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Tailoring self-care education to heart failure patients through a narrative medicine approach using DNM, a web-based digital platform

Giovanni Menafra, Livia Pescarollo, Roberta Coluccia, Giovanna Gallo, Nadia Attalla El Halabieh, Caterina Santolamazza, Erika Pagannone, Cristina Cenci, Massimo Volpe, Marco Testa*

Abstract

The burden of disease is changing worldwide, new concepts are needed to approach chronic conditions and the Italian National Plan for Chronicity suggests that empowerment, ability to cope and self-care should be the lever for the efficacy and efficiency of a modern health system. Nowadays, the most prevalent diseases are heart diseases, and particularly heart failure, the common final manifestation of many heart conditions, a highly prevalent, complex clinical syndrome, characterized by severe symptoms that affect functional capacity. The prevalence of heart failure is increasing, mostly because of the growing elderly population, and thus heart failure represents a major challenge for health care systems. Furthermore, about 60% of heart failure patients suffer from five or more comorbid conditions, which worsen prognosis and make management more complicated. One of the crucial tasks in heart failure management is to provide proper education to foster self-care, defined as the "naturalistic decision-making process that influences actions that maintain physiologic stability (maintenance), facilitate the perception of symptoms (symptom perception), and direct the management of those symptoms (management)." Heart failure self-care can be influenced by attitudes, cognitive function, physical function, depression, social support, the presence of caregivers. Riegel and coworkers defined and validated a classification system or typology for the self-care capabilities of patients with heart failure, in which each patient was characterized as 'expert', 'inconsistent', or 'novice' in self-care, on the basis of a variety of characteristics. This classification is useful in clinical practice and for allocating resources to disease management efforts. Our work hypothesis is that education to self-care for heart failure patients, and their caregivers, may be best tailored exploiting the stories of illness peculiar to each patient, and to her/his human environment. To this aim, we propose a narrative medicine approach, performed using a

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web based digital platform called DNM (Digital Narrative Medicine), which allows to exploit the illness narratives of patients and caregivers in order to build an empathic digital network to personalize treatment.
Keywords: *self-care; heart failure; narrative medicine; illness; education.*

I. Introduction

At the beginning of the 20th century, the average life expectancy in Western countries was just over 40. In 2015, it was over 80. We find ourselves confronted with new men and women, bearers of bodies, relationships, needs and identities very different from those of the past and, to some extent, unknown.

The burden of disease is also changing worldwide, with a relentless increase of chronic conditions. The new patient is a multimorbidity and polypharmacy patient. He is seen and often treated as a conglomeration of juxtaposed guidelines, resulting in the intake of more than 10 drugs a day with absolutely no certainty of their efficacy. (Cenci, 2016; Mastromarino *et al.*, 2014) Our medical systems are best suited to diseases of the past than to those of the present and health organizations, medical knowledge and clinical practice are among the contexts that have most strongly felt the impact of this shift. (Jones *et al.*, 2012)

The scientific community is increasingly calling into question the current disease-focused approach in favour of a more patient-centered one, which promotes both appropriateness and adherence. (Mannucci & Nobili, 2014)

The importance of a lay-led chronic disease self- management program, originally pioneered by US researchers, and afterwards implemented also in England, in 2001, by the Department of Health through the Expert Patient Programme is also increasingly recognized. (Taylor & Bury, 2007)

2. Heart Failure

Heart failure is a complex syndrome characterized by a number of symptoms and clinical signs resulting from any structural and/or functional cardiac disorder that impairs ventricular filling and/or ejection, leading to difficulty in maintaining an adequate cardiac output, both during physical activity and, in advanced stages, at rest.

The most common symptoms and signs of heart failure are dyspnea and fatigue, which may limit exercise tolerance, and fluid retention, possibly leading to pulmonary and/or peripheral oedema. Chronic heart failure is an important medical condition whose prevalence and incidence are increasing worldwide, affecting approximately 15 million people in Europe and more than 5 million in the United States, especially individuals aged >80 years and with many other comorbidities. (Mozaffarian *et al.*, 2015; Ponikowski *et al.*, 2016)

From the prognostic point of view, according to the latest data, one-year mortality is 20% in hospitalized heart failure patients and 7% in stable patients undergoing follow-up in out-patient clinics. Five-year mortality is 59% in men and 45% in women.

This clinical syndrome causes a heavy burden for patients, families, and healthcare professionals due to symptom severity, frequent hospital admissions and high healthcare costs. The number of hospital admissions for heart failure is very high in the elderly, an ever-increasing and a more fragile section of the population. (Albert *et al.*, 2015) Despite treatment optimization, there has been no change in heart failure hospital admission rates over the past decade.

Even if heart failure is a leading cause of hospitalization and early death, in more than half of the cases it is not the most important issue influencing the quality of life of patients. (Heidenreich, 2016)

More than disease-related symptoms, other factors are often responsible for anxiety and frustration, and have a relevant impact on illness perception and coping strategies: depression; family and friends not understanding the situation; uncertainty about treatments and symptom improvement; forgetting to take medications or making mistakes, due to polypharmacy. (Albert *et al.*, 2015)

The most recent European and American Heart Failure societies guidelines stress the need to create a support network providing continuity of care within and outside the hospital. The implementation of a comprehensive management system necessarily entails the organization of multidisciplinary programs aimed at improving all outcomes through strict follow-up, patient education, optimization of drug treatment and counselling.

The process of heart failure patient education should include:

1. giving patients responsibility for managing drug regimens, monitoring parameters such as heart rate, blood pressure, body weight and suspicious signs of decompensation;
2. instructing patients on behaviours leading to decompensation;
3. recommending a mild to moderate physical activity.

This information should be conveyed in an easy-to-understand language.

Furthermore, physicians and other health professionals should try to listen to point of views, concerns, and fears of their patients, sharing decisions with them and understanding the significance of the illness in their specific social and psychological context. (Cowie, 2012; Bos-Touwen *et al.*, 2015)

3. Self-care in heart failure patients treatment plan

Self-care is defined as "a naturalistic decision-making process that patients use in the choice of behaviors that maintain physiological stability, the response to symptoms when they occur, management and evaluation of their outcomes." (Riegel *et al.*, 2012; Riegel *et al.*, 2004) The term "naturalistic decision making" is used to describe how people make decisions

in real-world settings. More specifically, heart failure self-care maintenance regards following the advice to take medications, diet recommendations, such as a low-sodium diet, exercise, daily weighing to access fluid retention, preventive behaviours like smoking cessation, limiting alcohol intake and keeping immunization records. Active observation of signs and symptoms refers to self-care monitoring. However, when changes in homeostasis condition occur, such as increasing edema or dyspnea, patients should be able to recognize them, to take therapeutic decisions, such as increasing drug dosages, and to evaluate the response to treatment. All these processes are part of self-care management. (Riegel *et al.*, 2011; Jaarsma *et al.*, 2009; Lainscak *et al.*, 2011)

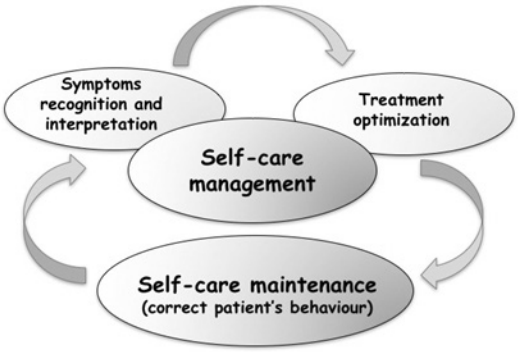

Figure 1: different steps in the process of self-care management

The progression of heart failure is, in part, preventable if patients are engaged in the active management of their disease. In fact, guidelines on heart failure stress the importance of lifestyle advice and self-management strategies. Specialized heart failure services improve adherence to self-management strategies, improve quality of life and show a clear benefit in terms of reduced number of hospital admission and mortality. (McAlister *et al.*, 2004)

Riegel *et al.* (2007) (cfr. Dickson *et al.*, 2008), the leading group of research on self-care, from University of Pennsylvania, Philadelphia,

> defined and validated a classification system or typology for the self-care capabilities of patients with HF, in which each patient was characterized as "expert", "inconsistent" and "novice" in self-care. Self-care 'experts' consistently perform adequate self-care maintenance and management behaviors. They regularly engage in 'body listening' and link specific changes in signs and symptoms to worsening heart failure, make cogent decisions about the changes, rely on a learned repertoire of effective responses, and can evaluate

whether a particular response was effective and should be repeated. 'Experts' have positive attitudes about their health and are confident in their self-care abilities. As self-care 'experts' are typically experienced with the diagnosis of heart failure and have been functionally compromised by their illness, they believe that self-care is important for their well-being.
Patients who are 'inconsistent' in their heart failure self-care behaviors fall into three groups. Some are no longer vigilant, they become relaxed about their diagnosis and give themselves permission to intermittently lapse in self-care. Others have cognitive issues and trouble remembering how to perform self-care correctly. The third subgroup is made up of individuals who make poor self-care decisions, owing to inadequate self-care management skills. For example, a patient might perform self-care maintenance adequately, but lacks a plan to manage signs and symptoms when they occur. Although not necessarily newly diagnosed with heart failure, self-care 'novices' lack self-care maintenance and management skills. They are unable to rapidly categorize health-relevant situations; uncertainty, limited time, vague life goals, and unstable physical conditions contribute to poor self-care decisions. 'Novices' typically hold negative attitudes about self-care, lack confidence in their abilities to perform self-care consistently, or both. For example, patients who believe that diuretic titration is harmful or has unpleasant adverse effects are unlikely to take an extra diuretic in response to weight gain. In addition to being cognitively impaired, patients poor in heart failure self-care are more sleepy during the daytime, are more depressed, and have poorer family functioning than 'inconsistent' or 'expert' patients.

It is, therefore, possible to identify several areas that consistently predict expertise, inconsistency, or novice ability in heart failure self-care.



Figure 2: classification of heart failure patients according to their attitude towards self-care management

These can be summarized as follows: attitudes, cognitive function, physical function, depression, social support, daytime sleepiness. Self-care expertise improves patient outcomes, getting better health status and decreasing the number and duration of hospitalizations.

The effectiveness of self-management can be substantially optimized when interventions are better tailored to individual patients. Factors such as low income, low literacy, low educational level, and low baseline self-management capacity point at those patients with the largest potential for improvement. Identifying those patients with a high likelihood for success can increase effectiveness of interventions. Particular emphasis should be placed on proactive screening and attempts to develop and validate tailored strategies for patients with cognitive or emotional dysfunction. (Bos-Touwen *et al.*, 2015)

Patients involved in self-care learn about their condition and become active participants in the management of their illness, with decreased disease-related hospital admissions (Roccaforte *et al.*, 2005), improved health-related quality of life (HRQoL) (Grady, 2008) but without significant results in mortality rate. (Bos-Touwen *et al.*, 2015) In addition to these outcomes, patient satisfaction, health status, and healthcare utilization may be improved by a tailored approach, based on sharing objectives, action planning, agreeing on what, when, where, and how often specific actions are required.

Another key aspect is the caregivers' contribution to heart failure self-care. They play a major role in heart failure self-care. Caregivers contribute substantively to heart failure patients' self-care characterized from concrete (weighing the patient) to interpersonal (providing understanding).

A multidisciplinary approach is strongly supported, with professionals working together with the patients and their caregivers in a co-ordinated manner. (Illingworth, 2010)

Family-focused behavioral and psychosocial interventions have been demonstrated to be effective in other chronically ill populations, such as diabetics, suggesting a useful role in heart failure patients. Patients could begin self-care education in the hospital, supported in the transition to the outpatient setting, especially in case of low health literacy and older age.

4. Narrative medicine and self-care in heart failure patients

New concepts are needed to approach chronic conditions and the Italian Piano Nazionale per la Cronicità (National Plan for Chronicity), published by the Ministero della Salute (Ministry of Healt) in 2016, mentions *feasible health*, *illness*, *maintenance* and *coexistence* (as opposed to *healing*). It also suggests that *empowerment*, *ability to cope* and *self-care* should be the lever for the efficacy and efficiency of a modern health system.

Narrative medicine, addressing the relational and psychological dimensions beyond physical disease (illness), may be a promising intervention to promote and improve self-care.

Narrative medicine has been defined by Charon as the

> medicine practiced with these narrative skills of recognizing, absorbing, interpreting, and being moved by the stories of illness. As a new frame for health care, narrative medicine offers the hope that our health care system can become more effective than it has been in treating disease by recognizing and respecting those afflicted with it and in nourishing those who care for the sick. (Charon, 2001)

Charon has also proposed the very fascinating metaphor of the activated cellular membrane as a figure for the effective clinician/patient contact: "If our ligands are stories, then what patients say can activate the clinician, causing cascades of transformative meaning-making reactions that culminate in contact, recognition, and clinical action." (Charon, 2012)

Another, more pragmatic, definition is the one proposed by the Italian Istituto Superiore di Sanità:

> The term narrative medicine refers to a clinical assistance methodology based on a specific communicative competency. Narrative is the fundamental tool to acquire, understand and integrate the different points of view of those involved in an illness and in the treatment process. The goal is to develop a shared personalized treatment plan (*care story*). Narrative Based Medicine (NBM) is integrated with Evidence-Based Medicine (EBM) and, by taking into account the various perspectives, makes clinical assistance decisions more complete, personalized, effective and appropriate. (Istituto Superiore di Sanità, Centro Nazionale Malattie Rare 2015)

This latter definition places narrative medicine firmly within the context of a treatment plan and clinical assistance decisions.

The output of a narrative medicine intervention is a "care story" that integrates clinical evidence and experience with the patient's story and offers a personalized treatment plan that has purpose and meaning from the individuals' point of view and not only from that of physicians or healthcare organizations. The care story not only indicates the most appropriate drug and action mix for that patient, but also the words and metaphors that give purpose and meaning to that mix for the patient and the caregiver. Giving back to patients not only the treatment, but also the narrative behind it, promotes a therapeutic alliance and improves self-care. An effective "care story" could help to transform an inconsistent patient into an expert one, focusing on the patients and caregivers' emotions, needs and relationship patterns.

Our work hypothesis is that education to self-care for heart failure patients, and their caregivers, may be best tailored exploiting the stories of illness peculiar to each patient, and to her/his human environment. To this aim, we propose a narrative medicine approach, performed using a web-based digital platform called DNM (Digital Narrative Medicine), which

has very high standards of safety and allows to exploit the illness narratives of patients and caregivers to build an empathic digital network to personalize treatment.

To be effective, narrative relationships, those between people telling and listening to stories, require an appropriate setting. Hospitals, clinics (even private ones), and diagnostic centers all suffer from the same paradox: they are places charged with emotions, fears, expectations, life and death, but at the same time are non-places (Augé, 2008): anonymous, de-personalizing and all made to look alike. The waiting room, which may vary in size and be more or less crowded, is the symbolic space of the non-place. Everything invites depersonalization and standard inclusion into the institution as a whole. The storytelling setting, on the other hand, enhances the individual, his or her unique and inimitable identity. The co-building of a personalized and shared treatment path necessitates a place. The difficulty doctors encounter in applying narrative medicine is often attributed to a problem of a lack of time. But the real problem is not the lack of time, but the lack of a setting. There is no storytelling space in the non-place of treatment. A digital platform can offer this setting. It can offer a protected space for both patients and doctors, a space where only the patient, his or her story and his or her doctor exist, a space on one's smartphone, tablet or computer where there is no waiting rooms, a space for the subject and not the object of treatment. The DNM platform has been developed not simply as a tool for collecting patients' and caregivers' stories, but also as a means to offer a setting for a relationship different from the still fundamentally hierarchic one offline. In the space created on the DNM platform, patients are guided to tell their stories with the help of narrative prompts that facilitate the expression of each person's individuality and unique life story. An example of a prompt is, "It all started when…", or "The journey with illness is different for each person and here I will tell you mine..." Contrary to the traditional medical setting which has a "serial" and "standard" approach to the patient, the digital context of DNM aims to enhance the subjective individuality of each patient and has as its goal a personalized tailored approach. There are many studies underway which include determining patient and caregiver perceptions from digital narrative medicine projects. As of date, the preliminary assessments of DNM often demonstrate the increased effectiveness of a digital setting in favoring the emergence of aspects that are not strictly clinical, but linked to the patients' priorities in everyday life. (Cenci, 2018)

The platform has advanced features including: 1) setting up of lists of narrative stimuli to bring out the impact of the disease; a guided narrative path to allow the patient to share her/his experience, understand and improve therapeutic adherence; 2) enabling the healthcare professional to share stories in a team and exchange remarks concerning the identification of coping strategies, to talk about stories with patients through the platform itself or face-to-face during a follow-up visit; 3) creating a patient profile allowing the team to enter patients' clinical data to readily link stories to clinical and quantitative parameters.

The digital diary shared with healthcare professionals and their team is one of the most effective instrument of digital narrative medicine, because it combines autonomy with condivision.

Patients decide when to write, and caregivers choose when to read and to write. The digital setting enhances the value of the stories both for patients and for healthcare professionals.

5. The contribution of a narrative medicine approach to self-care plan in heart failure patients

O.M. a 65 yo men with ischemic dilated cardiomyopathy, heart failure with severely reduced left ventricular systolic function but fairly good functional capacity, on pharmacological therapy with 5 different drugs.

In response to the narrative stimulus "disease is a journey, different for each one: let me tell you mine…" subministered through DNM platform, he answers:

> I have accepted my problem and I manage to live with it in the best way. Sometimes I make jokes about it. It does not prevent me from carrying out my activities, as a hobby I work my land, go to the gym regularly and I easily drive my motorhome. One of the problem is that sexually it is not like before. I don't know if this problem depends on the therapies or on other things.

His sexual problem, that he hypothetically attributed to the drugs he is on, never came out during several visits in our heart failure outpatient clinic. The platform setting ensured freedom of expression on issues which cannot be easily dealt with in an outpatient clinic setting in the presence of doctors and nurses and allowed the healthcare professional team to detect a major problem concerning both the patient quality of life and the adherence to the pharmacological regimen. It was not possible to understand the problem on the basis of the impressions the healthcare professionals had about the patient, briefly described in our parallel chart:

> Virtually no functional limitations. RV owner for many years, last summer he travelled 45 consecutive days (France, Spain, Portugal) with his wife and other motorhome friends, suggesting the absence of negative experience related to the disease and therapy management.

Another patient, G.D.C., a 73 yo lady, with diabetes, ischemic dilated cardiomyopathy, heart failure with moderately reduced left ventricular systolic function and only minor impairment in functional capacity, on pharmacological therapy with 7 different drugs, 3 of them to be assumed twice a day, plus insulin 4 times a day, in response to the narrative stimulus "the therapy, how do I deal with it…" wrote:

> The things that weigh me down most are: taking so many pills and on schedule, especially [drug-name]. What bugs me most is that it worsens my diabetes. My doctor told me that [drug-name] raises creatinine. I used to go for longer walks and diabetes was more regular.

Such a problem has never been brought out during several visits in our outpatient clinic. As a matter of fact, at the penultimate visit she complained of a commonly reported side effect (cough) of a very commonly used drug, that was discontinued. In the last visit, she reported she was much happier with the new therapy, nevertheless did not report her awkwardness about taking so many drugs, with such a difficult time schedule. Afterwards, we understood that she was actually obsessed with taking the drugs at the specific time we had indicated, when a more flexible schedule could certainly be indicated. Furthermore, she blamed a drug for worsening her diabetes, and appointed to it most of her attentions, but that drug in no way could be thought responsible for that. A subsequent clinical interview was dedicated to explaining the reasons for taking every single drug and the rationale of time schedule indicated, also underlining the possible flexibility of this schedule. This very simple intervention improved, as stated by herself in a subsequent interview, her quality of life and the adherence to pharmacological therapy and self-care behaviour. Also in this case, the impression the care team got, as stated by the parallel chart:

> active patient, attends a senior center where she does theater and a computer course; accompanied by her daughter who lives next door. Enthusiastic about changes in therapy made during the last visit ([drug-name] discontinuation) with regression of coughing; very careful and conscientious, she precisely remembers the therapy. She worries more about her planned dental treatment than about her heart disease

was quite far from what actually came out from the narrative obtained through DNM.

A third patient, G.M. a 76 yo men with ischemic dilated cardiomyopathy, heart failure with severely reduced left ventricular systolic function and severly reduced functional capacity, on pharmacological therapy with 9 different drugs, including benzodiazepines, in response to the narrative stimulus "everyday I tell myself that…" wrote:

> Now, in my daily life, I feel very limited, even because I am not young any more, I'm scared of everything, of the present, but above all of the future and the thought of not being able to help my daughters and my wife makes me really nervous. My character has changed as day and night. Not being self-sufficient as I once was, but having to rely on others makes me nervous, an entirely different person from who I was. I am no longer able to help them and this, together with my fear of tomorrow, troubles me and hurts me. I hope that in time and with medical help I can get back to normal. I

> am sorry I have not explained things right and I have been repetitious, but I feel like I am not clear-headed as I once was. I hope I can recover my self-confidence as soon as possible and get rid of the anguish that is troubling me and making me feel bad.

More than the symptoms reported by the patient, and his accompanying family members, this narrative led us to refer him to a psychiatrist for an assessment on the need for a more effective treatment than a benzodiazepine alone to stabilize mood, which has proved to have a relevant impact on illness perception and coping strategies.

6. Conclusions

Heart failure is a syndrome with a very complex clinical presentation and many comorbidities. It is a heavy burden on patients and causes hospital readmissions and complications. It also crucially compromises the quality of life of patients and families and has direct and indirect effects on the society as a whole. To make it possible for the patient to live with her/his chronic condition and to manage her/his life at full capacity, there needs to be a change in the perspective of treatment planning and, more generally, of care pathways. This allows them to become actors in their pathway and to take part in their treatment program with their wealth of personal experiences.

The main goal of the narrative approach in our heart failure patient follow-up clinic is to refocus attention on each patient. Our preliminary experience enabled us to come up with a few considerations concerning the introduction of this method into clinical practice.

Narrative medicine proves to be an instrument focusing on patient levels of complexity and values which could not otherwise be detected.

On certain occasions, the narrative allowed us to personalize care with additional explanations concerning the management of drug regimens through a debate on alleged side effects and the identification of specific coping instruments.

Using the DNM platform allows patients to make us aware of problems which do not arise in clinic settings.

As a matter of fact, during face-to-face interactions, the patient, acting as a patient, in a classical patient-physician relationship, might focus more on the biological aspects (*disease*) of his/her health problem than on the implications the disease entails in everyday life (*illness*). DNM might create a more "neutral" setting that allows patients to bring up aspects of illness.

The introduction of a digital narrative medicine tool may favour continuity of care between clinic visits, making it possible to create a climate of respect for patient personality and values.

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