high level of dependence due to their comorbidities, and furthermore they wanted to protect their adult children (or other family members) from the burden of caring. They also expressed the need to exclude their children in order not to feel guilty about involving them in the care process. This was easily understood from the type of action verbs used by the caregivers, which were mainly actions substitution for, or helping, the patients.

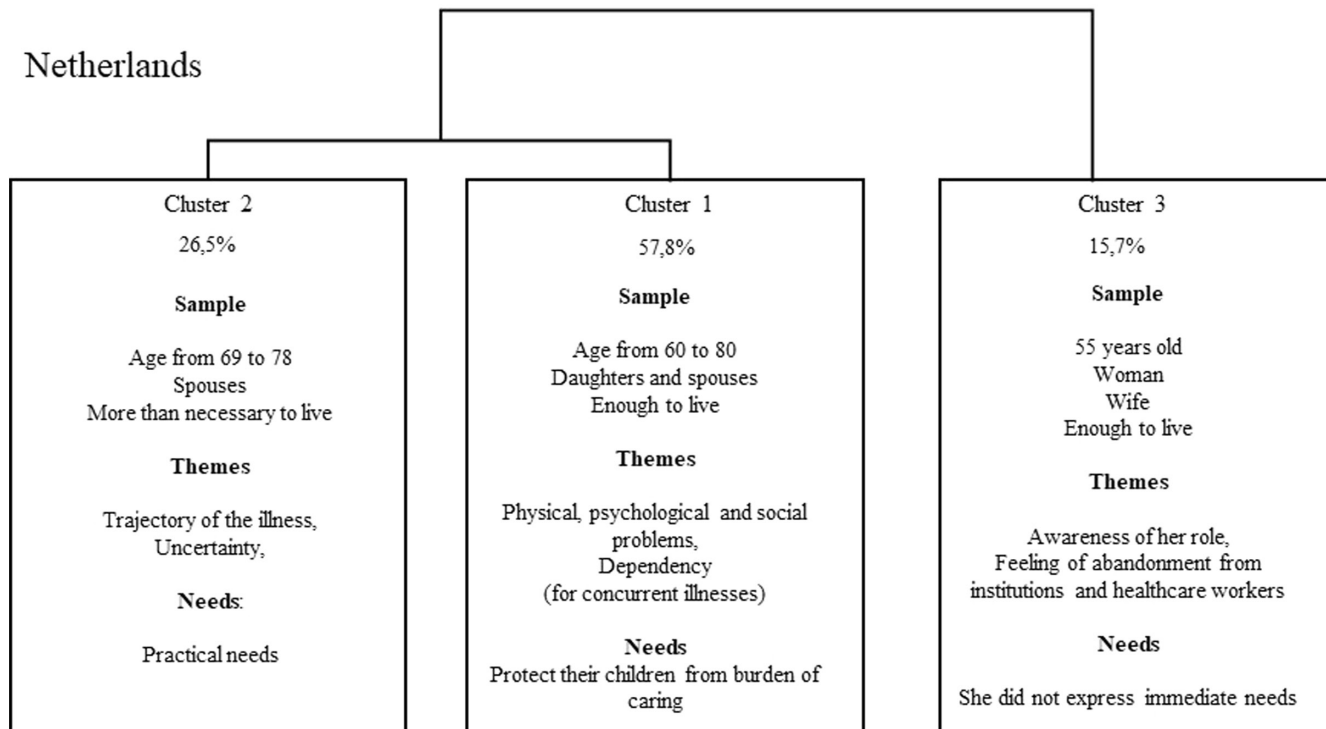


FIGURE 5 Dutch clusters

The high frequency of time adverbs such as every day, every time, often, and constantly, matched with help requests suggests that the patients were highly dependent on the caregiver care.

We reported below the caregiver's quotations from the themes emerged from the content qualitative analysis:

*"Oh yeah, it's heavy! Oh, you don't want to know how much. And yes, he learned everything at the \*clinic name\* and then he sits in his chair and then he says: "\*caregiver name\* take me to the bathroom!". So, I say: "come on \*patient name\*, you can do it yourself". But no, he's not able to do it.... So, I have to bring him to the bathroom and put on the toilet. And when he's done, he calls again, "Can you pull up my trousers?". I say: "\*patient name\*, you can do it!" and he says: "No, it's not possible, let's go". And so often six times in one night I have to take him to the bathroom". (Dutch woman, 78 age, from Dutch Cluster 2).*

*"Well, he will be a little less able to cope, but otherwise, I hope he will, yes, something can happen that you cannot foresee, but as long as he stays among people and continues to do so. What he does now, I think that goes very well." (Dutch woman, 69 age, from Dutch Cluster 2).*

*"If something bad happens, they are already at the door, so it's not that they are not there...But you know, they also have their family, they have their work, they also have their social life, yes...I have to give them this chance. For the small things we manage by ourselves. It's what we can do, well as long as it's good..." (Dutch woman, 69 age, from Dutch Cluster 2).*

### 5.3.3 | Cluster 3%–15.7% of the variance

The third cluster is derived from an independent arm of extraction. This cluster covered 15.7% of the variance. This cluster was composed of one woman, who was keenly aware of her role as a caregiver and fought against the institutions to claim her rights and support. She also complained about the communicative detachment of healthcare workers, especially physicians. She was the 55-year-old wife of a 67-year-old patient and declared that financially she had only what was necessary to live.

The main themes that emerged from the interview were the awareness of the role of caregivers, and they experienced the problem of being abandoned by institutions and they need more support by healthcare workers.

We reported below the caregiver's quotations from the themes emerged from the content qualitative analysis:

*"I don't want to hear about bureaucratic authorities, I'm powerless. I need to calm down. I am alone against the "wall", I am abused, mentally abused every day. Every second, I am abused, and I have no way to choose because I have to do it and I am alone." (Dutch woman, 55 age, from Dutch Cluster 1).*

## 6 | DISCUSSION

This study enabled in better understanding the needs and problems of informal caregivers and described them according to their

sociodemographic characteristics. There is considerable overlap between the clusters in the three countries. However, the extent to which some sociodemographic variables were decisive for the definition of the clusters was unexpected. The importance of gender in caregiving has been stressed in literature (Hwang et al., 2010). Our results underlined the vulnerability of women, especially wives, to psychosocial problems (e.g., 'lonely' and 'suffer' in the clusters). Both the Italian and Spanish samples, the participants in the clusters that mostly included wives declared poor financial status. Especially in Spanish Cluster 3 and Italian Cluster 2, mostly composed of spouse peers of the patients or daughters, these wives were strongly aware of their role and their commitment of caring towards their patient, but they felt overstressed and wished a sort of relief from stressful routine. Therefore, socioeconomic status and poverty in combination with female gender can greatly affect the caregiving process and involves more challenges for the caregivers. Healthcare providers can be more mindful of the gender of caregivers and their socioeconomic status when designing teaching for the individuals and their caregivers with heart failure.

In the Italian Cluster 3 and Spanish Cluster 1, which was mostly composed of female caregivers emerged, as a novelty, that women were stressed by the uncertainty of the illness trajectory and complained about a little comfort information by healthcare workers and wished a spontaneous informal help by other family members maybe because they were ashamed to ask it. Due to their multiple roles, as workers, mothers or caregivers of other familiar members they were overwhelmed by overlapping of different duties and claimed they had no spare to spend for themselves. In Italy and Spain, like other Mediterranean countries, family resulted in the first care provider (León & Migliavacca, 2013) and care commitment is chiefly entrusted to women of the family (e.g., wives and daughters) putting place socially disadvantaged position (e.g., not having a job, declining promotions in order not to accumulate new commitments). Our results emerged that women preferred to cooperate (e.g., daughter towards mother) and were supportive of each other in the absence of state welfare to protect them. They strongly reported wishing for some time for themselves and a sort of relief from care burden. This finding has implications for community-based organizations and nurses to establish mechanisms for emotional, moral and caregiving support for female caregivers.

In Italy and Spain, spouse caregivers, as affirmed above, were most uncertain about the trajectory of HF given the institutional lack of support; they were also anxious about preserving their well-being to not fail their 'mission' of caring. They expressed a need to talk to others and share their caregiving experiences; they also wished to receive support from people other than their relatives. Except for the female spouses, the other caregivers spoke of good financial circumstances. This study found that male caregivers lacked sufficient awareness of their role, that they had only accepted it because of moral and social obligations.

Unlike the Spanish and Italian caregivers in the Dutch clusters, which were primarily composed of women too, they declared they had more than necessary to live, and were most aware of their role

as care providers. Echoing previous results, this study found that most caregiver complaints were related to emotional, physical and social areas (Grant & Graven, 2018). Conversely, while Spanish and Italian female caregivers support each other within the family, the Dutch caregivers safeguarded their adult children to buffer from caring for and let them free to live their lives and develop their job careers. In fact, despite some children wanting to help their mothers with the caregiving load, the patient's wives were very protective and did not want to burden their children's lives. This was particularly evident in the example of the Dutch Cluster 2, where they sought to protect their young son by letting him enjoy his family and not have to sacrifice his work to assume a caregiver role and set them free of the burden of care. This meant that the relationship between the person with HF and the caregiver was mainly exclusive. The caring was entirely borne by the caregiver, as shown above, in the description of Cluster 2. Although Dutch caregivers do not ask for help from their adult children, they complained about their welfare government. They felt 'abused' (term used in interview NL02-Cluster 3) because of bureaucratic complications or delays in access to government concessions. This finding enhances the need for a better organization of the help delivered for caregivers according to the cultural setting, which should involve clinicians in planning policies considering the social structure.

Some participants in the Italian and Spanish samples, particularly those who were not spouses, found it exceedingly difficult to accept their caregiving role, especially when they had to look after the HF person. They found it challenging to deal with the fact that caregiving would become part of their daily routine. They obviously had jobs, and not all countries, including those involved in this study, have officially recognized the role of informal caregivers, offering them proper support. The younger caregivers also had their own families and children to look after. Given that caregiving requires time and physical presence, most (80%) choose to live with the person they cared for (Table 1); this means a change in family routine, habits and structure, especially for caregivers who have a family and do not live with or near their family of origin. Unlike spouses, the young caregivers tended to seek help from outside the family. Furthermore, male adult children admit that their caring was guided by a sense of gratefulness for the care received in childhood. Our results thus illustrate the importance of a caregiver's type related to the person cared in dealing most effectively with their circumstances.

The lexicometry analysis shows that most of the words used by Spanish and Italian caregivers were adjectives or verbs in their active form. The use of such words for daily life activities confirms what was noted by Grant and Graven (2018) that caregivers perform multifaceted tasks and accept various roles that revolve around daily HF demands. Meanwhile, the adjectives used to describe the persons and the situations they experienced, demonstrate the caregivers' desires to be heard and understood.

Conversely, the Dutch caregivers, who were over 70 and most women in spousal relationships with the person cared, were strongly aware of their role. Although there is a national policy in

the Netherlands that covers the care and support of caregivers and provides both indirect and direct financial support (Casanova et al., 2017) it results in a lack of recognition of real needs and problems. Financial situations were not an issue, and in fact, all Dutch caregivers declared that they had the necessary means or more to live, it dealt with social recognition.

Uncertainty, expressed as above in the caregivers' words, is another problem that has been alluded to by the literature (Grant & Graven, 2018). In our all interviews, the connection between a lack of information about the illness and the trajectory of the illness was evident. Nurse-family meetings acknowledge the suffering and vulnerability of families when a loved one is critically ill and afford families an opportunity for honest sensitive communication with nurses. Nurses should make space and find time to listen to families' stories of illness to become aware of what beliefs may support and encourage family well-being and healing (Årestedt et al., 2015).

## 6.1 | Implications for nursing

Considering the increasing prevalence of HF and its grave implications for patients and informal caregivers, healthcare providers should focus their attention on preventing caregivers from feeling overwhelmed and dedicate more time in listening to doubts and fears addressing concerns. Understanding the importance of the sociodemographic variables (e.g., gender, relationship type) that can affect a caregiver's condition would help healthcare professionals anticipate their needs and provide them with the necessary support. The study extends the knowledge towards the topic in two ways. First, there is the possibility to create clusters of problems and needs of caregivers according to sensible sociodemographic variables and including the context. Second, there are common threads through Europe, even considering the cultural differences, that characterize each population, that if extended, confirmed and generalized with further research; can help in defining policies to support informal caregivers according to their real needs. Informal caregivers continue to be an underrepresented section of the population, and it is recommended that clinicians and future research investigate their complex role in depth considering the context, to mitigate their problems and satisfy their needs, supporting the development of protection policies. In conclusion, the results of our study provide valuable information about caregivers' views of society. These new findings enrich information not only for health professionals engaged in the clinical setting but for health and non-health professionals engaged in the organizational management setting for building social policies in favour of psychosocial health.

## 6.2 | Limitations and strengths

Although a culturally heterogeneous sample can be considered a strength, it can also be seen as a potential limitation to qualitative interviews, for two main reasons. We were cognizant of the fact that

the inclusion of non-native speakers would increase the likelihood that some words or expressions would not be correctly used and understood, however, their exclusion would mean ignoring an important aspect of the multicultural society in which we live today (especially given the historically massive immigrations); further, it would not cohere with the ethics philosophy of this research group. Second, the data analysis took place in three non-English speaking countries, and we decided not to translate the entire interviews. However, the researchers who performed the analysis were fluently bilingual. The heterogeneity of the sample could have also undermined the transferability of our findings.

## 7 | CONCLUSIONS

Informal caregiving is a complex and multilevel process influenced by various sociodemographic factors in a specific HF population. Sociodemographic variables especially relationship type, and economic status cannot be ignored when planning to develop approaches to address the needs of caregivers serving people with HF. Special attention should be directed to young female caregivers, who may be involved in multiple social roles (e.g., mothers, spouses, workers), and may be more vulnerable. A different approach should be taken when dealing with spouse/non-spouse relationships, based on their awareness of their role as caregivers. Poor financial status can be an additional contributory factor to the complexity of a caregiver's circumstances.

### AUTHOR CONTRIBUTION

All authors have agreed on the final version and meet at least one of the following criteria (recommended by the ICMJE): Substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data: AD, JB, RJV, EV, SS. Drafting the article or revising it critically for important intellectual content: AD, AC, AY, BB, EV.

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Research data are not shared.

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