

# Perception and Challenges of Time Management for Caregivers of People with Heart Failure

## A Qualitative Study

Angela Cuoco, PhD; Ahtisham Younas, PhD; Josiane Boyne, PhD; Raul Juarez-Vela, PhD; Bridgette M. Rice, PhD, MDiv, APRN, FAAN; Ercole Vellone, PhD; Angela Durante, PhD

**Background:** Informal caregivers contribute substantially to the self-care of people with heart failure (HF) by helping with concrete and interpersonal tasks. Time perception and management are essential issues among caregivers. However, investigators have not explored this topic in caregivers of people with HF. **Objectives:** The aim of this study was to describe the perceptions and challenges of the time management experience among caregivers who support the self-care efforts of their relatives with HF. **Methods:** Adult informal caregivers of patients with HF, taking care of the patient for at least 3 months and without cognitive limitations, were recruited from Spain, Italy, and the Netherlands. Data were collected using semistructured interviews. Maryring's qualitative content analysis strategy with both a deductive and an inductive approach was used for analysis. **Results:** We enrolled 50 participants (20 Italians, 19 Spanish, and 11 Dutch). Caregivers had a mean (SD) age of 62.8 (12.8) years and were mostly female (84%). They dedicated 31.2 (SD, 21.7) hours per week to providing caring activities for their patients. After extracting 33 codes from their qualitative interview data, we summarized them into 8 categories and identified 4 main themes: (1) time for yourself, (2) house management, (3) time for the patient (dedicated to directing care), and (4) time for own socialization. **Conclusion:** Caregivers navigate the complexity of time management by balancing dedicated time for supporting patients with HF and their own personal time.

**KEY WORDS:** caregivers, heart failure, nursing, public health, time perception

About 26 million people worldwide are affected by heart failure (HF).<sup>1</sup> This number is expected to increase because of the aging population and increased

life expectancy.<sup>2,3</sup> The management of HF is complex in terms of pharmacological treatment and recommendations related to self-care behaviors (eg, exercise, and

### Angela Cuoco, PhD

Department of Biomedicine and Prevention, University of Rome "Tor Vergata," Italy.

### Ahtisham Younas, PhD

Assistant Professor, Faculty of Nursing, Memorial University of Newfoundland, Canada.

### Josiane Boyne, PhD

Researcher, Department of Cardiology, Maastricht University Medical Center, The Netherlands.

### Raul Juarez-Vela, PhD

Professor, Unidad Predepartamental de Enfermería, GRUPAC, University of La Rioja, Spain.

### Bridgette M. Rice, PhD, MDiv, APRN, FAAN

Associate Dean for Research and Innovation; and Richard and Marianne Kreider Endowed Professor in Nursing for Vulnerable Populations, M. Louise Fitzpatrick College of Nursing, Villanova University, Pennsylvania.

### Ercole Vellone, PhD

Associate Professor, Department of Biomedicine and Prevention, University of Rome "Tor Vergata," Italy; and Visiting Professor, Department of Nursing and Obstetrics, Wrocław Medical University, Poland.

### Angela Durante, PhD

Researcher, Unidad Predepartamental de Enfermería, GRUPAC, University of La Rioja, Spain; and Assistant Professor at Università del Piemonte Orientale (University of Eastern Piedmont), Novara Italy.

This work was supported by the Heart Failure Association of European Society of Cardiology within the Heart Failure Nurse Research Training Fellowship and the Center of Excellence for Nursing Scholarship (CECRI), Rome, Italy. The authors have no conflicts of interest to disclose.

### Author Contributions

A.C., A.D., J.B., R.J.V., B.M.R., and E.V. made substantial contributions to conception and design, acquisition of data, and/or analysis and interpretation of data. A.C., A.D., A.Y., E.V., and J.B. were involved in drafting the manuscript or revising it critically for important intellectual content. All authors gave final approval of the version to be published. Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content. A.C., A.Y., A.D., and E.V. agreed to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

### Correspondence

Angela Durante, Grupo de Investigación en Cuidados, Facultad de Ciencias Jurídicas y Sociales, Escuela de Enfermería, University of La Rioja, C/Duquesa de la Victoria 88, 26006 Logroño, La Rioja, Spain (angela.durante@unirioja.es).

DOI: 10.1097/JCN.0000000000001027

exercise and a healthy diet).<sup>4</sup> The regimen required is complex, burdensome, and mainly possible due to the endless support of informal caregivers, who are generally family members, close relatives, friends, and neighbors.<sup>5</sup>

Caregivers contribute substantively to the self-care of people with HF, including helping with concrete activities (eg, weighing) and understanding medical terms and plans for treatment regimens.<sup>6</sup> According to the situation-specific theory of caregiver contributions to heart failure self-care, caregiver contributions to HF self-care are interacting processes of self-care maintenance, symptom observation and perception, and self-care management.<sup>7</sup>

Caregiving in HF is often onerous and closely related to the hours of caregiving provided per day.<sup>8</sup> Caregivers' contributions to the self-care of HF are usually performed daily and require time that caregivers would otherwise spend on their personal life and needs. These time constraints limit caregivers' well-being or take away time from other family members. In addition, the trajectory of HF is characterized by unpredictability and instability with crises. Caregivers' experience of unpredictable progression of HF and the complexity of HF management decrease caregivers' perception of control and negatively change their perception of life.<sup>9</sup>

How caregivers face these daily challenges and manage their time during illness may vary and greatly impact caregiver lives. However, little is known about time management for caregivers of people with HF and how time management for caregiving affects their lives. To date, investigators have not focused on the perception of time and its management by caregivers of patients with HF. Thus, it is important to address this relevant issue to understand how caregivers organize their time and prioritize their needs while considering caregiver duties. Hence, in this study, our aim was to describe the perceptions and challenges of time management for caregivers of people with HF while supporting the self-care efforts of those living with HF.

## Methods

### Design and Sample

In this secondary analysis, we used the qualitative data from 50 caregivers, collected for a larger mixed-methods study conducted in 3 European countries (ie, Italy, Spain, and the Netherlands).<sup>10</sup> A detailed description of the sample used can be found in the parent study.<sup>10</sup> Consolidated Criteria for Reporting Qualitative Studies<sup>11</sup> were used to report. The inclusion criteria of caregivers were as follows: (a) being an informal caregiver (family members, close relatives, friends, and neighbors)<sup>12</sup> of a person with a diagnosis of stable HF documented at least 3 months before data collection and (b) having no illness that significantly affected their cognitive capacity and independent decision making (eg, dementia, Alzheimer's,

psychiatric disorders) based on the Montreal Cognitive Assessment (exclusion criteria score < 26).<sup>13</sup>

### Data Collection

Data were collected through individual semistructured face-to-face interviews.<sup>14</sup> We conducted the interviews without the presence of the person with HF to allow caregivers to speak freely and to obtain in-depth descriptions. The interview guide created for the parent mixed-methods study was structured into 3 sections: past experiences of caring, current experiences and daily challenges due to caregiving, and future thoughts about HF trajectory and care. Each interview lasted an average of 1 hour (range, 17–120 minutes), and 137 pages of transcription were generated. Three trained researchers, 1 per country involved, conducted all interviews in their native language. The interviews were recorded and transcribed. We also collected participants' sociodemographic characteristics and asked them to quantify their hours in caregiving activities. Enrollment was suspended at the 50th interview when, while analyzing, data saturation was obtained according to Saunders et al's<sup>15</sup> theoretical saturation criteria. For this reason, saturation was reached in a different number of caregivers per country.

### Data Analysis

All interviews were analyzed in their native language to retain typical expressions of the Italian, Spanish, and Dutch etymological and semantic meanings by at least 1 researcher per country. When differences in coding occurred, an external qualitative expert resolved them. Therefore, 6 coders (2 from each country) performed the complete analysis, and 3 independent supervisors (1 from each country) were involved in solving coding issues.

We conducted content analysis according to Mayring<sup>16</sup> using the specific content structuring/theme analysis technique. These techniques consist of initial deductive and secondary inductive steps. We performed 2 rounds of coding per step. This was done to obtain a condensed but thick description of the phenomenon.<sup>17</sup> We developed codes, subcategories, and themes directly in English to facilitate discussion among the multilingual research team and report the quotation in double languages for internal consensus.<sup>18</sup>

### Deduction: Content Structure Analysis

We developed an a priori codebook composed of deductive codes from the concepts of the “situation-specific theory of caregiver contributions to heart failure self-care”<sup>7</sup> (1 code per each self-care contribution area) and previous studies discussing caregiver time in other chronic conditions.<sup>9,19–24</sup> We applied descriptive coding<sup>16,25</sup> to have a shared and unique coding, and then codes were grouped into subcategories according to their meaning.

### Induction: Theme Analysis

We brought subcategories to a higher level of abstraction,<sup>16</sup> to build themes, using inductive logic to explore caregiver perception of time as a criterion for forming categories. To do so, we applied pattern coding to all subcategories with the intention of obtaining a more meaningful and parsimonious category.<sup>25</sup> Therefore, subcategories were grouped into main categories to elevate them to a higher level of abstraction<sup>26</sup> and organized into themes through a discussion among the research group members. The final report and the quotations were translated into English by proficient certified English speakers. Qualitative data were managed using NVivo 12, whereas quantitative data were analyzed using JASP (version 0.17.1).<sup>27</sup>

### Rigor and Trustworthiness

We used 4 criteria to ensure rigor and trustworthiness.<sup>28</sup> Credibility was ensured by investing time before the interview to become familiar with caregivers and explaining the scope of the research to make them comfortable in sharing confidential information. Data triangulation was performed by collecting interviews from caregivers of different ages to reduce the potential for researcher bias or subjectivity but principally to compare and contrast the data collected from each age group to identify similarities and differences in experiences, perspectives, or attitudes; this provided a more nuanced understanding of how the phenomenon was experienced or perceived differently across age groups.<sup>29</sup> Therefore, we obtained the opinion of caregivers who were the patient's peers (eg, elderly wives or husbands) and younger people such as grandchildren or children, thus considering the opinion of caregivers belonging to different generations or with different types of routines (eg, workers or retired people).

In addition, data were collected from 3 different countries to understand better how cultural factors may influence the phenomenon and explore cultural differences in attitudes, beliefs, and behaviors.<sup>30</sup> Dependability was ensured by a data audit performed with an external qualitative expert reviewer explaining how the data were reduced for analysis, discussing the interpretation and presentation of the findings to verify the abstraction process.<sup>29</sup> Confirmability was guaranteed by reflexivity by asking for clarifications from caregivers when needed during the interviews, summarizing the main concepts for confirmation before closing the interviews, and sharing within the research group any personal beliefs that may incidentally affect the research before the analysis procedure. Transferability was ensured by a thick and detailed description of the caregivers' experience.

### Ethical Considerations

The ethics committee of each center, where caregivers were enrolled, approved the study protocol before data

collection began. Caregivers gave signed informed consent, stating that withdrawal was possible at any moment and that information about sociodemographic data and the content of the interviews would be used with confidentiality and for research purposes only.

## Results

### Sample Characteristics

Fifty (20 Italian, 19 Spanish, and 11 Dutch) caregivers participated in the interviews. The mean (SD) age of Italian caregivers was 64 (12.2) years, and 85% were women. In this sample, most (90%) were married, and most were spouses of people with HF (75%). Forty percent were employed outside the home, and 80% of the sample lived with their care partner. Most caregivers' financial status was considered sufficient to cover their necessities (85%).

The Spanish sample's mean (SD) age was 58.0 (14.2) years, and 84% were women. Seventy-four percent of caregivers were married. Half of the caregivers were the son or daughter of people with HF (58%). Twenty-six percent were unemployed due to caregiving responsibilities, and 69% of the sample lived with their care partner. The financial status of most caregivers was declared as sufficient to cover their necessities (90%).

The mean (SD) age of Dutch caregivers was 69.1 (8.6) years. Most caregivers were women (82%), and all were married. Most (82%) were spouses of people with HF and were mainly retired (64%). Most caregivers' financial status was declared sufficient to cover their necessities (73%), but different from the other samples, some also declared they had more than necessary to live (37%).

Caregivers dedicated a mean (SD) of 31.2 (21.7) hours per week to activities supporting their patients (Table 1). Most of the care recipients were men (54%). The mean (SD) age of the care recipients was 78.1 (9.3) years, and they were married (62%) and retired (84%) (Table 2).

### Themes of Caregiver Time Management

From the qualitative analysis, in the first deductive step, we extracted 33 codes. Of those developed in the a priori deductive phase, only those related to caregiver contribution areas (3) kept the nomenclature. The other codes, drawn from the literature, underwent modifications to fit the context, for example, from "Balancing employment"<sup>24</sup> to "Adjustment in job." The 33 codes described actions caregivers performed throughout the day. Subsequently, these codes were summarized in 8 subcategories fully described in Table 3. We finally found 4 themes by merging 8 subcategories: (1) time for yourself, (2) house management, (3) time for the patient, and (4) time for own socialization.

**TABLE 1** Participants' Characteristics Divided by Country

	Italy (N = 20)	Spain (N = 19)	Netherlands (N = 11)
	n (%) or Mean ± SD		
Age	64 (±12.2)	58.0 (±14.2)	69.1 (±8.6)
Gender			
Male	3 (15.0)	3 (15.8)	2 (18.2)
Female	17 (85.0)	16 (84.2)	9 (81.2)
Marital status			
Single	1 (5.0)	3 (15.8)	0 (0)
Married	18 (90)	14 (73.7)	11 (100)
Divorced	1 (5.0)	2 (10.5)	0 (0)
Relation with patients			
Wife/husband	15 (75)	5 (26.3)	9 (81.8)
Son/daughter	0 (0)	11 (57.9)	2 (18.2)
Son-in-law/ daughter-in-law	4 (20.9)	1 (5.3)	0 (0)
Brother/sister	1 (5)	0 (0)	0 (0)
Other	0 (0)	2 (10.5)	0 (0)
Cohabitation with the patient			
Yes	16 (80.0)	13 (68.4)	7 (63.6)
No	4 (20.0)	6 (31.6)	4 (36.4)
Area of residence			
Urban	17 (85.0)	18 (94.7)	10 (90.9)
Rural	3 (15.0)	1 (5.3)	1 (9.1)
Employment			
Retired	5 (25.0)	5 (26.3)	7 (63.6)
Unemployed	7 (35.0)	2 (10.5)	3 (27.3)
Unemployed due to caring	0 (0)	5 (26.3)	0 (0)
Employee	8 (40.0)	7 (36.8)	1 (9.1)
Economic income			
Excellent	0 (0)	2 (10.5)	3 (27.3)
Sufficient	17 (85.0)	17 (89.5)	8 (72.7)
Financial problems	1 (5.0)	0 (0)	0 (0)
Not reported	2 (10.0)	0 (0)	0 (0)
Caregiving activities			
Hours per week	24.6 (±18.5)	44.3 (±18.7)	20.5 (±22.2)
Meal preparation	5.2 (±4.8)	10.21 (±5.8)	6.90 (±6.6)
Domestic activities	7.1 (±5.1)	5.9 (±3.8)	6.8 (±7.9)
Shopping	4.7 (±3.0)	3.95 (±1.4)	5.7 (±4.2)
Accompanying to medical visits	4.3 (±3.2)	1.6 (±0.8)	3.6 (±4.3)
Personal care	3.0 (±5.0)	2.5 (±3.8)	5.4 (±6.2)
Assistance in social activity	3.3 (±3.1)	5.4 (±3.01)	0.8 (±1.2)
Other activities	0 (0)	14.7 (±8.4)	2.0 (±3.4)

### Time for Yourself

The theme of time for yourself was defined as the time caregivers did not spend providing care for the patient. It consisted of 2 subcategories: limited free time and professional lifetime.

#### Limited Free Time

Most caregivers cohabit with the person they care for, which is described as a limitation of their free time. It was not apparent to caregivers that they had free time for themselves. Any free time resulted from a mindful

organization of their scheduled care activities for the person with HF. The limitation of freedom was experienced in different ways. For example, some people with HF had limited mobility due to their illness, and caregivers were forced to spend all their time with the person they cared for at home or were limited to staying nearby: "I'm locked up here all day" (Spanish woman, daughter, 63 years old) and "You can't go where you want" (Spanish woman, daughter, 56 years old).

However, many caregivers prioritized time for personal well-being. In general, our findings suggest that caregivers who were adult children prefer to plan physical activities: "Time is limited, but I go to the gym... time is all to fit together even if I only have a brief moment, but I try to have some time for me" (Italian woman, wife, 48 years old). Sometimes caregivers had to anticipate the beginning of the daily routine to be able to perform their own self-care, for example:

I'm a federal instructor, but this is all over. I could not. I have been doing it for about fifteen years, but twice a week, I really forced myself to do my daily jog. I do my jogging before going to work. In the morning, I get up at 5:30 AM because that's the only time I can, and then I go to the office. (Italian man, son, 60 years old)

#### Professional Lifetime

Caregiving was described as an obstacle to maintaining one's profession, but professional life experiences differed across the countries. For example, a Dutch caregiver said: "My own life, for my own life, I have always been very independent, a career woman, this had had a horrible effect on my dream about future, my career what I want to achieve for myself here" (Dutch woman, wife, 55 years old). On the other hand, a job was also described as a sort of escape, creating physical distancing from house worries and gaining personal space: "The only thing I need is a job that is...part-time, to get out of the house and during those 4 hours not to be at home, you know?" (Spanish woman, daughter, 48 years old).

Although not yet retired, Spanish and Italian caregivers, particularly women, were more likely to leave or change their jobs to devote themselves entirely to the care of their family members. In fact, women described their career ability as further compromised due to their multiple roles, such as parenting, caregiving, and working, for example, "Well, nine years ago, I stopped working to take care of her" (Spanish woman, daughter, 63 years old). In contrast, Dutch caregivers were willing to anticipate retirement to avoid having their adult children take over the burden of care.

I anticipated retirement because I couldn't work and care for my husband. The economic compensation I get for being a caregiver is not comparable to what I was getting as a salary, which caused me many financial problems. With my husband's pension and what I get, we only manage to pay for our fixed expenses, which are about €1600 (~1750\$).

**TABLE 2** Care Recipients' Sociodemographic Characteristics Divided by Country

	Italy (N = 20)	Spain (N = 19)	Netherlands (N = 11)
	n (%) or Mean ± SD		
Age	73.8 (±10.3)	82.9 (±8.3)	77.6 (±9.2)
Gender			
Male	13 (65)	7 (36.8)	7 (63.6)
Female	7 (35)	12 (63.2)	4 (36.4)
Marital status			
Married	15 (75)	7 (36.8)	9 (81.8)
Divorced	1 (5)	0 (0)	0 (0)
Widow/er	4 (20)	12 (63.2)	2 (18.2)
Employment			
Retired	12 (60)	19 (100)	11 (100)
Unemployed	2 (10)	0 (0)	0 (0)
Unemployed due to caring	1 (5)	0 (0)	0 (0)
Employee	4 (20)	0 (0)	0 (0)
Not reported	1 (5)	0 (0)	0 (0)
NYHA class			
I	3 (15)	0 (0)	0 (0)
II	11 (55)	0 (0)	1 (9.1)
III	6 (30)	0 (0)	4 (36.4)
IV	0 (0)	0 (0)	0 (0)
Not reported	0 (0)	19 (100)	6 (54.6)

Abbreviation: NYHA, New York Heart Association.

Sometimes I think I wish I still had my mother here with me, to help me, so that I could go somewhere...and you know, you don't want to burden your children with that, with that constant crying. They have their own life, and it's only fair that I take care of their father. (Dutch woman, wife, 78 years old)

### House Management

Caregivers were commonly involved in the usual activities of house management (ie, shopping, housekeeping, and meal preparation) by helping the person with HF or doing it for them. In this theme, we have 2 subcategories: housekeeping and rearranging.

#### Housekeeping

In our sample, most women had to juggle the needs of their families. Family members who already played the role of caregiver (eg, mother) for 1 family member, such as a child, were more involved in taking charge of a second family member needing assistance. We also found cultural differences in house management. Dutch caregivers were more inclined to pay for professional help with housework, for example, "No, no, my mother has domestic help, so I don't have to do the household here" (Dutch woman, daughter, 60 years old). On the other hand, Italian and Spanish caregivers viewed these tasks as part of their duty and were less inclined to allow someone outside the family to take care of them. This was particularly true if they were in a marital relationship with a family member with HF; caregivers perceived house management as a duty to be respected as

a family member, for example, "I do everything in the house for him" (Italian woman, wife, 77 years old).

#### Rearranging

Because of physical barriers in the homes of dyads, such as stairs, which make mobility difficult, caregivers' time was also spent rearranging their homes to accommodate the new needs of their relatives. A Dutch woman said, "I think we will have made even more adjustments in the house. For example, if he can no longer go up to the second floor, we will need a stairlift or something. The adjustments may still have to come" (wife, 68 years old).

#### Time for the Patient

This theme also has 2 subcategories: caring activities and coping strategies. About the first one, to make time caring for the person with HF more efficient and manageable, caregivers planned their time by doing things such as setting rules and scheduling visits. In some cases, caregivers require external help from a professional caregiver. With the professional caregiver, they negotiate for efficient use of time. Time spent in person with HF care focused on assisting the person in self-care activities (eg, medication administration, diet supervision, and evaluation of symptoms). The contents described in this theme are consistent with those already described in the caregiver contribution theory in the maintenance, monitoring, and management domains of HF.<sup>31</sup>

#### Caring Activities

Caregivers' time devoted to care activities was reported to be divided chiefly into 2 parts, before and after HF. Caregivers often refer to the past when the patient had no HF or was in its early stages. Now, HF generates apprehension and worries caregivers who remain in a state of overmonitoring, as reported in this quote: "Now I have one more thought, because before I wasn't careful about so many things and instead now, I always have the thought that he might feel bad...even when he goes out with the car... I always think that something might happen. It's changed so much. There's always this thought because you never know he might feel sick with all these pills he's taking. I monitor him every day" (Italian woman, wife, 77 years old). This overmonitoring attitude is increased for caregivers co-living with the patient, who also felt engaged in caregiving activities at night. For example, a Spanish daughter, herself in her 60s, discussed the burden of having to assist her mother: "During the night, it is necessary to carry her to the bathroom...it is a dead weight...." She further added that this was especially difficult because her mother was obese. Furthermore, caregivers who had responsibility for very time-consuming activities without any help or repeated practical tasks over time (eg, positioning in the bed) reported this as burdensome. Caregivers found ways to ease the burden through external resources, as exemplified by the statement of 1 woman who explained:

**TABLE 3** Qualitative Data Extraction Coding, Subcategories, and Themes

Theme	Subcategories	Codes
1. Time for yourself	Limited free time	Adornment Coeval time (lack) Creating free time Limiting free time (due to domestic partnership) Time for personal well-being Renunciations
	Professional lifetime	Adjustment in job Missing promotions Quitting a satisfying job Time as a commodity
2. House management	Housekeeping	Renovating house Moving to a new house
	Rearranging	Considering architectural barriers Getting secure the environment Rearrange the spaces
3. Time the patient	Caring activities	Contribution to self-care maintenance Contribution to self-care monitoring Contribution to self-care management
	Coping strategies	Adaptation Anticipating Balance (in relationship) Balance (need) Combining Family functioning Managing multiple roles Negotiation Prioritization Purposeful planning Repeating
4. Time for own socialization	With the patient	With family With the person with HF (exclusive)
	Without the patient	With friends With colleagues

Abbreviation: HF, heart failure.

“However, we managed to achieve a balance with the caregiver (referring to a professional, formal caregiver)” (Italian woman, daughter, 57 years old).

Caregivers reported information-gathering experiences and continuous learning, reading, or searching the Internet for information about HF, medications, and caregiving activities. However, sometimes caregivers failed to receive accurate information, which led to inappropriate caregiving practices. On the contrary, caregivers improved their skills by learning through observation of nurses who cared for family member or friends with HF. Observation and experience improved caregiver confidence. An Italian caregiver (son, 60 years old) reported his long experience with his mother: “In the long experience of ‘almost’ professional specific assistance that I had to acquire to deal with the physical and daily absence of the nurse or a professional collaborator, I have stolen with my eyes those many times that I had to call a nurse, a cardiologist, or a geriatrician, and from their prescriptions and their techniques, I have acquired an autonomy that I must say in some cases it was better than theirs.”

In our sample, caregivers generally experienced worry and stress at different levels. They were side by side with family members or friends with HF every day, especially during exacerbations of the disease. These moments were experienced with deep feelings of anxiety and loss. Adult children were especially anxious about providing care to their parents. Once the moment of “heart crisis” passed, this feeling changed in daily life to steady apprehension. To “appease” the pedantic sense of apprehension, caregivers reported that they constantly monitored the person with HF over time. Caregivers apprehensively observed the patient and the progress of their symptoms over the days. Finally, as in the case below, he reported making decisions such as moving in together to have more control, thus forcing the balance of the couple's life: “He didn't go to get checked because he said he had work to do, but that night, at 3:00 a.m., he started to break out in a cold sweat and got so scared.... He had surgery, and right after that, rehabilitation was the worst period because we didn't expect it...he is a guy who never accepted his clinical situation so much that he wanted to let go. So there took over my strength to

be close to him and go live with him. He couldn't be alone anymore" (Italian woman, wife, 43 years old).

### Coping Strategies

Caregivers used many coping strategies related to their time management. The caregivers need to understand the process of adapting to life with a person with chronic illness. The illness alters the family's habits, especially in planning long-term activities. Caregivers reported chronic diseases, such as HF, and related consequences and precautions had changed their long-term planning and family routine. An Italian woman (wife, 61 years old) said, "The limitation subsists on vacation because my husband always has to carry the case with the cardiac monitoring device. So many things have suddenly changed a lot from before. It's hard and challenging, but you get used to it."

Caregivers had to adapt to a new structure of life including paying formal help to manage their time in the best way possible: "I had to choose hourly care, paying a (formal) caregiver, which still affects my private life more than the economic aspect. Why? Because the (informal) caregiver finished her hours alternating shifts with mine, she goes away, works 8 hours, and leaves. I am left with all the remaining time, and she gets very agitated at night" (Italian man, son, 60 years old).

Our findings highlighted cultural differences in the relationship with institutions among caregivers of the 3 European countries. Dutch and Spanish caregivers were more involved in negotiations with authorities and institutions than Italian caregivers. Instead, Italian caregivers were more inclined to negotiate with doctors and the person with HF for better acceptance and awareness of the disease. Below are 3 compared experiences:

He says everything I can think of, that everything comes from the stress situation that is going on with bureaucratic authorities. (Dutch woman, wife, 55 years old)

Not at the moment. For the moment, I can manage on my own. Now I asked (for information) because they told me that they (government institutions) gave aid, social workers... they gave it, something from the government of Aragon, they gave it for people who are so (chronic). And I have a visit with the social worker on Thursday the 30th, they will give me something, well no, I will take it, it's just a matter of going to talk about it. (Spanish woman, wife, 74 years old)

[referred to pacemaker] He thought it was a disability to put on a foreign body. He said he would never do that, but we managed to convince him and the doctors. (Italian woman, wife, 79 years old)

### Time for Own Socialization

Caregivers reported that, compared with the past, they had reduced or limited leisure activities with other people in favor of home activities they could do while supervising the patient. An Italian woman (wife, 63 years old) reported, "I liked doing things on the computer and going to the pool with friends, and not all of this.... I can't take it anymore. It is also for the place where I live that there are no autobuses, but I don't even want

to let it go and spend a day doing nothing. More than one friend told me, 'Come and spend the day with us...' but I can't go out. I have him. He is my priority."

### With the Patient

Caregivers spend most of their time exclusively with the person with HF or if, in the company of others, these are mostly family members. For example, a Spanish caregiver (daughter, 63 years old) said, "In my free time, we watch television because my mother likes it. In the meantime, while we watch television, I do crosswords, I read a magazine, I always do something while I stay with her." All caregivers reported this finding regardless of the country from which they came.

Although Spanish and Italian caregivers preferred to spend leisure and recreational time mainly with family, Dutch caregivers reported limited phone contact with family and infrequently spent time with them. Time spent with friends, especially for Spanish and Italian caregivers, was easily sacrificed, for example, "Without friends, there is very little to do. When grandchildren don't go to school, they come home and play a bit. I wish I had more free time to do my thing. I would like to have more free time for myself; however you have to settle for the best" (Italian woman, wife, 77 years old).

### Without the Patient

Caregivers also experienced deprivation of leisure time spent in the social community and with peers. Many caregivers who live in rural areas expressed experiencing isolation and loneliness. Evenings with friends were frequently set aside to be available for the person with HF: "I can carve out some time on Saturday night or Friday night with colleagues. Of course, I had more time previously" (Italian woman, daughter, 57 years old). Dutch caregivers were more inclined to be supported by friends and stay with them briefly. Their experience was reported as "I have a very, very good girl, a friend of mine, who supports me in everything, whatever it is, and me the other way around" (Dutch woman, wife, 63 years old).

Furthermore, unlike Spanish and Italian caregivers, they do not spend most of their time with family: "We don't see every day, but yes, we have a call every day. Just phone, yes, this is the contact with my family" (Dutch woman, wife, 55 years old). Dutch caregivers also reported spending their free time in organized group activities: "Monday morning, I will see my friend because I will go to the sewing club" (Dutch woman, wife, 80 years old).

The time spent on social life was reported to be the most sacrificed. Caregivers had to manage multiple social roles (eg, parent, caregiver, worker). Managing multiple roles leads to combining different activities; however, caregivers were more inclined to prioritize care of persons with HF. This Dutch woman (daughter, 60 years old) shared how she experienced her time for sociality: "You always take her into account, although

she doesn't want her to be in the first place. She thinks she should have a life of her own. But, of course, you think, yes, you are there every day, and then you are busy with it. You participate all day." Thus, considering that caregivers prioritize the care of the person with HF above personal commitments and relationships, it is not easy to distinguish a time devoted to themselves and their social relationships.

## Discussion

In-depth information on time perception was provided. Caregivers noted that they experienced time constraints and emotional turmoil while navigating the complexities of caring for a person with HF. According to previous studies,<sup>21,24</sup> caregivers who provided care for a long period had limited free time, especially if they cohabitated with people with HF. We found that these caregivers were limited not only in free time duration but also in space. Because of functional limitations, the patient's world shrank to where the disease allowed them to move. Consequently, if people with HF and caregivers are considered a dyad, their range of limited movement and action can be compared with a bubble that isolates them from the rest of the world. Furthermore, because of architectural barriers, in city environments (eg, absence of wheelchair ramp) or in-home organization of the home (eg, bathroom on a different floor, stairs), caregivers spent their time dealing with these obstacles. These time-consuming obstacles forced the dyad to stay at home.

Like previous studies,<sup>21,24,32</sup> caregivers in our study also experienced many burdensome deprivations, especially women caring for their partners prioritized and often forgot themselves. Caregivers also felt the urgent need to take time for personal well-being. Our findings are consistent with a previous study that affirms that caregivers never neglected themselves despite the burden of caring for a person with chronic disease because paying attention to themselves led to more effective care.<sup>33</sup> Interventions are needed to relieve caregivers of this burdensome perception. Home-based stress relief interventions for caregivers are required to mitigate the stress of being constantly involved in the care process and the burdensome perception caused by the restriction due to caregiving activities. Activities or practices such as mindfulness or virtual reality can be easy to implement at home and provide relief without the possible guilt of being physically removed from the caregiver.

In time management, caregivers prioritized the needs of their relatives with HF and had to juggle patient care and personal commitments in their professional lifetime. Many caregivers in this study had an irregular career course by adjusting their jobs or altering their career trajectory because they could not live up to the

heavy commitment of care and work obligations. Even caregivers considered early retirement or had to quit a satisfying job. Such early retirement and leaving a career eventually led to financial problems.<sup>34</sup>

We found that culture in the 3 countries was one of the key factors in time management. First, cultural differences were evident in managing one's work obligations and retirement time in our sample. Dutch caregivers were more likely to retire early, whereas Italian or Spanish caregivers quit or reduced working hours. Cultural differences were also evident in home management. Spanish and Italian caregivers preferred to manage their home commitments without seeking formal caregivers' help, because caregiving was perceived as a familial duty. In contrast, Dutch caregivers tended to seek help from paid formal caregivers. This result should be further studied in light of the economic direct or indirect impact this help may have.

Differences in welfare perception were also observed. Spanish and Italian caregivers relied heavily on family-based welfare (often missing), whereas Dutch caregivers based their requests for aid on government subsidies. The lack of response from the state or the family meant caregivers spent more time looking for ways to cope with the care. In our sample, many caregivers complained about dealing with huge care demands due to the time-dependent activities required. Dutch caregivers were especially more involved in spending their time fighting the local system to gain social protection (eg, family allowances and formal supportive caregivers). The caregivers' time management findings related to culture suggest that interventions should consider the home culture of the caregivers.

Caregivers reported that their experiences were incredibly stressful when linked to caring activities (eg, posturing, taking the family member or friend with HF to the toilet), especially those physically heavy and requiring many repetitions per day. The time spent by caregivers on self-care activities was in line with what was found in a previous study.<sup>8</sup> Noticeably, however, they spent much time seeking knowledge to improve their confidence in providing care by searching for online information or observing nurses' activities. Many caregivers also reported no formal educational intervention from healthcare workers. This finding highlights the essential role of formal and structured health education in reducing time for searching for necessary knowledge and improving caregiving confidence by avoiding the sense of inadequacy and self-made remedies reported by caregivers. We could not explore the nature and extent of this self-acquired knowledge they sought in this secondary analysis. Thus, healthcare professionals should assess caregivers' knowledge about HF and HF self-care and identify the best way to improve awareness and compliance among caregivers.<sup>35</sup>



## What's New and Important

- Time management was a burdensome task for caregivers, and they felt limited by the functional limitations of the person they cared for.
- Caregivers had to navigate the complexities of dedicating time to self-care and assisting their relatives with HF in performing effective self-management.
- Caregivers' time management was influenced by cultural expectations, systemic and governmental support, family duties, and the philosophy of healthcare professionals regarding patients' care.

Caregivers in our sample reported that adaptation was the main coping strategy implemented, and time was required to make the house habitable according to the new health needs produced by HF. According to a previous study, after the diagnosis,<sup>9,24</sup> caregivers restructure their life-changing organization or the pattern of their routine to accommodate a new care need of the friend or family member with HF. The necessity of dealing with illness embedded itself in the family routine, affecting its balance. The restructuring also occurred in family relationships. Caregivers also reported long-term planning as challenging due to the disease. These changes required adjustments over time. These findings suggest that healthcare professionals be sensitive in their adaptation stage and challenges in restructuring and provide available resources to help their long-term planning and adaptation.

## Limitations

This was a secondary analysis of qualitative data collected for a mixed-methods study. Thus, the interview guide was not built for this study, and extracting data and analyzing content related to time perception could be limited. Despite this, our limited findings suggest that questions built on time orientation could elicit more in-depth answers on past, present, and future perspectives/orientations.

## Conclusions

Caregivers navigate the complexities of dedicating time to assisting their relatives with HF in self-management and their personal time management. Cultural experiences of time management in caregiving should be considered when developing caregiver interventions. Structured knowledge-based intervention could help caregivers manage their time efficiently with confidence in caregiving.

## REFERENCES

1. Ponikowski P, Voors AA, Anker SD, et al. 2016 ESC guidelines for the diagnosis and treatment of acute and chronic heart failure: the task force for the diagnosis and treatment of acute and chronic heart failure of the European Society of Cardiology (ESC) developed with the special contribution

- of the Heart Failure Association (HFA) of the ESC. *Eur Heart J*. 2016;37(27):2129–2200. doi:10.1093/eurheartj/ehw128 % J European Heart Journal.
2. Corrales M, Paolillo S, Mercurio V, et al. Comorbidities in chronic heart failure: an update from Italian Society of Cardiology (SIC) Working Group on Heart Failure. *Eur J Intern Med*. 2020;71:23–31 <https://doi.org/10.1016/j.ejim.2019.10.008>.
3. Heart Failure Policy Network. *Heart Failure Policy and Practice in Europe*. London, UK: HFPN. 2020. <https://www.healthpolicypartnership.com/app/uploads/Heart-failure-policy-and-practice-in-Europe.pdf>. Accessed July 28, 2023.
4. McDonagh TA, Metra M, Adamo M, et al. 2021 ESC guidelines for the diagnosis and treatment of acute and chronic heart failure. *Eur Heart J*. 2021;42(36):3599–3726. doi:10.1093/eurheartj/ehab368.
5. Kitko L, McIlvennan CK, Bidwell JT, et al. Family caregiving for individuals with heart failure: a scientific statement from the American Heart Association. *Circulation*. 2020;141(22):e864–e878. doi:10.1161/cir.0000000000000768.
6. Buck HG, Harkness K, Wion R, et al. Caregivers' contributions to heart failure self-care: a systematic review. *Eur J Cardiovasc Nurs*. 2015;14(1):79–89. doi:10.1177/1474515113518434.
7. Vellone E, Riegel B, Alvaro R. A situation-specific theory of caregiver contributions to heart failure self-care. *J Cardiovasc Nurs*. 2019;34(2):166–173. doi:10.1097/jcn.0000000000000549.
8. Durante A, Greco A, Annoni AM, Steca P, Alvaro R, Vellone E. Determinants of caregiver burden in heart failure: does caregiver contribution to heart failure patient self-care increase caregiver burden? *Eur J Cardiovasc Nurs*. 2019;18(8):691–699. doi:10.1177/1474515119863173.
9. Chung ML, Liljeroos M, Moser DK, Lennie TA. Perceived control prevents perception of negative changes in life as a result of caring for a patient with heart failure. *J Cardiovasc Nurs*. 2021;36(3):206–211. doi:10.1097/jcn.0000000000000717.
10. Durante A, Cuoco A, Boyne J, et al. Needs and problems related to sociodemographic factors of informal caregiving of people with heart failure: a mixed methods study in three European countries. *J Adv Nurs*. 2022;78(9):3034–3047.
11. Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *Int J Qual Health Care*. 2007;19(6):349–357. doi:10.1093/intqhc/mzm042.
12. Deschler DG, Walsh KA, Friedman S, Hayden RE. Quality of life assessment in patients undergoing head and neck surgery as evaluated by lay caregivers. *Laryngoscope*. 1999;109(1):42–46. doi:10.1097/00005537-199901000-00009.
13. Nasreddine ZS, Phillips NA, Bédirian V, et al. The Montreal Cognitive Assessment, MoCA: a brief screening tool for mild cognitive impairment. *J Am Geriatr Soc*. 2005;53(4):695–699.
14. Brinkmann S, Steinar K. *Doing Interviews*. 2nd ed. London, UK: SAGE Publications Ltd; 2018. doi:10.4135/9781529716665.
15. Saunders B, Sim J, Kingstone T, et al. Saturation in qualitative research: exploring its conceptualization and operationalization. *Qual Quant*. 2018;52(4):1893–1907. doi:10.1007/s11135-017-0574-8.
16. Mayring P. *Qualitative Content Analysis: Theoretical Foundation, Basic Procedures and Software Solution*. Klagenfurt, Austria: SSOAR; 2014. <https://nbn-resolving.org/urn:nbn:de:0168-ssoar-395173>. Accessed July 27, 2023.
17. Elo S, Kyngäs H. The qualitative content analysis process. *J Adv Nurs*. 2008;62(1):107–115. doi:10.1111/j.1365-2648.2007.04569.x.
18. Younas A, Fàbregues S, Durante A, Ali P. Providing English and native language quotes in qualitative research: a call to action. *Nurs Open*. 2022;9(1):168–174 <https://doi.org/10.1002/nop2.1115>.

19. Rodríguez-Madrid MN, Del Río-Lozano M, Fernández-Peña R, et al. Gender differences in social support received by informal caregivers: a personal network analysis approach. *Int J Environ Res Public Health*. 2018;16(1):91. doi:10.3390/ijerph16010091.
20. Walker RC, Howard K, Morton RL, Palmer SC, Marshall MR, Tong A. Patient and caregiver values, beliefs and experiences when considering home dialysis as a treatment option: a semi-structured interview study. *Nephrol Dial Transplant*. 2016;31(1):133–141. doi:10.1093/ndt/gfv330.
21. Kim EY, Oh S, Son YJ. Caring experiences of family caregivers of patients with heart failure: a meta-ethnographic review of the past 10 years. *Eur J Cardiovasc Nurs*. 2020;19(6):473–485. doi:10.1177/1474515120915040.
22. Sampaio C, Renaud I, Leão PP. Illness trajectory in heart failure: narratives of family caregivers. *Rev Bras Enferm*. 2019;72(1):162–169. doi:10.1590/0034-7167-2018-0645.
23. Timonet-Andreu E, Canca-Sanchez JC, Sepulveda-Sanchez J, et al. Overestimation of hours dedicated to family caregiving of persons with heart failure. *J Adv Nurs*. 2018;74(10):2312–2321. doi:10.1111/jan.13727.
24. Bangertner LR, Griffin JM, Dunlay SM. Qualitative study of challenges of caring for a person with heart failure. *Geriatr Nurs*. 2018;39(4):443–449. doi:10.1016/j.gerinurse.2017.12.017.
25. Saldaña J. *The Coding Manual for Qualitative Researchers*. London, UK: SAGE Publications Ltd; 2021:440. <http://digital.casalini.it/9781529755992>. Accessed July 27, 2023.
26. Lindgren BM, Lundman B, Graneheim UH. Abstraction and interpretation during the qualitative content analysis process. *Int J Nurs Stud*. 2020;108:103632. doi:10.1016/j.ijnurstu.2020.103632.
27. JASP Team. JASP (version 0.17) [Computer software]. <https://jasp-stats.org/>. Accessed March 25, 2023
28. Lincoln Y, Guba Y. *EG: Naturalistic Inquiry*. Beverly Hills, CA: Sage Publications; 1985.
29. Korstjens I, Moser A. Series: practical guidance to qualitative research. Part 4: trustworthiness and publishing. *Eur J Gen Pract*. 2018;24(1):120–124. doi:10.1080/13814788.2017.1375092.
30. Cuoco A, Arcadi P, Figura MC, et al. Designing and conducting qualitative research across countries and cultures: challenges for inclusiveness and rigour. *Eur J Cardiovasc Nurs*. 2022;21(8):873–879. doi:10.1093/eurjcn/zvac067.
31. Vellone E, Riegel B, Alvaro R. The situation-specific theory of caregiver contributions to heart failure self-care. In: Im EO, Meleis AI, eds. *Situation Specific Theories: Development, Utilization, and Evaluation in Nursing*. Cham, Switzerland: Springer; 2021. [https://doi.org/10.1007/978-3-030-63223-6\\_14](https://doi.org/10.1007/978-3-030-63223-6_14)
32. Piolli KC, Decesaro MDN, Sales CA. (Not) taking care of yourself as a woman while being a caregiver of a partner with cancer. *Rev Gaucha Enferm*. 2018;39(1):e2016–e2069. doi:10.1590/1983-1447.2018.2016-0069.
33. Eslami AA, Rabiei L, Abedi HA, Shirani M, Masoudi R. Coping skills of iranian family caregivers' in caretaking of patients undergoing haemodialysis: a qualitative study. *J Ren Care*. 2016;42(3):162–171.
34. Pitsenberger DJ. Juggling work and elder caregiving: work-life balance for aging American workers. *AAOHN J*. 2006;54(4):181–185. doi:10.1177/216507990605400408.
35. Durante A, Paturzo M, Mottola A, Alvaro R, Vaughan Dickson V, Vellone E. Caregiver contribution to self-care in patients with heart failure: a qualitative descriptive study. *J Cardiovasc Nurs*. 2019;34(2):E28–E35. doi:10.1097/jcn.0000000000000560.