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Patient resources in the therapeutic education of haemophiliacs in France: their skills and roles as defined by consensus of a working group

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Summary. The activities of ‘expert patients’ or ‘patient tutors’, who help educate their peers, are gaining recognition in the health care system. This study investigates the role played by such patients in therapeutic education programmes organized by caregivers to validate the role of patients in implementing the therapeutic education of haemophilic patients and to define the skills required for such activities. This study employs the consensus methodology recommended by France’s National Authority for Health. The working group includes seven caregivers from Hemophiliac Treatment Centers (HTCs) and three patients from the French Association of Hemophiliacs (FAH). The role of patients in haemophilia education is recognized. Patients participating in the education of their peers are referred to as ‘patient resources’. A patient resource should be an adult, a volunteer and live in the same region as his peers. Candidates are chosen by the FAH and the HTCs to serve based on their motivation to facilitate

the education of other patients as well as on their psychological and pedagogical aptitudes. A patient resource participates in the conception and administration of therapeutic education programmes. He also mediates between the caregivers and the patients. He ensures that the patients understand the material and are able to apply their knowledge in daily life. His activities are governed by professional ethics. Seven categories of skills were defined, permitting the group to determine precisely which skills are required to function as a patient resource. Supervision of the patients is planned to reinforce reflexive practices in the patients. Evolution of the health care system has led patients to become involved in therapeutic education. This phenomenon calls for a framework to be developed and an evaluation of its eventual effects.

Keywords: consensus method, French Association of Hemophiliacs, patient resource, roles, skills, therapeutic patient education

Introduction

The therapeutic education of patients (TEP) permits a sick person to acquire the essential skills needed to

live best with their specific chronic illness. The patient is considered autonomous, not just capable of making his or her own health-related decisions, but a full partner in the process of providing care.

Studies have revealed that TEP provides numerous benefits to the patient: better perceived quality of life, better long-term control of complications, less stress and anxiety and fewer acute or emergency situations [1,2]. In addition, TEP confirms the practical utility of knowledge and skills acquired and implemented in the patients’ daily lives [1].

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At the same time, 'patient associations' are filling an increasingly important role in TEP [3]. Today, such associations do not limit their efforts to delivering information and providing psychological support to their members. Many wish to participate actively in therapeutic education programmes [3].

In France, the National Authority for Health (NAH) and National Institute for Prevention and Health Education¹ recommend the involvement of patients and associations in the conception, implementation and evaluation of TEP programmes [4]. They even propose that patients should participate in education sessions, working alongside the caregivers in a complementary fashion. The creation of this new role, referred to variously as the 'expert patient' or 'patient educator', raises several issues which this study hopes to address.

What is the real place of patients in TEP and is there consensus between patients and caregivers on this question? What skills are required for these patients to exercise their expected activities? What factors facilitate such an intervention and what factors impede it? Is training necessary?

To answer these questions, the French Association of Hemophiliacs (FAH)² has formed a working group composed of health professionals, patients and relatives of patients. This work reports on results obtained by the group following a methodological approach based on models of consensus. For the purposes of this study, we focus on individual patients who have won a degree of *formal* acceptance. The point is to investigate the nature of a recognized function or an attributed position within the double community of patients and caregivers.

Context

The peer approach

Historically, education by one's peers has always been a factor [5]. Patients discuss their practices, transmit the knowledge and skills needed for remaining active and preserve a heritage of ideas. In the field of health care, this approach first developed as a means of primary prevention, particularly in health education. In this context, TEP has been described as 'the transmission or exchange of health-related information, values, and behaviors among members of an age category or group' [6].

We can distinguish between two kinds of peers: 'multiplying peers' disseminate information, whereas 'support peers' receive information or serve as relays [7].

The terminology used to describe this activity varies according to the roles. One speaks of 'peer tutoring', 'peer counselling', 'peer apprenticeship' or simply 'help from peers' [8].

Likewise, an intervening patient may be described as 'tutor', 'resource', 'expert', 'trainer' or 'partner' [7]. The expert patient is defined as 'a trusted person with the skills and knowledge necessary to take a central position in the management of life with a chronic illness' [9]. This definition may foreshadow one of the requirements for becoming a peer. The presence and participation of peers in TEP, however, still require some clarification. This is what the FAH proposes.

The FAH, an association engaged in therapeutic education

Founded in 1955 by haemophiliac patients and specialist doctors to promote information sharing and mutual assistances. Since 1975, FAH has been involved in training patients to care for themselves at home. This training is carried out in conjunction with health professionals from transfusion centres, and since 1985, has been offered at both transfusion centres and specialized vacation camps run by the FAH. Following a tragic incident involving contaminated blood in the years 1985–1990, the FAH distanced itself from the realm of caregivers. Hemophiliac Treatment Centers (HTCs) were created, belonging to the health care system, but dissociated from the transfusion centres. Despite the fact that HTCs are independent from the FAH, educational activities continue to coexist in the two settings [10]. These activities are aimed at teaching patients and their relatives to manage the illness and treat it themselves. The courses can be individual or collective, given as consultations or practical training, divided into several sittings over a period of 2–3 weeks or spread out over an entire year. Students also have the opportunity to meet other patients and share experiences with their peers.

Thus, the FAH has a long history of working side by side with caregivers, focusing on the problem of patient education. Early, prophylactic treatment is essential to the prevention of a debilitating joint condition [11]. It is thus essential for the patient or a relative to acquire and maintain skills of auto-treatment and adapting to

¹In French, these organisations are *la Haute Autorité de Santé* and *l'Institut National de Prévention et d'Éducation pour la Santé*.

²In French, *l'Association Française des Hémophiles*.

the illness. Health professionals and the FAH have also noticed that young patients may reject the treatment and adult patients may not keep abreast of recent developments in treating and managing the disease. As a consequence, such patients may experience severe physical repercussions and great difficulties with their daily life and personal relations. The FAH is now considering the feasibility of asking haemophilic patients to participate in therapeutic education programmes in collaboration with caregivers.

Method

Composition of the working group

The FAH solicited participants in the working group via e-mail. All participants were required to have experience in TEP. Seven caregivers were retained: four doctors (including one paediatrician), two nurses and a physical therapist. Each one has between 8 and 30 years of experience with haemophilia, the average being 17 years. All have participated in TEP programmes at HTCs. Two caregivers have been formally trained in TEP, one for 6 days and the other for 12 days.

Three haemophilic patients and relatives were also chosen for the working group: two men and one mother with an afflicted 7-year-old child. One of the men, who took charge of this project, is the Vice-president of the FAH. The second is the President of a regional FAH. Both suffer from severe haemophilia. The mother is co-chair of the FAH committee on families. She herself has benefited from a therapeutic education programme consisting of ten three-hour sessions. In total, the group has 10 participants: six women and four men between 37 and 66 years of age. The average age is 49 years.

Procedure

Our working principle was to obtain consensus within the group. To this end, we adapted a short version of the formalized consensus methodology, as described by the French NAH [12].

The consensus work took place from September 2007 to June 2008. The group followed three modes of investigation:

1. Four seminars, each one lasting a day and a half. During these sessions, the group shared a common thinking and broached possible decisions.
2. Six meetings with various experts: a psychoanalyst, a diabetologist, a doctor in public health, two

representatives of patients' associations and a haemophilic patient. Notes were taken during these meetings and the information obtained was used to support and elaborate upon the results of our seminars.

3. The process was completed by reading through a bibliography of related works. Nineteen articles were identified in the Medline database as particularly relevant.

After absorbing these seminars, presentations and papers, the group was able to arrive at a number of unanimous decisions. Each proposition was validated only after achieving consensus within the group.

Results

First of all, the participation of patient resources was validated by the group, but only in the context of TEP sessions.

Definition of a patient resource

A patient resource – this name having been agreed upon by consensus – is defined as a person with moderate-to-severe haemophilia who has had to deal with auto-treatment.

A patient resource is nominated by the FAH and the HTC team from a pool of volunteers and is chosen based on predispositions and skills. Other skills will be acquired through training, setting the patient resource apart from his peers. By applying numerous pedagogical and communication techniques, he encourages other patients to express themselves and helps them understand the discourse of caregivers. He verifies that his peers have acquired the ability to apply the content of TEP sessions in daily life. He relies on live experiences, his own and those of other patients, to encourage effective management and the resolution of common problems.

The patient resource is a volunteer and a member of the FAH. He is chosen and considered a partner by the caregiver team. Ideally, he should come from the same region as the HTC, so that he shares the same values in TEP and the same references concerning offered care. However, a patient resource can come from some other region for occasional interventions.

The patient resource should be at least 18 years old, with no upper limit on age. Ideally, he addresses peers in the same age group, but a young adult patient can speak with older peers and vice versa. This flexibility is necessary given that number of patient resources is likely to be limited, haemophilia being a rare affliction.

The relatives of haemophiliacs are acceptable patient resources for an audience composed of relatives. In this case, the group determined that the patient resource should have at least 3 years of experience with auto-treatment.

Operating rules of a patient resource

After recognizing that patient resources should participate in TEP, the group defined some basic principles governing the position. The patient resource should respect the rules of professional confidentiality. Being significantly involved in the education process and integrated into the team, he is naturally subject to the same rules protecting the patient. His participation should be constant, and he should regularly attend summary meetings held by the caregiver team. The patient resource must agree to continuous training and supervision and participate in meetings where the caregivers analyse medical practices. He should not presume to judge or question medical practices, however, and cannot substitute for a caregiver in therapeutic decisions.

According to the group, there are two possible means of acquiring a patient resource: either the HTC identifies a candidate or the FAH calls on its members via normal communication channels. Confirming a patient resource then requires several more steps: the candidate must submit a letter describing their motivation, and meet with a HTC caregiver and a member of the FAH. The purpose of the interview is to understand better the candidate's motivation and aptitudes.

Role of the patient resource in TEP

The patient resource plays a different role in each educational activity.

The patient resource can reformulate medical knowledge to make it more accessible to his peers. He elicits questions from his peers, then illustrates and provides concrete examples for the medical discourse based on his own daily life. He takes an interest in how other patients apply their lessons in auto-treatment. He promotes interactivity and helps other patients develop social skills under the constraints of adapting to the disease and its treatment.

On his own, he can also help his peers prepare and formulate questions prior to a medical consultation.

Only a caregiver may teach patients the technique of injection, but the patient resource can show other patients how he administers his own treatment if it happens to be his day for a perfusion. He explains and shows the reconstitution of products, calling

attention to important moments in the process of administering the drip. By this means, he can provide advice on making the technique more efficient.

The patient resource also reformulates medical advice on authorized physical activities and their limits.

He can intervene in support group meetings, under the auspices of a caregiver (who might be a psychologist). In this role, the patient resource works to create a climate of welcome and trust, so that his peers are encouraged to express their difficulties. By this means, the patient resource can identify those beliefs meriting discussion.

He participates in summary meetings with the caregivers, describing his observations. For example, he can identify difficulties with the learning process and situations of distress. According to the working group, caregivers should retain full responsibility for the design of a TEP programme, but the patient resource can participate in the final phase by sharing his point of view.

Finally, the working group defined the skills that a candidate should already possess before training in new skills to serve better as a patient resource (Table 1). It also identified factors that might help or hinder the integration of patient resources into TEP programmes (Table 2).

The training and monitoring of patient resources

According to the group, a system should be in place to educate the patient resource at regular intervals (every 2 to 3 years) in addition to their initial training. The continued education of patient resources allows them to maintain existing skills as well as acquiring new ones. This system is also a means of sustaining their motivation and discussing limits on their level of involvement related to the progression of their illness. The training takes place on a national scale, with groups meeting at their local FAH offices. Several sessions are required, usually during weekends. The content delivered by caregivers during these sessions concerns the illness, treatments, complications and incidents. The FAH provides instruction on its own operations and illustrates the medical content with examples from its members' experiences. It joins with the caregivers in explaining the context of haemophilia, resource utilization, the operation and role of institutions, auto-treatment and physical activity. Training in TEP techniques and personal development, offered by an external provider, has two facets: the TEP methodology and general techniques of communication, mediation and leadership.

Table 1. The skills of a patient resource (skills accompanied by an asterisk ‘*’ will be reinforced during training).

Categories	Prerequisites	Skills acquired through training
Understanding his role	Presents himself through his experiences, expresses his personal motivations Does not impose his views and beliefs on others	Work within the team Transmit useful information to caregivers, know his limits and defer to another person (caregiver, patient) whenever necessary, participate fully in conceiving the programme
Pedagogy and mediation	Is capable of... Empathy* Listening*	Lend confidence and aid to peers, so that they can express their difficulties clearly. Explain the discourse of caregivers, reformulate the discourse of peers Public speaking and encourage a climate of welcome and confidence Co-teach a group of patients and facilitate communication in the triangular relationship among caregiver, patient and patient resource
General communication skills promoting peer training	The candidate knows how to explain the importance of physical activity and describe the feelings linked to haemorrhagic signs and pain Illustrate the content using his own or shared experiences and carry out demonstrations along with the caregivers	The patient resource can define a language for the illness He can explain the various treatments, their complications, traceability and the process of fabrication The principle of auto-treatment and its importance The preparation of products and the installation of a containment system The principles of TEP Finally, he can effectively pass on advice and helpful techniques to other patients.
Skill at explaining the illness	Explain the physiopathology*, transmission* and complications* of the illness Explain the principles of auto-treatment and training, as well as their importance	Explain the evolution of haemophilia in a patient and its current context Explain the organization and purpose of HTC's and the FAH Describe the network of care and the association

Table 2. Obstacles and helpful factors in the involvement of patient resources.

Obstacles
Insufficient numbers or unavailability of patient resources
Non-conformity and misconceptions of TEP practices
Unsustainable interventions
Density of training programmes
Rejection of professionals or peers
Inability to accept limitations on the patient resource's role
Helpful factors
Ability to meet the needs of patients and teams, status recognized by peers
A unifying theme
The FAH has strong motivation, as its good relationship with health professionals attests
The patient resource is recognized for offering the benefit of experiences that haemophilic patients have not yet encountered in their training
Training, motivation and determination
The FAH is composed of regional organizations but has a strong incentive to harmonize its TEP practices on the national level
Participation in programmes

Discussion

The patient resource, mediator and relay

According to the working group, the role of a patient resource is closely related to that of a ‘peer assistant’ described elsewhere in the health education literature. The latter’s mandate is to listen to patients and relay information [5]. A peer assistant witnesses the difficulties experienced by his peers in daily management of the illness and its treatments and supports them as best as he can. A particular role concerns parent’s resource. The working group is agreed to improve parent’s resource. They can communicate with other parents and participate in their training. They have to be really clear with parent’s resource status. For instance, they have to control their own experience to take some distance to it. This is important to avoid that their own emotion invades the other parents. In the same way, they cannot criticize the parents in their haemophilia self-

management or their way of life. They have to help other parents to find their own solution.

Indeed, the group finds that 'facilitating communication in a triangular relationship among patient, caregiver and patient resource' lies at the heart of a patient resource's role. The patient resource shares the worries and difficulties of his peers with caregivers and simultaneously listens and responds to their needs [13]. The presence of a helpful third party in this triangular relationship strengthens the voice of the patient.

Indeed, during the group's meetings with outside experts, the psychoanalyst considered patient resources to play a fundamental role in patient/caregiver communication. Moreover, their participation can cut short the difficulties in communication and comprehension previously noticed in a study of patients and caregivers, especially with respect to generalist doctors [14].

The effectiveness of 'peer assistants' is especially prominent among patients living with HIV and presenting symptoms of depression. One study suggests that merely talking with another HIV-positive person has an effect comparable to taking medicinal antidepressants [15].

However, the peer assistant's role is not limited to establishing dialogue. He also acts as a mediator between patients and caregivers. In effect, two viewpoints coexist in the context of any chronic malady: the caregiver-educator's conception of the patient's life and what the patient actually has to live through [2]. On this level, the peer assistant serves as a 'gateway between two universes', between two logical frameworks according to an approach that has been described by peers in health education. For example, when the caregiver proposes a therapeutic treatment to the patient, the peer assistant can call their attention to any constraints on performing the treatment perceived by the patient.

The patient resource in a patient's learning

The role of a patient resource is not limited to mediating and relaying information between a patient and his caregiver. He can also illustrate the proper way of conducting oneself in certain situations such as travelling, running out of material or a haemorrhagic emergency. Through such illustrations, the patient resource uses their personal experience to solidify and contextualize the caregiver's lessons. His example can also fuel discussions with and among the other patients. It is a known pedagogical principle that the process of decontextualization promotes learning in general and skill

acquisition in particular. However, patients have more difficulty implementing cognitive and problem-solving skills than any other kind [16]. Another study emphasizes the difficulty patients have making certain daily decisions, demonstrating the necessity of more rigorous training [17].

Thus, a patient resource can enhance auto-treatment workshops by sharing techniques, advice and lessons gleaned from his own experience. Such concrete examples represent a body of knowledge directly and immediately applicable by the other patients. The patients can rely on this knowledge, using it as a foundation for their own procedures. That is, the peer can profit from these experiences and eventually make them his own.

Moreover, a study on the peer approach in health education has shown that peer educators have superior impact on their students. This can be explained by the phenomenon of peer identification [18].

Through this position and the value placed on his words, we can suppose that the patient resource enhances skill acquisition in his peers.

According to Coulter [19], only the patient experiences his illness. Thus, associating the caregiver's knowledge with the patient's own experiences is necessary to managing the condition. However, the role of the patient resource is not that of the caregiver. Under no circumstances can he substitute for a caregiver, but he can complement health care professionals by adapting academic knowledge to the practical experiences of his peers.

The patient resource, skills

With respect to skills, the working group referred to the definition of Wittorski [20], who wrote that 'skill is the mobilization of knowledge to action within a given context'. Other authors have reinforced this idea. For example, to Philippe Jonnaert [21] a skilled person is 'one who implements a diverse, but coordinated ensemble of resources in a particular context'.

The group described various knowledge categories (learning, expertise, personal skills), only then distinguishing those required at the beginning from those that a candidate must acquire to become a patient resource.

A patient resource is skilled at managing his illness, as well as possessing the qualities of adaptation, anticipation and decisiveness that result from broad practical experience. Nonetheless, it is not enough for the patient resource to understand 'his' illness and 'his' treatment. He must also acquire an exten-

sive knowledge of haemophilia in general, the evolution of its management and the various treatments. To generalize his knowledge, the patient resource must distance himself from his own experience. But above all, he must be capable of explaining this knowledge to his peers, that is, he must possess skills of pedagogy and communication. To support his role as a peer assistant, the patient resource must be able to speak in public and administer education sessions to a group of patients. Furthermore, he must resist centring the discourse on his own experiences in favour of encouraging his peers to absorb the message. This skill demonstrates a certain aptitude for interpersonal relations with peers and health professionals. Recall that another of his roles is to facilitate the exchange of information between these groups and reformulate their communications.

Finally, we note a few other important skills. One such element, emphasized by the working group, is a capacity to recognize and express feelings such as haemorrhaging, pain and other warning signs. Recognizing these signs requires vigilance as well as the aforementioned skills. The point is not just to listen to one's body and notice symptoms, but to explain the process to one's peers. In effect, only the patient resource is able to evoke and share his perceived symptoms, perhaps by defining a new semiology. A recent study has found that a similar capacity develops in certain diabetic 'sentinel patients' who perceive their symptoms earlier than usual [22].

The educational objective of caregivers is to sensitize patients to and restrict the appearance of debilitating complications such as haemarthrosis, whose repercussions can have a severe impact on physical well-being and mobility [14]. This aspect brings up another of the patient resource's roles: preventing complications from arising and managing the risk of accidents among his peers. According to the group, here the patient resource plays a fundamental role: since the advent of prophylaxis, haemorrhagic accidents have become not only rarer but also less perceptible to the patients [23]. To respond to these events, a patient needs to learn to notice very subtle sensations in his body [22].

The peer approach in health education has demonstrated that constant supervision is necessary to predict possible difficulties [6]. Note that the group consensus called for implementation of continuous training. Supervision would take place during interventions, followed by sessions with the HTC team to analyse the practices. This system is of fundamental importance and could integrate a programme of continuous patient training via a

combination of pre-essential sessions and distance learning (e-learning, an Internet site). The World Health Organisation (WHO), in its 2007 report on teaching by patients, underlined the importance of a system for training and maintaining the skills of patient resources. According to this organization, such a system would be a determining factor in the sustainability of peer education programmes [24].

Conclusion

This study reports on the findings of the working group following a methodology based on achieving consensus. The group, composed of caregivers, patients and relatives of patients, validated the participation of patient resources in therapeutic education programmes. It defined the roles of a patient resource, as well as various predispositions and skills associated with the position. Some of these are required at the outset, whereas others can be acquired by a candidate through specific training. The working group also determined the modes of recruitment and affirmed the need for a system of ongoing training. Thus, in collaboration with caregivers, the patient resource can play an important part in the therapeutic education of haemophilic patients.

Haemophilia poses several obstacles to its victims, both daily and in the long-term. Afflicted patients must acquire skills of auto-treatment and adaptation. The intervention of a patient resource can promote acquisition of these skills. But the group specifies that patient resources should never assume sole responsibility for the education of patients. From this perspective, patient resources join with medical professionals on a complementary basis in the domain of TPE. The pertinence of their participation in this field should be evaluated [24].

Disclosures

The authors stated that they had no interests which might be perceived as posing a conflict or bias.

References

- 1 Gagnayre R. Education thérapeutique du patient. In: Bourdillon F, Brücker G, Tabuteau D eds. *Traité de Santé Publique*, 2ème édition. Paris: Flammarion Médecine-Sciences, 2007; 216–21.
- 2 Ivernois (d') J-F, Gagnayre R. *Apprendre à Éduquer le Patient. Approche Pédagogique*, 3ème édition. Paris: Maloine, 2008; 155 p.
- 3 Lecimbre E, Gagnayre R, Deccache A, Ivernois (d') J-F. Le rôle des associations de patients dans le développement de l'éducation thérapeutique en France. *Rev Fr Sante Publique* 2002; 14: 389–401.

- 4 Haute Autorité de Santé (HAS). Guide méthodologique. *Structuration d'un programme d'éducation thérapeutique du patient dans le champ des maladies chroniques* 2007; 1–103. [en ligne]. Available at: <http://www.has-sante.fr>. Accessed June 3, 2009.
- 5 Baudier F. *Education Pour la Santé par les Pairs*. Paris: IIèmes Journées annuelles de l'INPES, 2006. [en ligne]. Available at: http://www.inpes.sante.fr/jp/pdf/2006/jp2006_session_4.pdf. Accessed June 3, 2009.
- 6 Arwidson P, Bury J, Choquet M *et al.* *Education Pour la Santé des Jeunes. Démarches et Méthodes*. Paris: Inserm, 2001: 247 p.
- 7 INPES. Les journées de la prévention. Les différentes places du patient dans la démarche éducative. *IIIèmes journées annuelles* 2007. [en ligne]. Available at: <http://www.inpes.sante.fr/jp/cr/pdf/2007/session3/synth.pdf>. Accessed June 3, 2009.
- 8 Green J. Peer education. *Promot Educ* 2001; 8: 65–8.
- 9 Shaw J, Baker M. Expert patient dream or nightmare? The concept of a well informed patient is welcome, but a new name is needed. *BMJ* 2004; 328: 723–4. [en ligne]. Available at: <http://www.bmj.com/cgi/content/full/328/7442/723>. Accessed June 3, 2009.
- 10 Ayçaguer S, Gagnayre R. Réflexion sur la contribution d'une association de patients dans le champ de l'éducation thérapeutique. *EP&ES* 2007; 68: 235–42.
- 11 Mulder K, Llinas A. The target joint. *Haemophilia* 2004; 10: 152–6.
- 12 Haute Autorité de Santé (HAS). Guide méthodologique. *Bases méthodologiques pour l'élaboration de recommandations professionnelles par consensus formalisé* 2006; 1–37. [en ligne]. Available at: <http://www.has-sante.fr>. Accessed June 11, 2009.
- 13 Save the Children. *Effective Peer Education: Working With Children and Young People on Sexual and Reproductive Health and HIV/AIDS*. Londres, 2004: 207 p. [en ligne]. Available at: <http://www.savethechildren.org.uk>. Accessed June 11, 2009.
- 14 Barlow JH, Stapley J, Ellard DR. Living with haemophilia and von Willebrand's: a descriptive qualitative study. *Patient Educ Couns* 2007; 68: 235–42.
- 15 Thoresen TB. *Effective Symptom Management of Depressions Symptoms: A Descriptive Research of Symptom Management Strategies Used by PLWH With Symptoms of Depression in Norway*. Prague: Rapport du séminaire européen HIV, Work and Social issues, 2008. [en ligne]. Available at: http://integration-projects.org/keydocs/praguehivandwork/Saturday%20March%2010/Thoresen_PresentationPhrahaMars2007.ppt. Accessed June 11, 2009.
- 16 Bonnet C, Gagnayre R, Ivernois (d') J-F. Learning difficulties of diabetic patients: a survey of educators. *Patient Educ Couns* 1998; 35: 139–47.
- 17 Harry I. *Analyse des Échanges Écrits Entre Patients Diabétiques Insulinodépendants sur le Thème de la Nutrition, sur les Forums de Discussion D'Internet non Médiatisés par les Soignants: Contribution à L'éducation Thérapeutique du Patient*, 2007. [en ligne]. Available at: http://www.inpes.sante.fr/jp/cr/pdf/2007/Session8/session8_2903_mat/l.%20Harry.pdf. Accessed June 11, 2009.
- 18 Kocken PL, Voorham AJJ. Interest in participation in a peer-led senior health education program. *Patient Educ Couns* 1998; 34: 5–14. In: Doumont D, Libion F. *Prévention des Lombalgies en Milieu Hospitalier et Éducation par les Pairs*. Bruxelles: UCL-RESO, 2001; Dossier technique 01–16: 1–26.
- 19 Coulter A. Paternalism or partnership? Patients have grown up-and there's no going back. *BMJ* 1999; 319: 719–20. [en ligne]. Available at: <http://www.bmj.com/cgi/content/full/319/7212/719>. Accessed June 11, 2009.
- 20 Wittorski R. De la fabrication des compétences. *Educ Perm* 1998; 153: 57–69.
- 21 Jonnaert P, Barette J, Boufrahi S, Masciotra D. Contribution critique au développement des programmes d'études: compétences, constructivisme et interdisciplinarité. *Rev Sci* 2004; 30: 667–96.
- 22 Crozet C, d'Ivernois JF. *The Perceptive Competence of Patients: The Example of "Diabetic Sentinel Patients"*. Conférence Therapeutic Patient Education 2006, April 27–30, 2006, Florence, Italy. Book of abstracts, p. 93.
- 23 Lambert T. *Le Traitement à Domicile: Un Contrat Entre Soignants et Patients*. Paris: Revue de l'Association Française des Hémophiles, 2006; 11–4.
- 24 World Health Organization. *Peer Support Programmes in Diabetes*. Report of a WHO consultation, 5–7 November 2007. Geneva: World Health Organization, 2008: 41. Available at: www.who.int/diabetes/publications/Diabetes_final_13_6.pdf. Accessed June 11, 2009.