

The Burden of Heart Failure: Physicians', Patients', and Caregivers' Perspectives Using Narrative Medicine

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Abstract

Background The TRUST (The Roadmap Using Story Telling) project used a Narrative Medicine (NM) framework to assess the impressions of people with heart failure (HF), their informal caregivers and HF specialists of the impact of heart failure (HF) on the daily life of patients and their carers.

Methods Italian HF specialists participated on a voluntary basis, completing their own narratives, and inviting patients and their caregivers to write anonymously about their experiences, all on a dedicated online platform. The narratives were analyzed according to standard NM methodology.

Results 82 narratives were collected from patients, 61 from caregivers, and 104 from HF specialists. Analysis of the three points of view revealed the extent of the burden of illness on the entire family, particularly that of the caregiver. The impact was mainly experienced as emotional and social limitations in patients' and their caregivers' daily lives. The analysis of all three points of view highlighted a strong difference between how HF is perceived by patients, caregivers, and HF specialists.

Conclusions This NM project illustrates the complex issues of living with HF and gave new insight into integrating three different perspectives into the HF pathway of care.

Key Points For Decision Makers:

- Patients and their informal caregivers have a strong need to be heard; narrative medicine provides this opportunity
- Two parallel lives were revealed: patients' lives, which are affected by their HF-related physical limitations, and lives of informal caregivers, burdened emotionally by caring for a family member
- NM offers HF specialists the opportunity to better understand the patient experiences of HF, and an opportunity to actively recognize the role of the caregiver, and educate both

1 Background

Heart failure (HF) is a progressive chronic disease that needs long-term management. It affects 1–2% of the European population and about 10% of people between the ages of 75 and 80 years [1]. The incidence of HF is currently increasing, mainly due to innovative therapies and improved survival from myocardial infarction [2].

Standard treatment for HF requires the patient to take several different drugs daily, which is not only difficult to adhere to but further burdens their daily lives, negatively affecting patient and caregiver quality of life [3, 4]. Moreover, most people with HF have comorbidities, including hypertension (58.4%), atrial fibrillation (25.3%), chronic kidney disease (51.4%), and dyslipidemia (44.6%) [5], which add to the burden on the patient and caregiver/family.

Patient symptoms of HF have been found to be associated with strain in their caregivers [6]. Indeed, the risk of depression and anxiety, as well as financial loss, increases over time in families as a direct consequence of providing care for a person with deteriorating health; this is especially true for female informal caregivers [7]. Risk of hospital readmission rates for people with HF are correlated with lack of social support [8], suggesting the important role of the family environment in the care of people with HF. The need for research into clinical- and person-oriented outcomes of both the person with HF and their caregiver(s) has been recognized [6].

Narrative Medicine (NM) is a methodology based on the analysis of narratives of illness experiences [9]. NM promotes the integration of the disease-centered approach, focused on the clinical aspects, with the illness-centered approach, focusing on personal coping with the pathology, and sickness-centered approach, focusing on social perception of a specific condition [10]. NM is considered a very informative tool, since the integration of all the points of view involved in the pathway of care help reveal common issues as well as possible interventions or solutions about living with a specific disease [9, 11–13]. The main tools of this methodology are parallel charts and illness plots, dedicated to healthcare professionals and patients-caregivers, respectively [14, 15]. Recent studies have demonstrated advantages of applying the parallel chart in exploring a healthcare professional's point of view about the pathway of care for chronic conditions (i.e., chronic obstructive pulmonary disease [COPD]) and doctor-patient relationships [16, 17]. Similarly, patient and caregiver illness plots were recently shown to be a source of information on personal coping with the disease, and on how patients and their families rearrange their lives after a diagnosis in studies in other chronic diseases [18–20].

The main aim of the TRUST (The Roadmap Using Story Telling) project was to investigate the impressions of people with HF, their informal caregivers and HF specialists of the impact of HF on the daily life of patients and their carers, by using NM methodology.

2 Methods

2.1 Participants

This was a cross-sectional project conducted at 21 HF clinics across Italy. Beginning May 2018, 25 HF specialists working at these clinics were invited to take part in a voluntary training session on NM where the methods and aims of the project were described. The 21 specialists who decided to participate then invited people with HF and their informal caregivers to participate, providing them with information materials about the TRUST project.

2.2 Narrative tools

A board composed of two Italian HF specialists (MV and MT) and one patient reviewed the NM tools and patient informed consent forms developed by the "ISTUD Foundation" (Fondazione ISTUD, Milan, Italy) [21], and adapted them for use in this project. The NM tools used were a semi-structured parallel chart (for physicians) and two different versions of illness plots (for patients and caregivers). In these tools the

prompts were composed of brief sentences with the aim of easing response writing (Appendix 1), and were specifically designed to overcome writer's block [22]. All narratives were written in Italian.

2.3 Data collection

From June to November 2018, physicians completed a parallel chart for each enrolled patient. There were no restrictions in terms of patients' disease severity or other clinical parameters; the only inclusion criterion was to write about a person with a confirmed diagnosis of HF whom they had seen at least twice. Patients and caregivers accessed a dedicated online platform to provide their narrations, allowing them to independently and anonymously describe their experiences. The platform is designed to facilitate research in the healthcare sector and includes safeguards to guarantee anonymity for survey participants by not registering sensitive data, such as country of residence or IP address. It is fully compliant with the European General Data Protection Regulations. Only the authors had access to the survey responses, and authors were blinded to the participants' identities.

2.4 Narrative analysis

All collected narratives were analyzed according to the Grounded Theory [23] by three independent researchers (AC, SN, MGM), with the aid of the qualitative data analytics software NVivo10 (QSR International). Additional analyzes were carried out according to Kleinman's theory [10], Plutchik's theory [24] and Frank's classification [25].

2.5 Ethical considerations

Since physicians, patients and caregivers completed their contributions anonymously, the patient described by physicians in the parallel charts could be different from the patient that participated in the project, and there was no possibility for physicians or researchers to identify any potential relationship between them. Informed consent was obtained online from all participants when they first accessed the online platform, prior to writing their narratives. The project was carried out in accordance with the Declaration of Helsinki and was approved by the Institutional Review Board of the Santa Maria Nuova Hospital (Florence, Italy).

3 Results

3.1 Sociodemographic characteristics

A total of 82 narratives were collected from patients, 61 from caregivers, and 104 from HF specialists, for a total of 247 narratives (Appendix 2). Most of the people with HF were male (75%) with a mean age of 68 years; most caregivers were patients' wives (47%) or daughters (35%), with a mean age of 60 and 46 years, respectively. Most patients were pensioners (71%) and 37% of caregivers were employed. The sociodemographic characteristics of participants, both patients and caregivers, were similar to those of the general Italian population, except for education attainment level, which was higher than the Italian

average [26]. The HF specialist narratives described patients with a similar sociodemographic profile to that of participating patients (Appendix 2).

3.2 Management and awareness of the disease

HF diagnosis frequently occurred before 60 years of age, and the mean disease duration was 10 years for patients and as described by caregivers, and was 8 years according to physicians (Table 1). Physicians reported other cardiovascular comorbidities affecting 63% of their patients. Families had to cover 37 km on average to reach the cardiology center, with follow-up every 6 months or more frequently (86%). At home, disease management included the administration of a mean total of eight different drugs per day across seven different times. Most patients reported having New York Heart Association (NYHA) class II or III HF (class II: 27% of patients, class III: 26%). However, physicians described the people with HF in their care as suffering from more severe HF (class II: 44%, class III: 34%). When patients and caregivers were asked to report the patient's ejection fraction (EF), 16% and 17%, respectively, did not know the answer (Table 1).

Table 1

Disease management and clinical characteristics of patients with HF reported by patients, HF specialists, and caregivers

	Patients (<i>N</i> = 82)	Patients described by physicians (<i>N</i> = 104)	Patients described by caregivers (<i>N</i> = 61)
Age (mean ± SD), years	57 ± 3	57 ± 3	–
Disease duration (mean ± SD), years	10 ± 2	8 ± 1	10 ± 3
Recurrence of specialist visits, <i>n</i> (%)	(<i>n</i> = 73)	–	(<i>n</i> = 52)
≥ 1 in 6 months	28 (38)	–	25 (48)
1 per 6 months	35 (48)	–	23 (44)
1 per year	8 (11)	–	2 (4)
< 1 per year	3 (4)	–	1 (2)
Just in emergency cases	–	–	1 (2)
NYHA class, <i>n</i> (%)	(<i>n</i> = 73)	(<i>n</i> = 92)	(<i>n</i> = 53)
I	18 (25)	4 (4)	17 (32)
II	27 (37)	44 (48)	16 (30)
III	26 (36)	34 (37)	18 (34)
IV	2 (2)	10 (11)	2 (4)
Ejection fraction, <i>n</i> (%)	(<i>n</i> = 73)	(<i>n</i> = 102)	(<i>n</i> = 52)
> 40% (HF-pEF)	18 (25)	17 (17)	14 (27)
< 40% (HF-rEF)	39 (53)	85 (83)	21 (40)
I don't know	16 (22)	–	17 (33)
<i>HF</i> heart failure, <i>NYHA</i> New York Heart Association, <i>pEF</i> preserved ejection fraction, <i>rEF</i> , reduced EF; <i>SD</i> standard deviation			

3.3 Analysis of the narratives

3.3.1 Frequent words

Analysis of the 100 most frequently used words in the narratives showed differences in the points of view between the three types of participant. The most frequently used words by patients evoked previous life conditions and expressed fatigue, tiredness, and difficulty carrying out activities that were previously

considered normal, like walking, working, and climbing stairs (e.g., «*Before my illness I was always active, I'd walk at least two hours a day and I had a balanced diet. The only unhealthy thing I did was smoking*»).

The word “fear” was used more commonly by the caregivers than the patients, revealing concern for the quality of life and life expectancy of the patients they cared for. Also present were words relating to the medical domain (e.g., “*physicians*”, “*therapy*”, “*follow-up visit*”).

The physicians’ narratives highlighted the improvements obtained with treatments, but the caregivers were represented as secondary, background figures, as helpers in the event that the patients should fail to comply with the treatments. In most of their narratives the physicians showed trust at the time of diagnosis but felt an urge to reassure their patients (e.g., «*none of them should blame themselves, but they all had to undertake to follow the doctor’s instructions from the time of diagnosis onwards*»). The physicians proved to be aware of the importance of knowing how to actively listen to their patients and in depth, not only in the clinical domain but also in the domains of emotions and planning everyday life.

3.3.2 Burden of the disease on the patient and caregiver

All the narratives were rich in detail about the level of the patients’ quality of life. The consequences of the disease were so burdensome that only 26% of patients and 16% of caregivers stated that they had returned to their usual life (e.g., «*I’ve had to reduce my working hours and ask my children and family for help. Today we spend much of our time at home. We don’t go anywhere*») [Table 2].

Table 2
Patients', physicians' and caregivers' perception of the impact of HF on daily activities

	Patients	Informal Caregivers	Patients, as described by physicians	Patients, as described by caregivers
Impact on work, n (%)	(n = 33)	(n = 21)		
No changes	6 (18)	5 (24)	–	–
Feeling disadvantaged at work	3 (9)	1 (5)	–	–
Limiting activities at work	14 (42)	9 (43)	–	–
Work interrupted	10 (30)	6 (29)	–	–
Spare-time activities before the diagnosis of HF, n (%)	(n = 70)	(n = 33)	(n = 79)	
Social Life (i.e. Dinner with friends, theatre, etc.)	32 (46)	19 (58)	39 (49)	–
Sport	17 (24)	5 (15)	10 (13)	–
Work and little spare time	10 (14)	–	13 (16)	–
Taking care of the family	7 (10)	8 (24)	13 (16)	–
Gardening	4 (6)	1 (3)	4 (5)	–
Impact on daily activities today, n (%)	(n = 69)	(n = 32)	(n = 74)	(n = 44)
Social Life (i.e. friends, theatre, etc.)	18 (26)	5 (16)	34 (46)	5 (11)
Light physical activities (i.e. bike, walk, etc.)	14 (20)	–	14 (19)	
Reading and watching TV	7 (10)	–	1 (1)	
Taking care of the family	5 (7)	7 (22)	4 (5)	
Art (i.e. painting, music, etc.)	3 (5)	–	5 (7)	
Limited activities	15 (22)	–	10 (14)	18 (41)
Impossible to restore activities	6 (9)	9 (28)	6 (8)	16 (36)
Activities not restored due to fear	1 (1)	11 (34)	–	5 (11)
<i>HF</i> heart failure				

Between the three types of participant in this project it was mainly the female caregivers who denounced their caregiving burden, and whose duration of caregiving exceeded 8 hours per day in 55% of the

narratives. A total of 34% of the informal caregivers' narratives considered a return to past activities impossible as it would imply leaving the patients on their own (Table 2).

Based on Kleinman's¹ classification of narratives [10], the most representative style of writing among participants was 'illness' (96% for patients, 100% for caregivers, 96% for physicians).

3.3.3 The emotional impact of the disease

The emotional impact of the disease on participants' lives and physicians' care practice was also investigated through the application of the Plutchik's classification² to the narratives [24]. Physicians' prevalent emotions at the diagnosis were predominantly trust and optimism (61%), and this positivity was still present at the time of writing the narrative (71%) (Fig. 1). On the other hand, the most frequent patient emotions at diagnosis were fear (53%) and sadness (15%), and this emotional impact on ill individuals was also confirmed by both caregivers' and physicians' perceptions. Although at the time of writing their narratives, patients' emotions were characterized by optimism and trust (31% and 23% of patients, respectively), a significant proportion still felt fear (34%) ['Today' Fig. 1], suggesting that they continue to feel afraid about the disease. Similarly, more than 80% of caregivers described having felt fear and anguish at the moment of diagnosis, and these emotions remained in a significant proportion at the time of writing narratives (38%) [Fig. 1].

Furthermore, the future was described as frightening by 21% of patients and 15% of caregivers, and 17% and 23%, respectively, declared they did not want to think about the future. Indeed, 41% of caregivers' narratives contained references to the fear of the sudden death of their loved ones.

3.3.4 Perception of the disease

Patients were asked to define their HF by using a metaphor (Fig. 2). The metaphors were analyzed and grouped into four main classes: (a) *malignant nature* metaphors, relating to something frightful or unpredictable (e.g., "volcano eruption"), (b) *limitation* metaphors, in which the disease is perceived as disabling (e.g., "a very fast car without fuel"), (c) *fight* metaphors, where the disease is seen as an enemy (e.g., a "trench war"), (d) *threat* metaphors, in which danger is the main feature (e.g., "the sword of Damocles"). The patients mostly expressed *limitation* metaphors (72% of patients), the caregivers *evil nature* metaphors (52% of caregivers) [e.g., "slowness" of life], as did the physicians (60%) [e.g., "earthquake", "panther"]. The physicians also frequently used *fight* metaphors (13%) [e.g., "trench war"].

3.3.5 Disease awareness

A high proportion of both patients (69%) and caregivers (84%) stated that they had not initially recognized the first symptoms of the disease, and this underestimation was also reported by 44% of physicians. No initial symptoms were described by participants since the disease occurred suddenly during daily activities (according to 39% of patients and 66% of caregivers), although 25% of patients reported having noticed unusual fatigue before the diagnosis (Fig. 3). In fact, 55% of physicians reported first meeting the person with HF in an emergency situation. Furthermore, several elements in both patients' and caregivers' narratives showed a lack of awareness about the disease (85% of patients and

74% of caregivers) exemplified by their misuse of clinical terms and lack of knowledge about what exactly HF is (Fig. 3).

3.3.6 Doctor-patient relationship

Relationships in the pathway of care were clustered in three main ways: 'easy' relations, when described as comfortable and trustworthy, 'difficult', when described as unsatisfactory, and 'evolved', when initially difficult but with a positive evolution.

Physicians established good relationships with patients and their families (Fig. 4). Furthermore, 7% of physician-patient relationships (from the perspective of the physician) that were difficult initially improved over time (Fig. 4). The highest proportion of difficult relationships early after diagnosis reported by patients were for those between patient and caregiver when the caregiver was a family member (48%). These caregivers were often described by the patient as being more afraid than necessary, and as annoying to the patient, who often desired more autonomy.

3.3.7 Perception of treatment

Therapies were described as effective and were often considered to have contributed to positive relationships between patients and caregivers. Generally, both patients and caregivers were satisfied with patient treatment (more than 80% of each considered them effective or very effective), while surgery, cited by 20% and 6% respectively, was considered the most critical treatment in terms of both risk and effect on outcomes. On the other hand, HF specialists perceived the treatment plan for patients as complex and burdensome in 21% of the cases, more often than the patients and their caregivers did so themselves.

3.3.8 Participation in NM

The patients, physicians and informal caregivers reported their general appreciation for being able to write about their experience, and sharing it was perceived as a liberation and an opportunity to reflect (e.g., «*I was pleased I was able to describe our experience in the hope that it may be useful; indeed, I wanted to thank you for giving me this opportunity*»). Twelve percent of the narratives stated that it was difficult to share the experience (e.g., «*remembering the single moments arouses a feeling of emotional suffering for a situation that is still unsolved and that presents an objective uncertainty for the future of all our family*»).

¹Kleinman's theory [10] distinguishes between illness, disease and sickness. *Disease* means the disease in the biomedical sense, *illness* indicates the subjective experience of the disease and *sickness* means disease as perceived by a social group or population ('social recognition').

²Plutchik defines 8 basic emotions: joy, trust, fear, surprise, sadness, anticipation, anger, and disgust. Plutchik applies a framework to illustrate the various ways in which the 8 basic emotions relate to one another, including which ones are opposites and which ones can easily turn into another one [24].

4 Discussion

The TRUST project aimed to explore living with HF in a multiperspective way through the integration of patients', informal caregivers', and HF specialists' points of view. Firstly, the large number of narratives collected for this project can be considered an excellent result, highlighting the need of patients and their caregivers alike to be listened to. Indeed, participating in the project was rated as a positive experience by about 90% of patients and caregivers, and an even higher percentage of physicians perceived the task of writing as a way to reflect on their work.

Our project results show that HF strongly limits the life of both the patient and their caregiver. The narratives revealed two parallel lives: the life of the patients, which is physically limited, and that of the informal caregivers, which is affected by the need to look after a family member. A substantial proportion of patients adopted hobbies like playing cards or reading in place of strenuous activities such as sport. A strong emotional impact of HF emerged in terms of anxiety and fear of sudden death for both patients and caregivers. This anguish led to additional limitations to activities, and caregivers reported being not only responsible for co-ordinating the patient's complex therapy plan and medical visits, but also having to be constantly in close proximity to the patient due to their deep fear of the patient experiencing sudden disease worsening. Furthermore, most caregivers were women, partners, and daughters, and their narratives exemplified the sacrifices they made. This strong emotional impact of HF on the patient and their family is in agreement with a previously published study, in which caregiving demands have been related to depression in the caregiver [27]. Both had to change their daily lives to cope with this new condition.

Almost all project participants wrote about the patient's HF as an 'illness', according to our analysis using Kleinman's theory [10]. These results are in contrast with those seen with other chronic diseases, for example, COPD [19], in which patients report 'sickness narratives'. Therefore, although some people with HF had engaged in harmful behaviors (i.e., smoking, alcohol consumption, over-eating) that may have contributed to HF development, they did not feel judged for the onset of HF.

All the relationships were described with positivity and patients often expressed gratefulness to their doctors and for effective therapies, as confirmed by the high percentage of 'restitution' style of writing, according to Frank's classification³[25]. Our results are in contrast with a recent Swedish study, which showed that caregivers felt unrecognized for their role in HF management [28], which suggests that caregivers may have difficulty in establishing a positive relationship with the physician. HF care is particularly challenging, not only for the elderly age of occurrence and frequent comorbidities, but also for the high number of different drugs per day patients have to consume. However, it is interesting to notice that the complexity of the treatment plan was considered more burdensome by the physicians than by either the patient or their caregiver. A recent study in patients with COPD demonstrated a link between the physician's style of narrative writing about their relationship with their patient and the quality of care of their patients [29]. In that study, participating physicians wrote 'illness-centered' narratives. Our results were possibly biased towards a positive physician-patient relationship because the HF specialists participating in the TRUST project were already attentive to their relationship with patients.

Both caregivers and HF patients frequently avoided seeking the help of a HF specialist or other healthcare professionals until the patient's condition had dramatically worsened, even if they had recognized unusual fatigue. Participants' narratives included many elements of confusion, and lack of knowledge of HF emerged from their narratives, reflected by their deep feelings of fear and anguish, and those of their caregivers.

Moreover, even when the diagnosis was recent, almost 30% of the affected people and their families didn't know their EF, suggesting that they probably didn't understand the severity of their condition. Indeed, families' poor health literacy and knowledge of HF have been recognized in previous studies [30, 31], especially in terms of understanding specific terminology. Nevertheless, participating patients and caregivers in our project had educational attainment levels higher than the Italian standard, so they had the necessary means to understand the disease course of HF. Interestingly, scarce knowledge of HF was shown even in the case of participants involved in the 'HF Awareness Day' initiative launched by the European Society of Cardiology HF Association [31], suggesting that their desire to be involved in such initiatives was not correlated with higher acceptance or awareness of the disease. What could be inferred from their participation in the HF Awareness Day initiative was their greater desire for effective care, and ultimately complete healing. The metaphor analysis revealed a large difference between patients and physicians in how they defined the disease (essentially an 'internal' understanding or knowledge of disease). While doctors expressed awareness of the inevitable progression of HF, using 'malignant nature' metaphors, patients were mainly focused on the 'limitations' they experienced because of the disease (Fig. 2). Furthermore, the high level of fear and anguish felt by patients and the caring attitude of physicians could have contributed to the lack of communication from doctors of the severe disease prognosis. This requires further study.

A limitation of this project is that all data were gathered by self-report. The large number of narratives collected and the integration of different points of view may help reduce to some extent the possible bias of using a qualitative methodology. Another possible source of bias was the high level of educational attainment among participating patients and caregivers.

³Using the concept "narrative type" Frank [25] described three types of illness narratives: *Restitution*, *Chaos* and *Quest*. The restitution narrative evolved through three stages, beginning with health, followed by sickness, and then by looking forward to a return to health in the future.

5 Conclusions

Our NM project enabled us to describe the profile of those who live with HF and those who take care of people with HF in Italy. Through the integration of the three points of view, the burden of illness on the entire family emerged from understanding the key role of the caregiver in the daily management of the complex care of HF. The impact described in the narratives was mainly focused on the emotional and social limitations of both patients' and caregivers' daily lives, impeding their work activities and impacting on their hobbies and friendships. The strong presence of fear and anguish in patient and

caregiver narratives were probably a consequence of their general lack of knowledge and understanding of HF. Recent evidence showed that low levels of literacy and limited disease awareness are influenced by age-related factors and communication of information [32].

An area deserving multidisciplinary attention is that of the informal caregiver; the stress of caregiving affects not only the caregiver's wellbeing but that of the whole family, which may be defined as a "second victim" of HF. To improve the caregiver's condition, it would be useful to strengthen the therapeutic alliance of the physician-patient-caregiver triad, by acting in several directions:

1. (a) Providing individual psychological support such as brief or extensive counseling, organized in such a way as not to require an excessive time investment or constitute an additional burden on the subject's psychophysical resources.
2. (b) Promoting caregiver interaction within support groups, in order to stimulate and facilitate elaborative/transformational processes allowing the acquisition of new strategies in the daily management of the patient and preventing social isolation.
3. (c) Providing adequate information to the patient and caregiver at the time of communicating the diagnosis, so as to allow adequate understanding of the disease and make the necessary changes to their behavior.

An Italian study has demonstrated the effectiveness of including NM training in the education pathway of cardiology specialists in terms of obtaining relevant healthcare information that their patients may not otherwise disclose and optimizing visits with patients [33]. The application of NM could therefore be considered an effective tool for integrating the different perspectives on life with HF, and to strengthen the triad of care and the therapeutic alliance.

Abbreviations

TRUST - The Roadmap Using Story Telling

NM - Narrative Medicine

HF - Heart Failure

EF - Ejection Fraction

Declarations

Ethics approval and consent to participate

The project was carried out in accordance with the Declaration of Helsinki and was approved by the Institutional Review Board of the Santa Maria Nuova Hospital (Florence, Italy). Written informed consent was obtained online from all participants when they first accessed the online platform, prior to writing their narratives.

Consent for publication

Not applicable.

Availability of data and material

All data relevant to the project are included in the present manuscript. Original narratives are available in Italian upon request to the researchers at the following email address: areasanita@istud.it.

Conflicts of interest/Competing interests

A Cappuccio, S Napolitano, and MG Marini report grants from Novartis Farma Italy, during the conduct of the project. G Maiocchi and M Latella are employees in the medical department of Novartis Farma Italy. M Volpe, M Milli, and M Testa have no conflict of interest to declare.

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Authors' contributions

AC, ML, and MGM were involved in the conceptualization of the TRUST project. AC, SN and MGM contributed to data analysis, and MT, MV, MM, ML, and MGM contributed to project investigation. MT, MV, MM, and the TRUST Group enrolled people with HF. AC and MGM were involved in methodology; AC and SN were involved in project administration; AC, SN and MGM were involved in the analysis of the narratives; and MT, MV, MM, and the TRUST Group were involved in data validation. AC and SN contributed to writing; and all authors contributed to report visualisation and read and approved the final draft for submission.

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Figures

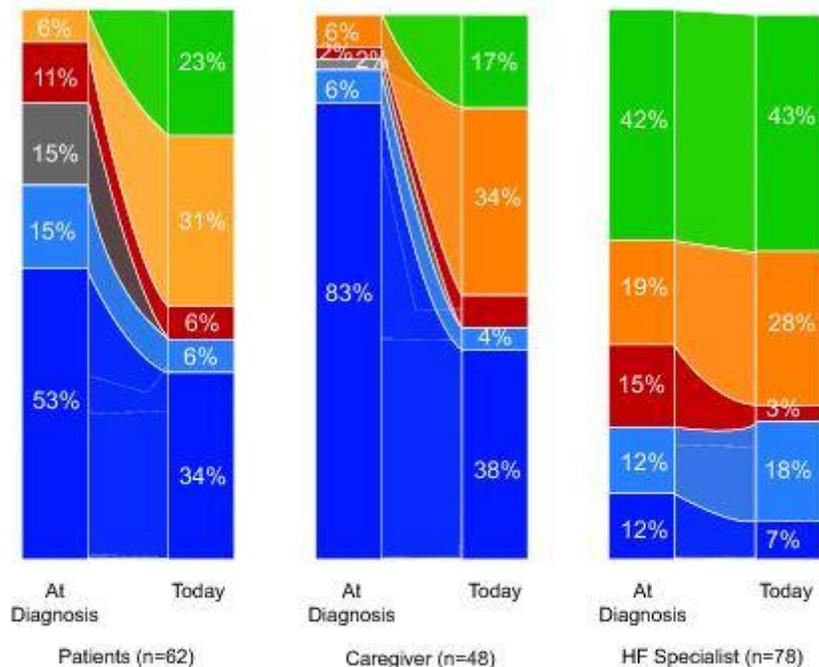


Figure 1

The emotional impact of HF reported by patients, informal caregivers, and HF specialists: a comparison of the emotions felt at diagnosis (via recall) versus those felt at the time of providing their narrative. Data are reported as proportion of patients/caregivers/HF specialists. HF heart failure

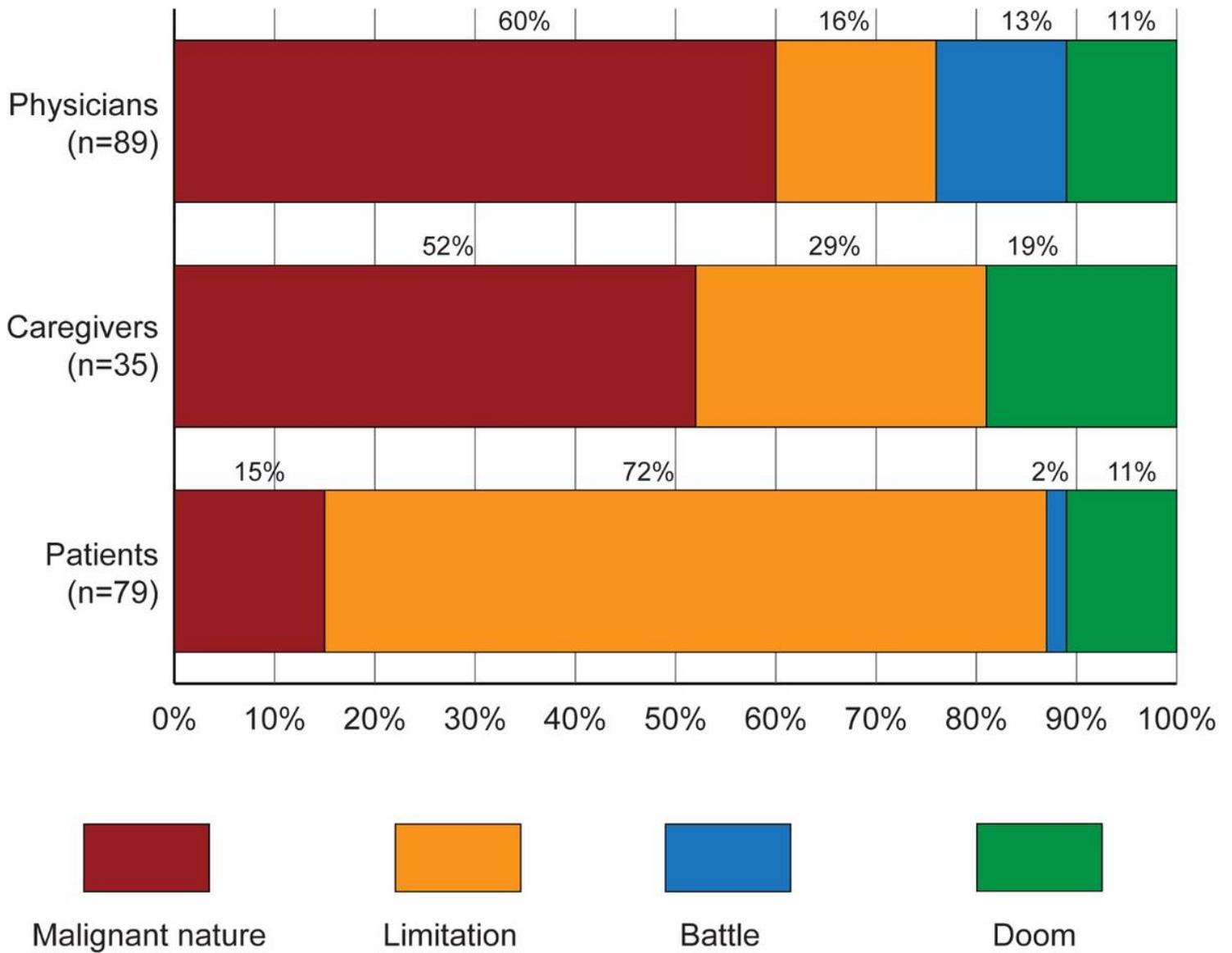


Figure 2

Language analysis of participants' metaphors to describe HF. Data are reported as proportion of patients/caregivers/HF specialists. HF heart failure

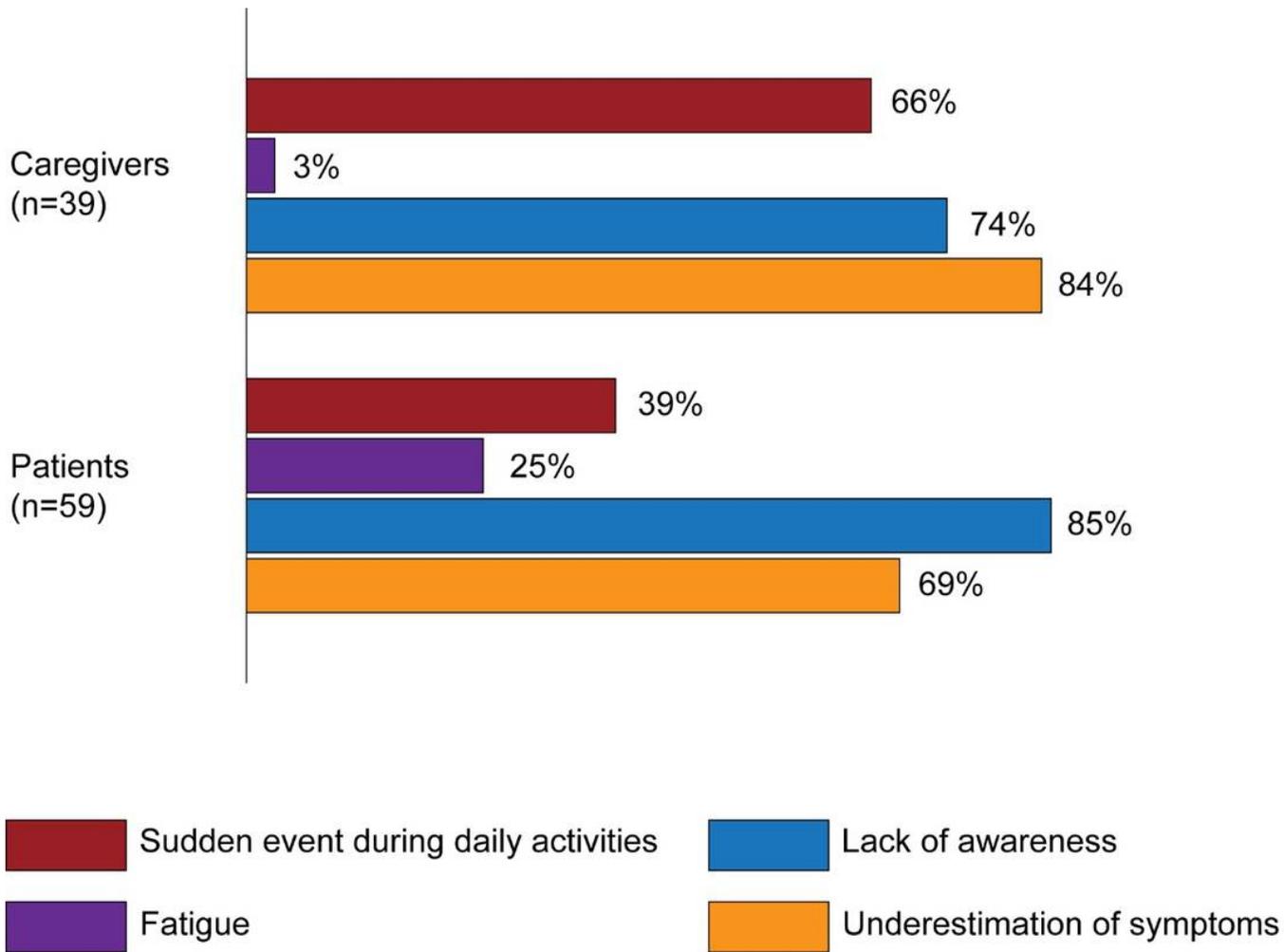


Figure 3

Awareness of the disease symptoms as described in patients' and caregivers' narratives.

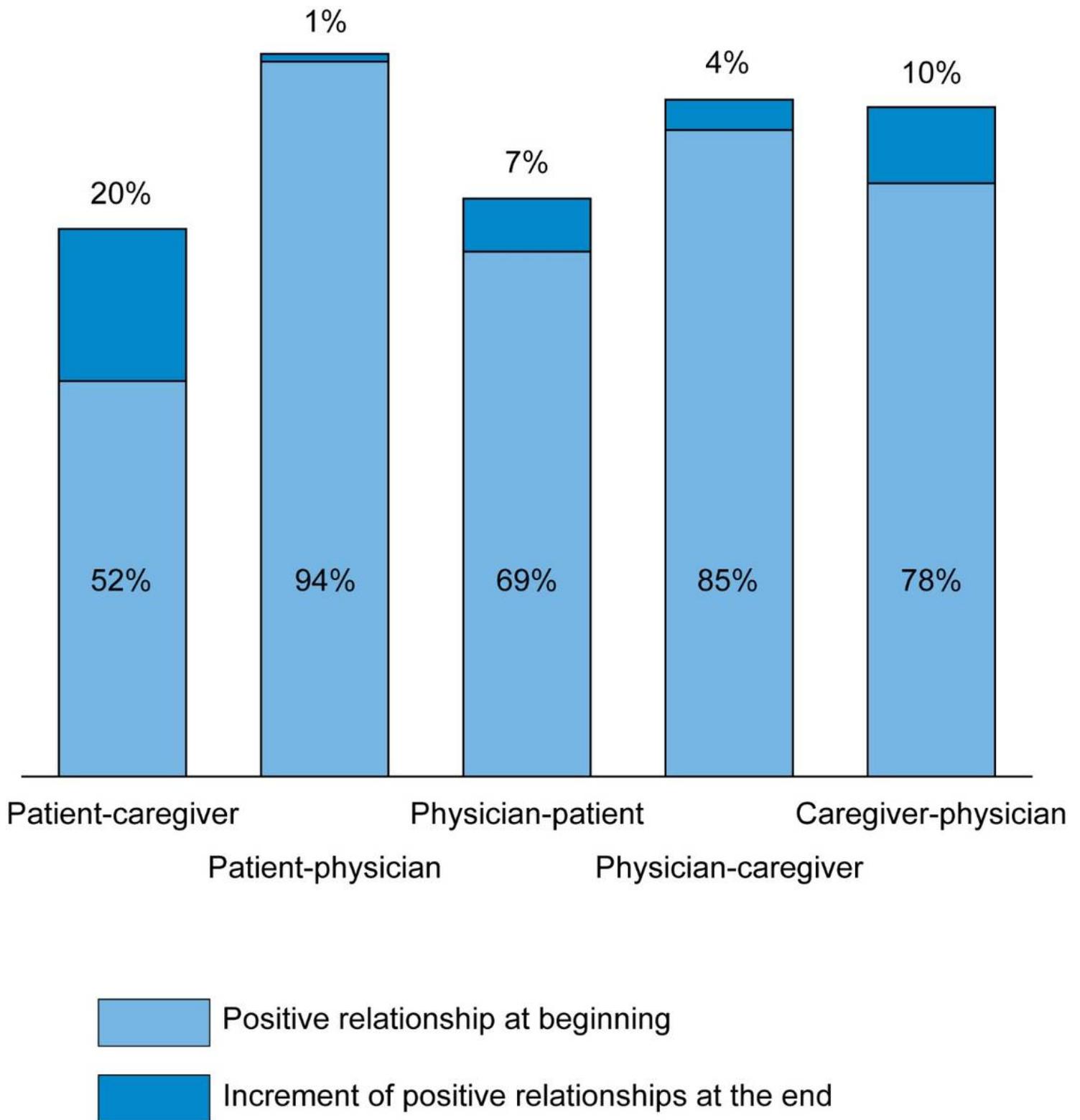


Figure 4

Positive relationships involving patients, caregivers, and HF specialists from the patients', caregivers', and physicians' perspectives, at the beginning of the narrative (light blue) and the incremental increase due to evolved relationships at the end of the narrative (blue)

Supplementary Files

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- [trustcoreq.pdf](#)
- [Marcoetal.Appendix.docx](#)