Research Article

Is patient education helpful in providing care for patients with rheumatoid arthritis? A qualitative study involving French nurses

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Abstract
This French study explored nurses’ involvement in patient education for patients with rheumatoid arthritis. The study design was qualitative. Semistructured interviews were conducted with 16 hospital nurses. Data analysis was performed according to Giorgi’s descriptive phenomenological method, and supported by specific qualitative analysis software (Sphinx). The results showed the important role of hospital nurses in rheumatoid arthritis care. Patient education is a core part of nurses’ work, allowing them to give patients information and emotional support. The interviewees displayed skills in helping patients learn to care for themselves. However, patient education mostly concerned patients who are already committed to their health care. Non-adherent patients warrant special attention; their acceptance of their disease, perceptions about disease and treatment, motivation, and autonomy should be specifically addressed. French nurses could benefit from more training, and could be aided by psychologists. Ambulatory services could also be developed for patient education in France, based on examples from other countries.

Key words
France, nurse, patient education, phenomenological approach, rheumatoid arthritis.

INTRODUCTION

New biologics have led to considerable progress in the treatment of chronic autoimmune diseases. However, non-adherence is a major barrier to improving health and reducing the suffering of patients with chronic diseases. Adherence is defined as “the extent to which patients’ behavior matches agreed recommendations from the prescriber”, which sees patients as autonomous actors in their own care (Horne et al., 2006, p. 12). In rheumatoid arthritis (RA), new biologics are able to treat symptoms efficiently, provided that patients adhere to the prescribed treatment regime. However, as reported by current literature, and also as described by health professionals (Blum et al., 2011), the extent of non-adherence continues to be a major concern.

Patient education (PE) was recently put in place by French health systems to overcome the problem of non-adherence and to improve the lives of patients suffering from chronic diseases. The term refers to measures taken by health professionals to inform patients, improve their healthcare behavior, and help them cope with their disease (Zabrisson & Hägglund, 2010). Among health professionals, nurses play an important role in RA care. This report seeks to understand how, through PE, nurses can help patients adhere adequately to their treatment and lead a better life with RA.

Literature review

RA is a chronic disease affecting less than 1% of the French population (Guillemin et al., 2005). It causes painful joints, swelling, morning stiffness, and tiredness. These symptoms impact greatly on patients’ quality of life (Elliot, 2008), resulting in functional disability (Conaghan et al., 1999) and emotional distress (Dickens & Creed, 2001). Clinical studies have shown that medical care improves RA symptoms (Hirano et al., 1994), providing that patients stick to their treatment. However non-adherence is considerable in RA (Elliot, 2008), even with biologics (Li et al., 2010). According to a recent review, the proportion of patients who adhere to RA treatments ranged from 41% to 80.9%, largely depending on which drugs were prescribed (Blum et al., 2011).

A number of factors can affect adherence, such as patients’ perception of medication (Treharne et al., 2004) and their autonomy (Elliot, 2008). These factors that educational measures can potentially modify. Indeed, previous RA studies have suggested that PE enhances adherence (Brus et al., 1998; Hill et al., 2001) and quality of life (Hawley, 1995),
as well as limiting disability (Hirano et al., 1994), pain (Núñez et al., 2006), and depression (Oh & Seo, 2003).

Many aspects of PE are performed by nurses, essentially to help patients with their health practices (Newbold, 1996). Nurses are closer to patients than other health professionals (Coughlin, 2008). In rheumatology, nurses have a role in educating and supporting their patients with RA. They also provide emotional support (Makelaïnen et al., 2009). A qualitative French study found that rheumatologists referred spontaneously to the crucial role played by nurses (Fall et al., pers. comm., 2009). International literature also describes the positive results achieved by nurses in educating patients (Hill et al., 2009).

PE was recently introduced into the French health context (HAS, 2007). Starting in 2000, some structures began to provide PE in an unstructured, uncoordinated fashion, based on the initiative of individual health professionals. Since 2005, the Department of Health has been involved in developing PE in hospitals, providing financial support. This practice was stepped up in 2007 with the introduction of policy to improve the quality of life of patients suffering from chronic diseases. Promulgation in 2009 of the Law on “Hôpital Patient Santé et Territoire (HPST) et éducation thérapeutique” showed the government’s firm intention to develop educational activities. According to this Law, “Patient Education is part of patient healthcare and aims to increase patients’ autonomy by facilitating their adherence to prescribed treatments and by improving their quality of life” (Article 84 of the Act of 21 July 2009). A regional body responsible for education program assessment and budget allocation was then set up (Agence Régionale de Santé [Regional Health Agency]). A recent political report emphasized the need to develop the ambulatory sector in this context, but up until now, PE has mainly been organized in hospitals (Jacquat & Morin, 2010). Although French patients with RA are managed by either an office-based or hospital-based rheumatologist, the decision regarding the first prescription of biologics has to be taken in hospital (HAS, 2011), leading many patients to receive PE from hospital nurses. There are no specific guidelines, such that each rheumatology hospital devises its own program, which can range from a single interview to a specific PE course during hospitalization. Nurses are often central to this PE. Research is therefore necessary to find out how nurses perceive their work.

Study aim
The benefits of PE in RA and the important role of nurses are now clearly established in the literature (Chen & Wang, 2007; Albano et al., 2010). However, very little research has been conducted into how rheumatologic nurses in France perceive their work. In our study, we focused on the nurses’ own accounts of their experiences with the help of a phenomenological qualitative method. The goal was to explore nurses’ involvement in educating patients with RA, as well as their perceptions about adherence to treatment for RA.

METHODS
Study design
We used a qualitative research design, with a phenomenological approach incorporating semistructured interviews to explore nurses’ perceptions of their work with patients. The phenomenological approach is used to identify phenomena in terms of how they are perceived by the population in question, as a way of studying participants’ life experiences and giving them meaning (Giorgi, 1997; Dowling, 2007). The question asked was: “How do nurses in France perceive their experiences of working with patients with RA, mainly from the point of view of their contribution to PE?” Accordingly, this paper focused on the experiences, perceptions, beliefs, feelings, and convictions of nurses working with patients with RA.

Participants
To define the target population, we performed a pilot study prior to recruitment. First, we conducted an investigation in four hospitals in different parts of France, with a view to obtaining the most representative sample possible of national diversity. In each area, we met with the health professionals responsible for organizing PE (physician and head nurse). Second, we interviewed five self-employed nurses, who performed home visits, about their specific role with patients, but found they had very few dealings with patients with RA, so we chose to limit our interviews to hospital nurses working with both outpatients and inpatients.

Between May and July 2009, 16 nurses were recruited from within the hospital where they worked (Table 1). Recruitment criteria included at least 2 years’ nursing experience and at least 1 year working in a rheumatology environment. Moreover, the head nurse chose participants according to their level of experience in rheumatology and PE, with a view to increasing the representativity of the sample. Recruitment ceased when the primary investigator deemed a full description of the phenomenon had been achieved, and the data collected had reached saturation point. On average, the nurses had spent 11.94 years working on a rheumatology ward (standard deviation [SD] = 9.54). Average nursing experience was 22.44 years (SD = 10.57).

<table>
<thead>
<tr>
<th>Participants</th>
<th>Hospital</th>
<th>Type of patient education</th>
</tr>
</thead>
<tbody>
<tr>
<td>1–5</td>
<td>1</td>
<td>Individual consultations 1 day/week</td>
</tr>
<tr>
<td>6–10</td>
<td>2</td>
<td>Face-to-face interviews with hospitalized patients</td>
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<tr>
<td>11–13</td>
<td>3</td>
<td>Specific days several times hospitalized patients</td>
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<tr>
<td>14–16</td>
<td>4</td>
<td>Specific group-learning modules</td>
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Table 1. Description of participants

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**Ethical considerations**

The hospitals taking part in the study gave their approval to the research project, which was accredited by a French ethics committee (Commission Nationale de l’Informatique et des Libertés). Before being asked to sign the consent form, the nurses interviewed were informed of the content of the study, and assured that neither they nor their place of work would be identifiable.

**Data collection**

Data were collected through semistructured, open-ended interviews lasting approximately 30–45 min. Based on a study of rheumatologists (Fall *et al.*, pers. comm., 2009), the work team developed an interview guide, reviewed after two pilot interviews, which provided a flexible framework for eliciting information about four main areas: practical activity, PE, treatment, and adherence (Table 2). Each interview began with the same open-ended question: “Please tell me about your work environment and your role in taking care of RA patients”. The order in which all content areas were then discussed was determined by the natural flow of conversation. Each area was introduced with one main question, and there were suggested probes for obtaining more information, if necessary. All interviews were conducted face to face by the first author, a trained psychologist. They were recorded on tape and professionally transcribed.

**Data analysis**

Data analysis was carried out according to specific guidelines for the phenomenological analysis of interview data (Giorgi, 1997). The 16 interviews were analyzed with regular feedback from a working group to improve study trustworthiness. For each interview, the researcher listened first to the audio recording and read the transcription several times to become familiar with the words of the interviewee. The data were then analyzed in three main steps: coding, categorization, and inference. For coding, Sphinx Plus2 V5 software was used to sort data into specific codes. With each interview transcription, informative statements about the research phenomenon were extracted into units of meaning. Once all the texts had been coded, units with similar meanings were categorized and organized by themes. The final step consisted of summarizing the themes to describe perceptions common to most interviewees, as well as individual variations. With a view to communicating them to the scientific community, participants’ statements were rewritten using research concepts, and illustrated with participants’ quotations. For the verbatim report in this paper, we used the internationally-recommended back-translation procedure usually used for scale validation (Perrin *et al.*, 1995). At first, two English psychologists independently translated the French verbatim into English. Then, they agreed to a common version. This latter was translated back into French by a bilingual psychologist who did not know the original French version. Comparison of the back-translation with the original French version revealed only minor discrepancies.

**RESULTS**

Two main themes emerged from the interviews: the central role of nurses and the specific profile of patients.

**Theme 1: the central role of nurses**

*A close relationship with patients*

Because RA is a chronic disease, patients saw their nurses frequently and became quite at ease with them. The nurses explained that they tried to spend time with each patient to give them both informational and emotional support, adding that they usually gave patients information about their RA treatment to complement the information given by physicians. Moreover, they stated that the main difficulty was patient turnover, which limited the time available for each patient.

They know the team very well. They want to see the same people, the same faces. They recognize our voice when they phone in. (Participant 14)
In recent years, health care has really changed; we have less time to care for each patient, to spend time with them, and listen to them. (Participant 11)

**Sharing information with physicians**

Almost all the nurses said they knew their patients very well and could provide physicians with useful information about them. Some explained they also received medical and therapeutic information from physicians and used this to inform patients. Although all treatment decisions were considered the responsibility of the physician, the nurses discussed treatment with physicians when they thought they had gleaned important information from patients, mainly with regard to the route of administration:

There is always coordination (with physicians); there is always a two-way exchange, always. (Participant 13)

When we feel a patient is very lax about treatment, as regards infection, which is still very serious, I will inform the physician that the patient is not able to continue his or her treatment. (Participant 8)

**A crucial role in PE**

Hospital nurses in our study formed an integral part of PE. Their aims were to make patients autonomous, give them information, and help them perform self-care. Nurses generally took part in regular face-to-face interviews with patients. They explained that an “educational diagnosis” was performed individually with each patient. Several nurses described this diagnosis in more detail; they targeted patients’ needs and questioned them on all aspects of their life (e.g. family, social environment, occupation, and housing). Then they provided the appropriate education for each patient:

The aim of this education is to help patients acquire or maintain the ability to live with their disease better. (Participant 12)

We interview patients about their disease, job, home, . . . We want to know the degree of their acceptance of their disease and the treatment they receive; whether this treatment improves their life and whether they are able to self-inject. (Participant 7)

Another frequent component of PE for RA was self-injection training, because biologics (e.g. antitumor necrosis factor-α [TNF-α]), which are the main RA treatments, are injectable products. The nurses explained that patients were referred to them for training by rheumatologists, and that they provided patients with essential information, explaining all the necessary injection steps with the help of gestures, and observing patients’ self-injections, correcting them where necessary. They said they questioned patients about their fears and tried to reassure them (e.g. anticipation of pain, action of self-injecting, making a mistake). Although this training was generally positive, some nurses mentioned difficulties that anxious patients or non-native French speakers had with understanding the gestures and important information:

For 97% of patients, there is no problem. (Participant 5)

There are sometimes difficulties in terms of understanding, language, or manipulation. (Participant 13).

**Theme 2: the specific profile of patients**

**Specificity of RA**

The nurses identified RA as a chronic disease. Some thought patients were anxious and demanding, and one described them as courageous people who complained very little. They raised the problem of a change in patients’ body image due to deformation and weight gain related to treatment, and emphasized the positive improvement in RA management in recent years:

Patients with rheumatoid arthritis are, in most cases, familiar with their disease and know that these are diseases that do not heal, and which are scalable, like diabetes. (Participant 7)

Patients with rheumatoid arthritis have a quite specific profile, which develops at the same time as the disease; they are quite demanding regarding health professionals. (Participant 8)

**Autonomous patients**

Many nurses said patients seen at the hospital were perceived as being relatively autonomous. They explained that patients are autonomous because RA affects mostly young people, who are still working and remain active. Several interviewees added that new treatments also helped patients maintain their autonomy. Since biologics are prescribed by injection, and people can choose to self-inject their treatment, they can work, travel, or engage in other activities without depending on a health professional for their injections, so patients administer their treatment alone, and are more aware of the essential precautions (hygiene, body infection, treatment preservation). Some nurses underlined patients’ high level of motivation and commitment in taking care of their disease:

The patients we see are quite autonomous and able bodied. In general, they are relatively young and have a good degree of autonomy. (Participant 9)

These people are dynamic, because they lead an active life. They work, so necessarily, self-management is obviously not really a problem in most cases. (Participant 13)

**High degree of adherence**

For almost all the nurses, adherence was not an issue with patients with RA who self-administered their treatment. They felt their patients took their treatments (e.g. anti-TNF-α with self-injection) as prescribed, and went along with it because it was necessary and effective. Biologics,
which are the main treatment for RA, were indeed perceived as extremely effective. Patients who stopped their treatment experienced both pain and physical disabilities. For many nurses, fear of adverse effects as the main negative predictor for adherence, but this factor was counterbalanced by the need for treatment and its efficacy. As some nurses pointed out, their patients were those most committed to their health care, and therefore, they were probably more conscientious about taking their treatment. The nurses explained that physicians pre-empted non-adherence issues by prescribing intravenous injections, responsibility for which does not lie with the patient. Finally, although adherence problems were scarce, several interviewees suggested that the situation could be improved by doing more for patients by way of information, emotional support, and follow-up care:

They find they have such a high degree of autonomy, such a comfortable life; their pain disappears almost entirely, so they take their treatment properly. (Participant 9)

By definition, the patients we see are those with the best adherence. (Participant 12)

DISCUSSION

The aim of the study was to explore the perceptions of nurses working in French hospitals with patients with RA, and to identify nurses’ involvement in PE and their perceptions of patient adherence.

Central role of hospital nurses in RA care: mediators in the relationship between patients and physicians, and providers of informational and emotional support through PE

Our results, which are consistent with a previous study of rheumatologists, show that nurses in France play a central role in RA care (Fall et al., pers. comm., 2009). One of their tasks is to inform patients, and in turn, to receive information from them. As patients receive emotional support from nurses, they are willing to confide in them. Previous studies have shown that patients with rheumatic diseases are fairly satisfied with their relationship with nurses (Hill, 2003), who are more available for discussion than physicians (Macdonald et al., 2008). Our study shows that nurses inform physicians about patients, and pass on medical information from the former to the latter.

In our study, PE accounted for a large part of nurses’ working time. Because of the educational diagnosis, PE could be tailored to each patient, based on their informational and emotional needs. All aspects of their personal life were taken into account, so that each patient could be given the appropriate education. Makelaïnen et al. (2007) found nurses were more likely to give information than emotional support, despite the fact that emotional support for patients with chronic diseases is extremely important (Barlow et al., 2002). PE enables nurses to give patients emotional support (Nolan et al., 2001). When they educate patients via an individual tailor-made approach, it raises their level of commitment toward patients and results in better emotional support (Zabrisson & Hägglund, 2010). In our study, the nurses’ approach was individual oriented, in that they took all aspects of the patient’s life into account and gave both kinds of support.

The study results show that patients in France with RA are mainly educated by hospital nurses. However, owing to recent budgetary restrictions, hospitals have to send more patients for home care treatment, meaning they spend less time in hospital. Because of education and recent improvements in RA treatments, most patients can cope by themselves when they leave hospital, and have no need for home visits from a self-employed nurse. Although it is a great advantage that many patients are able to manage by themselves, it could be useful to develop the ambulatory sector of PE, which is still underdeveloped in France (Jacquet & Morin, 2010), to help patients who experience difficulty with self-management.

Nurses perceived no apparent adherence problem because patients receiving education are extremely autonomous and committed to their health care

During the interviews, the nurses reported no problems with adherence. According to them, the explanation for this positive perception lay in effective biologic treatment for RA. Over the past 10 years, new biologic agents (e.g. anti-TNF-α) have become available, and have considerably improved RA management, especially nursing practices (Coughlin, 2008). Nurses now have to ensure patients understand all the treatment options available and that they are able to self-inject. Although these new molecules can only be administrated by injection, they probably ensure higher levels of adherence, because effectiveness of treatment is considered a positive factor of RA adherence (Berry et al., 2004).

However, several recent reviews failed to reveal the same optimism regarding adherence among patients with RA. Levels fluctuate from 16% to 84%, depending on the target treatment, and remain low even with biologics (Elliot, 2008; Li et al., 2010; Blum et al., 2011). There is also evidence in the literature that health professionals tend to overestimate adherence (Hirano et al., 1994). This positive assessment of adherence highlights the problem of patients included in education. In our study, the patients with whom nurses were dealing with showed extreme commitment to their care and a high level of autonomy. According to official French guidelines, patients are referred for PE by their physicians, general practitioners, and specialists, according to their level of motivation (HAS, 2008). Patients have to sign a consent form beforehand, and can only take part if they declare they are willing to accept changes in their treatment. To date, there are no plans to educate patients who do not volunteer (non-acceptance of their disease or poor motivation to self-manage), despite their needs. Even though such considerations can raise ethical issues, it is essential that this problem be regarded as an unsolved public health issue. Solutions are to be found in other countries, such as Switzerland, a pioneer of PE in Europe, where the ambulatory sector of PE is
well developed. Furthermore, there are a large number of research and training activities that help to improve education for patients with chronic diseases (Jacquat & Morin, 2010).

Much research work has demonstrated the positive impact of measures taken in respect of chronic diseases that are based on changing patients’ perceptions about treatment and disease, motivation, and autonomy (Petrie et al., 2002; Williams et al., 2007). Nurses’ knowledge and their ability to support non-adherent patients could probably be improved by specific training. These studies also highlight the important role that psychologists could play alongside nurses. Among existing education programs, psychoeducational measures based on cognitive-behavioral skills provide good ways of helping patients self-manage their disease (Hawley, 1995; Elliot, 2008). Cognitive-behavioral therapy (CBT) has been successfully applied to patients with RA to enhance adherence, and reduce pain and disease symptoms, and depression (Evers et al., 2002; Zautra et al., 2008). In the UK, rheumatology health professionals often receive CBT training (Hale et al., 2007; Macdonald et al., 2008). We believe it would be beneficial to develop this practice in France, so that each patient can play a more active role in his or her health care.

**Study limitations**

Although the qualitative study design meant we were able to provide a detailed description of nurses’ perceptions, longer interviews would have allowed us to delve more deeply into the experience of nurses working with patients suffering from RA.

Moreover, any generalization of the results must be carried out with caution. The transferability of the study is impeded by the fact that the sample consisted of hospital nurses, and might therefore not be fully representative of all French nurses. We originally planned to interview self-employed nurses in addition to hospital nurses to portray an overall picture of the role of nurses in France in RA. However, the pilot study conducted prior to recruitment revealed that self-employed nurses did not have much of a role in RA care. Nevertheless, participants were recruited from four different geographic areas to ensure a variety of respondent profiles. We also sought to interview nurses with different levels of experience, so that the results were as representative as possible of nurses in general. Another limitation was that the same experimenter was involved in both the interviews and data collection, and that the researcher received regular feedback from a working team.

**Conclusion**

The aim of the study was to provide a detailed description of RA management from the point of view of French nurses. Our findings confirmed the strong involvement of nurses in PE. While it is important to acknowledge the skills developed by nurses in helping patients acquire self-care, we must not forget that some patients do not benefit from the system, because they do not seek education. For these patients, specific actions are required to address their motivation, autonomy, disease acceptance, and personal perceptions. In future, the French healthcare system needs to reassess the education inclusion criteria, and patients with little motivation for self-management should receive special attention. Another means of improving PE could be to develop the ambulatory sector, based on examples from other countries.

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**CONTRIBUTIONS**

Study Design: EF, ND.
Data Collection: EF.
Data Analysis: EF, NC, ND, MI.
Manuscript Writing: EF, NC, MI.

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