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GUIDELINES

Therapeutic education in patients with chronic heart failure: Proposal for a multiprofessional structured programme, by a French Task Force under the auspices of the French Society of Cardiology

Éducation thérapeutique du patient atteint d'insuffisance cardiaque chronique : proposition d'un programme structuré multiprofessionnel par la Task Force française sur l'éducation thérapeutique dans l'insuffisance cardiaque sous l'égide de la Société française de cardiologie

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Abbreviations: PTE, Patient therapeutic education; HAS, Haute Autorité de santé.

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MOTS CLÉS

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Introduction

Diagnostic and therapeutic advances have led to improvements in the survival of patients with most chronic diseases, particularly cardiovascular diseases, and including congenital heart disease. Among these pathologies, heart failure is both common and severe, with a poor prognosis (30% survival at 5-year follow-up) [1] and a very high rate of hospitalization. With the availability of sophisticated therapies a high proportion of hospitalizations and complications of chronic heart failure could still be avoided; these adverse events are due to treatment interruption or inappropriate management related to failure to educate either the patients or their families about the disease [2]. As proved by many studies, patient therapeutic education (PTE) requires active participation by the patient in their process of care and follow-up, and is a key factor in avoiding disease progression and in improving quality of life and life expectancy [3–5]. In 2007, the French High Authority of Health (Haute Autorité de Santé, HAS) published recommendations in concert with the French National Institute for Prevention and Education for Health (*Institut National de Prévention et d'Éducation à la Santé*), in order to bring terms and conditions into play for supervising the practice PTE [6]. The European Society of Cardiology included the PTE approach among practices known to be necessary in the management of patients with chronic heart failure, with an extremely high level of recommendation and evidence (IA – corresponding to evidence and/or general agreement that a given treatment or procedure is beneficial, useful, effective, with data derived from multiple randomized clinical trials or meta-analyses) [7]. In 2007, the French Society of Cardiology established a special commission in charge of optimizing and assessing the influence of PTE policies in the cardiovascular field, and helping health professionals to transition simple therapeutic information into a joint programme of specific education for patients.

Background

In France, PTE for chronic heart failure [8] continues to develop and improve. The process is based on several different systems.

I-CARE programme

I-CARE (*Insuffisance cardiaque: éduCation théRapeutique*) [9,10] is a national, French-speaking programme, held under the auspices of the French Society of Cardiology and the French Federation of Cardiology, and with the institutional support of the Laboratoire AstraZeneca. I-CARE currently

involves more than 220 hospitals and clinics in France, Belgium and Luxembourg. The programme has been in place for more than 5 years, and involves cardiologists and paramedics managing PTE for patients with heart failure. With this programme, PTE and specially designed tools can be created for centres lacking an education component for heart failure patients. The programme is currently under evaluation by a national registry of heart failure (*Observatoire De l'INSuffisance cardiaque*), which will assess the profile of more than 3200 patients who did or did not receive PTE and who were followed-up by the I-CARE centres.

Loco-regional schemes

Loco-regional experience of heart failure management involves heart failure therapeutic units [11,12] and cardiac rehabilitation centres.

Network management

Some networks are specifically dedicated to heart failure management [13,14].

Local management experience

Dedicated health professionals, and sometimes individuals, have experience of heart failure management; while numerous, little information about these local schemes has been documented.

The situations described above are not exhaustive and comparative. They do not provide a comprehensive overview of the issues concerning PTE in heart failure across these different backgrounds.

Set of issues

These situations are diverse and require input from a broad range of dedicated and motivated healthcare professionals. This aspect has inevitably led to the development of a wide range of programmes and disparity in patient management. Neither a consensus for evaluation nor a model of reproducible financing exists.

Rationale for a structured programme of PTE for heart failure

A structured programme is the coordinated collection of PTE activities intended for patients and their families, run by health professionals either individually or as part of a team, with possible participation by other professionals and patients. The programme would provide a point of reference that should facilitate the development of a personalized programme for each patient; it does not have to be a series of actions and a mean of standardized care management.

The aim of this initiative is to enable all patients with chronic heart failure to profit from a formalized and structured PTE programme, with homogenous messages, taking into account the difficult balance between the expectations of health professionals and the individual needs of patients. The health professionals involved can thus bene-

fit from the same programme environment, facilitating PTE development and promoting the exchange of information and experiences between centres.

Major themes

Reminders concerning PTE and differentiation of information

Context

A large proportion of health professionals in the private or public health sector provide patients with information about the disease rather than offering them specific PTE materials. This is due to a variety of factors, including lack of teaching experience, time, means, and formalization of the educational component. Moreover, some educational proposals are unrealistic, largely inapplicable to routine practice or little adaptable for health professionals.

Objective

To define the basic criteria necessary for high-quality PTE materials.

While medical information and PTE cover very different notions, a continuum exists between the two. Health professionals should promote access to PTE for patients with chronic diseases, through specially adapted information. Physicians should respect the fact that the patient may refuse to participate, but also be prepared to suggest their involvement at a later time or propose alternative PTE materials.

Both medical information and PTE can cover a range of levels, with different suggested degrees of intervention. The mere provision of information should not be viewed as an exchange: simply offering information does not equate to a true PTE approach. The differentiation between simple information and specific PTE has been outlined clearly in the 2007 HAS recommendations [6].

With regard to PTE, it is necessary to focus not only on knowledge of the disease, but also on the objectives and the reactions of patients and their families, by encouraging, creating and developing an attractive and positive bilateral relationship. The main feature for the patient is the suitability of the knowledge rather than the simple transfer of information. Educational proposals should be appropriate for the sociocultural level of the patient concerned. PTE should involve professionals trained in both PTE and in the specific disease. PTE should meet quality requirements, be assessable and applicable in all centres in order to benefit most patients and thus to respect homogeneity in health-care quality. PTE should rest on a concept rather than an intangible programme.

The health professional, irrespective of their specialist area, should not work alone in their educational practice; they should be integrated within a management group involving different healthcare specialists, in a formalized and clearly defined common project.

Although one individual may initiate PTE, the programme should be developed by a team, which should include a physician. The attitudes and objectives acquired and maintained by each health professional practising PTE and their

involvement in a team are necessary to ensure a true and successful ongoing programme. PTE should therefore be interdisciplinary and inter-professional.

Target population: chronic heart failure patients and their families

Context

Patients with chronic heart failure present severe disease and a high rate of hospitalizations, some of which are avoidable. The chronic heart failure population is heterogeneous in terms of age and sociocultural level; PTE programmes therefore need a high level of flexibility.

Objective

To adapt PTE programmes according to patients' needs.

Polypathology as well as vulnerable situations (e.g., alcohol misuse, anxiety, depression) are frequent in the heart failure population and sometimes lead to problems of prioritization of educational proposals and/or surprising messages. Polypathology can lead to a number of different, but not simultaneous, PTE programmes. The course of PTE should be negotiated by the health professional, in agreement with the patient, taking into account priorities expressed by both the patient and the healthcare professional and the increasing importance of any concomitant diseases or conditions.

PTE can be offered to all patients, irrespective of the severity of their disease, their age, or the presence of comorbid conditions. Health professionals should adapt themselves according to the patient's sociocultural level and coexisting conditions. PTE may also be intended for, but not limited to, the patient's family or home help (whether or not a medical professional). PTE should be appropriate and follow the initial educational diagnosis.

PTE can be initiated at the time of an acute decompensation, according to local availabilities, programmes, and patients. This 'premature' approach is particularly important in high-risk patients, who are at risk of heart failure recurrence; however, the importance of continuing PTE during follow-up should be considered because of a potentially limited initial impact. In practice, the acute phase is a particularly difficult period for the patient, due to both psychological and somatic aspects. This issue should be taken into account in programmes undertaken in these circumstances.

In reality, there are no circumstances in which it is inappropriate to start or reinforce an educational programme for patients. However, the level of the intervention can be adapted according to the specific circumstances, within the framework of a formalized programme. For example, in some cases, patients can be presented with "micro-training", secondary to educational micro-objectives, as can be the case in private medicine during a patient's educational follow-up by general practitioners or private cardiologists. PTE can be performed at the patient's home, at a medical office, public hospital, private clinic or cardiac rehabilitation centre.

A patient's refusal to participate in PTE should also be respected, and a new invitation to participate in the programme should be offered at a later date. PTE should be performed within the framework of a definite and coordi-

nated programme; it cannot be dealt with during a simple meeting.

Training and qualification of health professionals offering PTE

Context

PTE is a new approach to the relationship between a health professional and their patient. Until recently it was rarely covered in the initial education of medics and paramedics (as currently is the case within the framework of License-Master-Doctorate nurse studies), though now it is now more frequently considered in medical faculties. Training and qualifications gained for PTE take some time to complete, and should be adapted to fit in with usual practice. Training should include theoretical elements reinforced by validated training. A PTE component should be included in the initial training of medics and paramedics.

Objectives

To define the structures necessary to deliver training and the required modalities; to define qualification standards as far as competence in cardiology (educational competence will be approached by another commission); and to put forward authentication of knowledge.

Health professionals not trained in heart failure cannot offer PTE in this disease area. Trainers should have the benefit of both clinical training and cardiology experience.

The programme should include training in PTE – common to all types of training, and whose the application comes under the decree made on 2 August 2010; it should also include specific training into the pathology, therapies and modes of follow-up of heart failure patients. Training authentication takes into account knowledge, and is connected with the learned societies involved. For this, it is important that such societies develop a rapidly available means of training across the country as a whole. This programme can involve, in part, e-learning and multimedia components. Practical training in physiology and heart failure management is an essential prerequisite for all individuals. The programme of training can be flexible and should be applicable to the spectrum of health professionals involved in heart failure care. It should include information not only about heart failure, but also about psychological and social fragility, which are frequent issues in heart failure patients.

Training authentication should largely involve verification of the experiences of the medical and paramedical health professionals who regularly perform formalized, documented and evaluated PTE according to the 2007 HAS recommendations [6].

Essential steps for a PTE programme for heart failure

Identification of patient needs: educational diagnosis

Context

An 'educational diagnosis' is performed by a health professional during the course of one or more discussions with

the patient or before an individual PTE session. Optimal results are achieved through the collaboration of a multiprofessional team, involving, for example, a dietician, physiotherapist, nurse, pharmacist and physician. All factors related to the person and their environment, as well as the interactions between the two, have to be taken into account. This is an essential step in the identification of patient needs and expectations, which are necessary to define and modify the objectives with the patient. Educational diagnosis takes into account the different aspects of the life, personality, potential, needs, and future plan of the patient. Educational diagnosis identifies situations of psychological, social and professional vulnerability for the patient, as well as receptiveness to the PTE proposal. The objective of a written educational diagnosis is to put the patient's priorities versus those of the health professional into perspective, using negotiated therapeutic objectives. At any time, the patient should be able to redefine objectives and modes of execution for educational care management. It is a major component upon which the entire educational process rests. However, it is necessary to be sure that formulated objectives are feasible in routine practice, and are adapted to current conditions of care.

Objective

To define the essential data in the educational diagnosis needed to identify the needs of patients and their families.

Before drawing up an educational diagnosis, it is necessary to collect and document the patient's consent to participate in the PTE procedure (decree of 2 August 2010). Educational diagnosis should be performed as an individual discussion. The value of the data collected and its influence on the rest of the educational programme is more important than its influence on the programme duration, which can be highly variable. As with existing micro-objectives, micro-diagnoses can be performed regularly and sequentially during patient follow-up; however, they should be the subject of a final integration in order to take into account the patient's diversity. The most complete educational diagnosis is essential during the initial phase of patient care management. It cannot be performed by phone or via the internet. The diagnosis should remain applicable and should not come down to a catalogue. It should be transmitted to all participants involved in PTE in order to adapt the messages delivered during PTE sessions, and it should be performed before the educational action. As with all aspects of a patient's medical record, all information should be treated with strictest confidence. All of these general principles are detailed in the HAS recommendations [6].

Formulating competence to develop, action or maintain, according to the chosen therapeutic strategy

Context

These competences are generally well known, and rest largely on expert consensus rather than on data reported in the literature. They have to be included in the strategies of follow-up and patient management; they must also be suitable for the specific population and its own discrete characteristics (e.g., food habits, sedentary lifestyle, age). In reality, the environment must not be too rigid.

Objectives

To define the patient's "minimal competences of security", as they are called in the HAS recommendations [6], and which should, by necessity, include the following:

- to be aware of warning signs and to react in an appropriate manner;
- to take the treatment regularly;
- to adapt levels of physical activity;
- to follow dietary recommendations;
- to organize medical follow-up and care management.

The notion of "competence" is not unequivocal; however, in the context of PTE, competences represent "as much opportunities of including knowledge and capacities at a certain point of their development" according to Roegiers [15].

De Ketele [16] specifies that, on the one hand, capacities consist of knowledge and know-how, and on the other hand, a competence only exists in the presence of a specific situation.

Acquisition of new competences should take into account:

- "know-act" – supposing to know combined with mobilizing relevant resources;
- "want-act" – referring to individual motivation and to more or less incentivising context;
- "can-act" – referring to the existence of a context, a life organization.

Selection of suggested contents and methods used during PTE sessions

Context

Individual PTE sessions are characterized by a discussion with a patient and possibly also their family. The discussion lasts for between 15 and 60 minutes on average, according to the different programmes. They can be shorter and focus on a specific set of issues (micro-objectives) provided that they are preceded by an initial educational diagnosis.

Collective sessions are characterized by the attendance of several patients, and sometimes family members. The advantage of these sessions is the gathering together of patients with the same disease in order to optimize PTE via the "group effect". Collective sessions are specifically suitable for experience sharing, and tend to involve between three and 10 people. The methods used differ from those used during individual sessions; they can be of all types and can partially involve multimedia and information technology, subject to the existence of interactivity at the disposal of acquisition of competences (and not only knowledge). PTE of a high standard will be appropriate for all patients, and will be transposable. Different techniques should be encouraged, without preconceived ideas, provided that they fulfil some conditions (e.g. bilateral relationship, adaptation to patients, respect of individuals, acquisition of competences and not only knowledge, development of patient autonomy).

Objectives

To establish the content of sessions through a matrix of generic competences; to list major themes to approach imperatively, and minimal competences necessary.

Individual and collective sessions should be complementary, and their distribution can vary from one training

structure to another without influencing PTE quality. What is important is to fit the patient and the local resources. Much knowledge and competences are important in cases of chronic heart failure. Acquisition should continue throughout the training process, and should be assessed and followed-up over time.

The types of knowledge and competences that should be acquired during a heart failure educational process are listed in Table 1. The features covered during a complete PTE programme include: knowledge of the disease, warning and urgent signs, diet, physical activity and treatments.

Proposal for practical tools

Context

A notice book should be used during the educational diagnosis and to facilitate data collection; this book should be linked to a multiprofessional training guide (proposal for a unique document for all health professionals involved). This is not a self-administered questionnaire, but a structured discussion support document. It should be appropriate for the specific chronic disease, and cover – beyond simple patient knowledge – information on health, disease, treatment and the dimensions of life and personality; these different components influence the individual's perception of and reactions against the disease. PTE resources include human resources, with health professionals trained to listen to and be receptive to the concerns of patients and their families, and multiple educational techniques and tools. These tools and techniques are insufficient by themselves, and influence only in addition to achievement of educational diagnosis, which allows using them at best. The materials should be tested by potential users (both health professionals and patients), who should consider whether they are appropriate for the target group. These tools and techniques constitute the medium for the educational programme and should be appropriate for the trained patient population (in terms of local or regional, cultural and religious aspects), and for patients and health professionals (modifiable tools). The tools can include help for health professionals in terms of data collection, use of educational-diagnosis data, training, mimicking real-life medical situations, and evaluation. These materials should be reassessed regularly and adapted if necessary. Application of adaptable, simple and possibly transverse common tools will help to avoid heterogeneity in patient management and limit costs. They will also facilitate rapid dissemination of PTE materials. The provision of PTE should not be based solely upon the tools. PTE act should not be limited to the use of tools.

Objectives

To suggest a structured medium for educational diagnosis; and to provide a list of the tools available.

The most frequently used tools and components given to patients in practice at the end of an audit performed in 2009 are detailed in Table 2.

Application of different PTE modalities: initial PTE, resuming PTE, reinforcing PTE

Context

The programme encourages health professionals to suggest a complete panel of PTE along the chain of care, not only an initial PTE as recommended by the French HAS. However,

Table 1 Proposal for educational objectives and tools in patients with heart failure.

Acquisitions for the patient	Complementary explanations for the health professional
<i>Concerning the pathology</i>	
Knowledge	
1 – To know the physiology of the normal heart To have some knowledge about blood circulation, the relationship between the heart and lungs, and the relationship of the heart to the body (drawing and schema)	1 – To know that the heart is a muscle
2 – To know the pathophysiology of the failing heart	2 – To know HF symptoms (patient experience and verbalizing)
To name the type of HF and to be able to explain it briefly	
3 – To know the main clinical signs of HF	3 – To understand and accept that a relationship exists between clinical signs and with the heart
To know the signs of cardiac decompensation (rapid weight increase, oedema, increase in dyspnoea)	
4 – To know the signs of cardiac decompensation	4 – To verbalize heart representation by the patient; to start with patient's own experience and progress to expressing own symptoms
To recognize own decompensation signs To know the risks of HF aggravation	
5 – To know precipitating factors for HF	5 – To start, from patient experience, listing precipitating factors
Knowing to do	
1 – To obtain competence in self-control	1 – To verify, each patient must have access to scales
Weigh oneself at least twice per week, and if weight increase is >2 kg in 2 days, multiply diuretic dosage by 2 for 2 days and/or call physician	
To recognize own symptoms	
2 – To act according to the remarks made by the GP or other professional	2 – To call general practitioner in the case of problems
To list reasons for calling practitioner	
Knowing to be	
1 – To recognize all competences; regular follow-up by professionals	1 – To reposition the role of each professional: cardiologist, general practitioner, nurse, dietician, physical therapist, pharmacist, HF network To make a weight curve; to use scales
2 – To understand that acquisition of competences will lead to improvement in quality of life	2 – To assure the link with the other units concerning low-salt diet and physical activity
To understand that medical treatment only is not sufficient	
To keep own weight-control curve up to date.	
To weigh oneself twice per week (or more or less according to the individual patient)	
To organize means for systematically controlling weight evolution twice per week, and more frequently if necessary	
To adapt behaviour according to the occurrence of symptoms: weight increase >2 kg in 3 days, leg oedema, dyspnoea, thoracic pain, palpitations, fever, bronchitis, fatigue	

Table 1 (Continued)	
Acquisitions for the patient	Complementary explanations for the health professional
<i>Concerning the treatment</i>	
<i>Knowledge</i>	
<p>1 – To recognize the name and mode of action of medications (international non-proprietary name/generics); to understand their aim, mode of action and place in the therapeutic strategy To mention name of medications, indications To mention dosage of diuretic drug To know name, actions and adverse effects of medications</p> <p>2 – To know the importance of observance to (medical and non-medical) treatments and the effects on the disease</p> <p>To know the risks of poor tolerance and risks of poor observance To take treatment assiduously To mention medications that are sometimes forgotten, and for which reason(s) they were forgotten (e.g. diuretics).</p> <p>3 – To know which medications to avoid. To know the main medical interactions with treatments (stability, vitamin K antagonist, etc.) as well as with self-medication</p> <p>4 – To understand the rationale for titration (beta-blockers, angiotensin converting enzyme inhibitors, etc.)</p> <p>5 – To know the name and significance of the main examinations, and the value of biological controls</p> <p>To know the main biological parameters to be controlled (serum creatinine, serum potassium, brain natriuretic peptide) To recognize the results of blood check-up</p> <p>6 – To interpret instructions for medications</p>	<p>1 – To recognize the treatments given for HF, the mode of action in the heart; to notice medications with the help of the patient's prescription (schema, patient prescription)</p> <p>2 – To understand the treatment should be taken regularly and permanently. To mention modality of treatment prescription and prescription renewal with patients</p> <p>3 – To avoid effervescent tablets Non-steroidal anti-inflammatory drugs and corticoids are not recommended To avoid self-medication To notice medications capable of modifying serum potassium concentration; to consider self-medication and possible sporadic treatments (e.g. antibiotics)</p> <p>4 – To know that increase of dosage is not synonymous with worsening of disease</p> <p>5 – To mention brain natriuretic peptide, serum potassium, serum creatinine (connection with anatomical schema) To do a regular blood check-up on prescription by the physician because of the adverse effects of medications, and to control the evolution of the disease and its possible complications</p> <p>6 – To collect patient perception of the message, possibly read in the drug instructions (analysis of instructions during a collective session)</p>
<i>Knowing to do</i>	
<p>1 – To be aware that HF is a chronic condition</p> <p>2 – To observe careful treatment/pill box management</p> <p>3 – To know to adapt attitude in case of therapeutic omission</p>	<p>1 – To anticipate prescription renewal as well as regular assessment of biological controls</p> <p>2 – To anticipate modalities of medications (to possibly anticipate the need for a pill box)</p> <p>3 – To know not to double the dosage; if in doubt, to call the general practitioner To know the possibility for moving diuretic taking</p>
<i>Knowing to be</i>	
<p>1 – To know to take note of the diuretic and its mode of action To adapt dosage of diuretics according to signs of water and salt excess (in agreement with the general practitioner)</p>	<p>1 – To know to adjust diuretic taking in the case of weight increase or to call the physician. To know to adapt diuretic taking in particular circumstances (trip, evening, etc.)</p>

Table 1 (Continued)

Acquisitions for the patient	Complementary explanations for the health professional
To create conditions needed to take medication without mistakes, at the appropriate time during the day	2 – To anticipate the appointments with the different health professionals
2 – To respect prescriptions and appointments with the different health professionals	
To inform health professionals of changes in patient healthcare	
<i>Concerning diet</i>	
Knowledge	
1 – To know to differentiate the reasons why we eat: need = hunger / appetite = pleasure	1 – To ask the question “Why do we eat?” to patients. Explanations and additional information are given by the team (patient verbalization)
2 – To explain the rationale for being on a low-salt diet appropriate to the patient’s status	2 – To teach patients to select food packaging in two groups. Summary and additional information are given by the dietician for each food group (patient active participation)
To know to notice and identify food with low or high salt content	
3 – To know the difference between salt and sodium, and being able to convert the sodium amount into the salt amount	3 – To know that sodium is one of both salt components; thus
To know the food equivalences corresponding to 1 g of salt	salt amount \neq sodium amount,
To identify high-salt food and those freely authorized	salt = sodium \times 2.5 (patient verbalization + explanation by the dietician)
4 – To know the amount of salt that should not be exceeded, and to manage daily	4 – To know that salt supply is assessed by the day
	Explanation by the dietician: 6 g = 2 + 4 g, there only are 4 g to manage by the patient (i.e. if 2 g of salt are present naturally in foods, the patient can add only a further 4 g in cooking 5 – To know about the role of spices, herbs, and aromatic vegetables, etc. (Patient verbalization + explanation by the dietician)
5 – To know modes of seasoning other than salt	6 – To understand the explanation by the dietician.
6 – To know potassium salt is forbidden in HF patients	Connection with the unit on medical treatment
Knowing to do	
1 – To know to manage diet gaps, festive meals, invitations	1 – To verbalize experience + explanation by the dietician
To face unexpected or unusual situations (trip, festive meals, etc.)	
2 – To know to manage meals at restaurants	2 – To recognize high-salt food
To adapt behaviour when faced with an occasional diet gap	To make the most shrewd choice for avoiding salt excess during meals eaten outside of the home (Patient verbalization + explanation by the dietician)
3 – To know to react in the case of an increase in weight of 2 kg between successive weighings	3 – To make the connection between high-salt food and weight increase. Connection with the unit “Treatment and self-control” (Patient verbalization + explanation by the dietician)
Knowing to be	
1 – To learn to avoid the use of the salt cellar at the table.	1 – To give a salt spoon (of 1 g salt) and to explain how to use it
2 – To learn to use modes of cooking and seasoning other than salt.	2 – To suggest contributing to cooking workshops supervised by a dietician
(Patient active participation + recipe index cards)	
3 – To know to manage the prescribed dosage of salt	3 – To use equivalences and a salt spoon (Poster presentation and given document)

Acquisitions for the patient	Complementary explanations for the health professional
4 – To practise regular weight control	4 – To weigh oneself at least twice each week Connection with the unit "Treatment and self-control"
5 – To know to plan daily menus that are balanced and adapted for salt content	5 – To prepare a day of balanced and low-salt menus, with help from a card game (patient active participation)
<i>Concerning physical activity</i>	
Knowledge	
1 – To know the relationship between HF and limitation of life actions by muscular deconditioning	1 – To know that the heart is a specific "muscle" (pump), and a relationship exists between the heart and the peripheral muscles (schema)
2 – To know the benefit of taking part in a form of physical activity To know the benefit of maintaining appropriate and regular physical activity	2 – To know that physical activity is a part of treatment for the same reasons as medications and low-salt food
3 – To take part in personalized, appropriate, and regular physical activity	3 – To know the difference between physical activity and competition Only a consistent pattern of exercise will result in improvement in physical condition and quality of life
4 – To encourage other patients to take part in a physical activity	4 – To take part in simple demonstrations of respiratory, segmental and relaxation exercises
Knowing to do	
1 – To take part in a physical activity	1 – To take part in a physical activity by alternating endurance exercises (walking, biking, etc.) and exercises seen in the education unit
2 – To respect duration of sessions and frequency of training	2 – To exercise for a minimum of 30 min three times per week for endurance; to do all other exercises every 2 days
3 – To recognize the competences of each person	3 – To adapt tastes, pleasures, limiting or predisposing factors (for patients, family circle, environment or professional activity) according to the physical possibilities of each person. To express it by the patients and to allow to determine the objectives negotiated, personalized and solved by a contract
4 – To help the patient take part in a physical activity	4 – To suggest rehabilitation sessions either for endurance exercises or only for respiratory, segmental and relaxation exercises, with a private physical therapist or in a rehabilitation department
Knowing to be	
1 – To incorporate physical activity into normal daily activities	1 – To know that complete cessation of all physical activities for 3 weeks leads to loss of any benefit gained previously
To know to adapt patient activity according to capabilities and tolerance	
To rest sufficiently	
To do a light daily activity, such as walking	
2 – To notice activities at risk and contraindications to taking part in a physical activity	2 – To connect with acquisition of competences to self-control and to notice factors predisposing to decompensation

PTE procedures should remain feasible in terms of time and staff.

Objective

To define the roles of the possible different aspects of the PTE programme.

The patient remains at the heart of the PTE process. This process should be permanent and requires a strong town-hospital relationship. PTE can be performed at the patient's home. PTE does not necessarily imply the existence of a formalized network, but an identified network of participants is needed to avoid "isolated" PTE. The support

Table 2 Most frequently used tools and components given to patients.

Unit	Tools used during the session	Tools given to patients
Knowledge of the disease, pathophysiology, etc.	Diagrams, educational session (interactive teaching, discussion with its different components), slides, paper-board, model of plastic heart	Simplified notebook, thematic index cards, I-CARE course ring binder
Warning signs	Drawing, course, metaplan, game "Knowledge Action Health" (Connaissance Action Santé – CAS)	I-CARE index cards
Treatments	Prescription for patients, colour stickers, pill box, empty boxes, game "Knowledge Action Health" (Connaissance Action Santé – CAS)	Equivalence scale for generics, I-CARE ring binder
Physical activity	Exercise demonstration and achievement, execution of outside activities, photo-language	Notebook with exercises
Diet	I-CARE food-card game and a game mat for menu compositions, I-CARE posters, diet game "Knowledge Action Health" (Connaissance Action Santé – CAS)	Guide notebook, low-salt patient-collected recipe book
Evaluation and tools for educational diagnosis	Contract for therapeutic education IPCEM-MSA (Institut National de Prévention et d'Éducation à la Santé – INPES and Mutuelle Sociale Agricole – MSA)	
Internet tools	www.heartfailurematters.org	

shown in the literature for a multidisciplinary approach reinforces the value of care management by complex structures, allowing easy access to medical and paramedical health professionals, at least during the initial phase of patient training; follow-up can be organized by different medical professionals in hospitals, private practice or in the network. Support from patient associations or patient-experts is a useful factor.

PTE programme evaluation

Context

Evaluation of the PTE programme is a key factor in the success of such an initiative. This process aims to improve the programme, from its inception, through to its organization, and then on to its achievements and evaluation. The evaluation should identify any adjustments necessary or the need to redirect applied PTE activities. The evaluation should focus on the patients, the health professionals and the programme organization. It includes an assessment of the competences acquired by the patient, and evaluations and influence of the personalized education project (e.g. biomedical, psychosocial, medicoeconomic aspects). The evaluation is included in the educational approach, and should be suggested at completion of each PTE programme or at any time in the management if the health professional considers it necessary. Its objectives are not to express an external opinion about the patient, but rather to evaluate its value to the patient through a structured dialogue, and to allow the patient personal satisfaction about the competences they have gained as a result of completing the initiative. The evaluation should be used to update the educational diagnosis and to suggest to the patient a new PTE programme, if needed. Constant evaluation of patient com-

petence is an integral part of care and includes formative education as a constitutive factor of the programme. Owing to the decree on 2 August 2010, the evaluation of PTE programmes is a prerequisite for accreditation by the French Health Regional Agencies (*Agences Régionales de Santé*). In all cases, evaluation procedures should be flowing and feasible – and not limited to economic issues – and allow for improvements to the programme.

Objective

To develop an evaluation through one or more easy and reproducible means.

At present, no plans exist for certification of PTE programmes. To ensure optimal quality, the evaluation should be made at three different levels: the patient; the educational process; and the results, compared to published recommendations. Evaluation is essential for adjusting the educational process and optimizing the use of resources assigned to PTE. Evaluation of the educational process should not be limited to a mere analysis of patient satisfaction but should be affected by other, sometimes very varied, factors (e.g. quality of life, physical activity, functional limitation, adherence to recommendations, diet, hospitalizations, death).

Coordination of participants and conditions of application: PTE charter

Context

The charter is used to tailor the programme coordination, to put forward criteria for the respect of patients, and for ethical considerations underlying each PTE action. The charter should not, however, present a limiting factor.

Table 3 Proposed commitment charter for a patient-therapeutic education programme for heart failure.

Health protagonists commit themselves to respect the basic principles of ethics:

- The patient's personality, dignity and beliefs should be respected
- The health protagonists will provide patient information, will obtain the patient's informed consent to participate in the PTE programme, and will respect the patient's right to decide whether or not to participate in the programme without affecting later care management
- The health protagonists will respect the confidentiality of all collected data and will keep the patient's general practitioner fully informed about the programme
- The health professionals will pay special attention to the consequences of chronic disease on the patient's emotional and relational status, and to the complexity of management for the patient and their family
- The patient's socioeconomic status, cultural and educational level and where the patient lives should not be discriminating, but should be taken into account and the PTE programme adapted accordingly
- The educational approach gives a key role to the patient as a protagonist for his/her health, by resting basically on a care relationship and a structured approach
- The objective of therapeutic education is to ensure that the patient develops the competence needed to routinely manage their disease, with the help of health professionals. Attaining patient autonomy is a complex process, requiring the patient to develop a health-conscious attitude towards their disease guided by the health professionals, and taking into account knowledge, belief and behaviour

Health protagonists commit themselves to respect the quality criteria for patient education:

The PTE programme should:

- Be focused on the patient and their family, taking account of adaptation processes to the disease, and the patient's needs that are provided by trained health professionals
- Be structured, formalized and incorporated into a continuous process of care, and at best multidisciplinary and, if possible, multiprofessional
- Be within the scope of a partnership between the health professional and the patient
- Be assessed in different dimensions (programme, effects and process)
- Be the same quality, irrespective of who delivers the programme and where it takes place

The dialogue between health professionals and patients or their representatives on the definition of aims, content and modalities of PTE programme justifies the need and the role of health professionals

Health protagonists commit themselves to respect quality criteria for cardiology practice:

The PTE programme should:

- Be focused around patient education in the course of their care, suggesting simple and feasible objectives related to the disease
- Inform the patient about the disease, HF treatments, low-salt diet, warning signs, benefits of taking part in a physical activity appropriate to their status, and all factors known to improve or aggravate disease care management
- Bring to the patient the competence, rather than the knowledge, to prevent HF recurrence and/or other cardiovascular complications

Objective

To describe the charter for setting up a PTE programme.

A proposal for a commitment charter for all participants in a PTE programme focused on heart failure (health professionals or not) is listed in [Table 3](#). All health professional participants should contract, in writing, to follow the charter. The charter should be made available to the patients in the premises in which PTE is provided. It includes commitment to confidentiality, patient information, collection of patient consent, and information for general practitioners. Beyond the charter, the existence of a coordinator is key in order to facilitate regular evaluation and relationships between participants.

Communication with other health protagonists

Context

Communication establishes the plan from a long-term perspective and for the process of patient care. Patient

associations play a role in communications, with the involvement of health professionals not initially involved in the educational process.

Objectives

To define forms of communication with other health protagonists influencing patient management. This communication is a key factor in managing the patient as a whole.

Clinical follow-up throughout patient care management is key, providing ongoing opportunities to encourage them to achieve their goals in terms of competency. PTE is not always easy because it comes on top of an already complex management; however, PTE is irreplaceable, and does not necessarily take long because it is a constant process. Evaluation can be done by the centre itself; however, it should be outlined and also documented. Ideally, evaluation should be subject to at least one communication to all concerned protagonists. It should be based on a PTE file related to the decree of 2 August 2010.

Programme limitations

The structured PTE programme should not present a limiting factor, but should provide a means for improving the lives of patients. The programme should respect the diversity of educational structures in terms of premises, PTE formulation and the importance of the teams involved. Neither health professional nor associated professional nor category of patient has to be separated. All data need to be taken into account in the programme, and this should be viewed as an advantage rather than a disadvantage.

Conclusion

Creation of a structured programme dedicated to heart failure is a key factor for the practical development of PTE, and an essential factor for optimizing heart failure management on a national scale. Health authorities need to take into account the financial aspects in order to support the quality of PTE programmes.

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Appendix A.

The French Task Force on Therapeutic Education in Heart Failure comprises:

- Alliance du Cœur: Association de patients cardiaques (ex-FNAMOC: Fédération nationale des associations des malades cardiovasculaires et opérés du cœur)
- ARSI: Association de recherche en soins infirmiers
- AFDN: Association française des diététiciens nutritionnistes
- CESPHERM: Comité d'éducation sanitaire et sociale de la pharmacie française.
- CNCF: Collège national des cardiologues français
- CNCHG: Collège national des cardiologues des hôpitaux généraux
- CNKS: Collège national de la kinésithérapie salariée
- FFC: Fédération française de cardiologie
- IPCEM: Institut de perfectionnement en communication et éducation médicales
- RSSMG: Regroupement des sociétés savantes de médecine générale
- SETE: Société d'éducation thérapeutique européenne
- SFC: Société française de cardiologie et ses groups de travail (GT) « Insuffisance cardiaque et cardiomyopathies » et « Paramédicaux »
- SFK: Société française de kinésithérapie
- SNSMVCV: Syndicat national des spécialistes des maladies du cœur et des vaisseaux

Steering Committee members:

- Chairmen: Patrick Jourdain (SFC, CNCHG, Pontoise) and Yves Juillièrè (SFC, Nancy)
- Representing cardiologists: Jean-Jacques Dujardin (CNCHG, Douai), Dominique Guedj-Meynier (CNCF, Paris),

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- Representing specialists in therapeutic education: Frédéric Giauffret (IPCEM, Toulon), Frédéric Sanguignol (SETE, Bondigoux)
- Representing general practitioners: Éric Drahi (RSSMG, Saint-Jean de Braye)
- Representing pharmacists: Claude Dreux (CESPHARM, Paris)
- Representing nurses: Didier Lecordier (ARSI, Nantes), Véronique Thoré (GT Paramédicaux SFC, Nancy)
- Representing physiotherapists: Patrick Prévost (SFK, Paris), Pierre-Henri Haller (CNKS, Marseille)
- Representing dieticians: Isabelle Parmentier (AFDN, Paris)
- Representing patients: Jean-Claude Boulmer (Alliance du Cœur (ex-FNAMOC), Paris)

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- Representing dieticians: Emilie De Haro (AFDN, Toulouse)
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- Dieticians: Delphine Dumay (CHG, Le Creusot), Catherine Pégé (CHG, Pontoise).
 - Nurses and Head nurses: Catherine Amoros (CDS, CHG, Montélimar), Chantal Bonnin (CHG, Le Creusot), Catherine Duc (CHG, Chalon-sur-Marne), Joëlle Englebert (CHU Sart-Tilman, Liège, Belgique), Isabelle Flaus (CHG, Sarrebourg), Laurence Greday (CHR Citadelle, Liège, Belgique), Florence Lacroix (CHU, Besançon), Sylvie Le Maître (CHU, Rennes), Nicole Pellen (CHU, Rennes).
 - Physiotherapists: Véronique Jan (Réadaptation cardiovasculaire, Machecoul), Régine Péres (Clinique Sainte-Marie, Osny).
 - General practitioners: Jean-Louis Demeaux (PU, Bordeaux), Patrick Dréno (Sautron), Jacques Grichy (Montlignon), Serge Moser (Hirsingue).
 - Patients: Jean-Louis Heulot (Club Cœur et Santé, Pontoise et sa région), Marie-Paule Masseron (Présidente de l'Association Nationale des Cardiaques Congénitaux (ANCC), Paris), Claudine Mekhazni (Club Cœur et Santé, Pontoise et sa région).
 - Public Health, Sciences of Education: François Alla (PUPH, Nancy), Odette Doyon (PU, Université du Québec, Trois-Rivières, Canada), Yves Magar (EduSanté, Vanves), Anne-Françoise Pauchet-Traversat (Paris).
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