RESEARCH ARTICLE

Patients' Perceptions of Drug Information Given by a Rheumatology Nurse: A Phenomenographic Study

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Abstract

Background. Pain, stiffness and functional restriction of the joints are the main problems experienced by patients with inflammatory rheumatic conditions. The majority of patients with rheumatic diseases require several drugs every day. Adherence is highest among patients who have repeatedly been given drug information by a nurse from the start of the treatment. When developing patient information, it is essential to utilize patients' experiences.

Objectives. The purpose of this study was to describe variations in how patients with rheumatic diseases perceive drug information given by a rheumatology nurse. **Methods.** The study had a descriptive qualitative design with a phenomenographic approach. Fifteen inpatients with rheumatic diseases who had received a new drug agreed to take part in the study and were interviewed. **Results.** Three descriptive categories emerged: autonomy, power and security. Autonomy was based on patients' experiences of taking responsibility and participating. Power meant gaining knowledge and being motivated to take the drug. Security involved trust, experiencing care and access to a rheumatology nurse. **Conclusions.** For patients with a rheumatic disease, drug information from a rheumatology nurse gave them autonomy, power and security. These factors could explain why information from a nurse increases adherence to drug treatment. Copyright © 2009 John Wiley & Sons, Ltd.

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Introduction

The aim of treatment for patients with inflammatory rheumatic conditions is to control joint pain and swelling, as well as to reduce permanent joint damage, prevent functional impairment and support the patients to master their disease and improve their quality of life (Bykerk and Keystone, 2005). The majority of patients with rheumatic conditions need to take a number of different drugs. In order for the treatment to be

effective, the patient requires information about the medication, how it works and how it should be taken, as well as possible side effects (Arthur and Clifford, 1998). One of the most common reasons for poor treatment outcomes is that patients are unwilling to try drug treatment. There may be several reasons, of which a major one is lack of knowledge. In order to improve adherence, it is important to encourage the patient to become a collaborative partner and an independent decision-maker (Hill, 2006). Patients' level of

knowledge of disease and treatment differs (Mäkeläinen et al., 2009a; Sierakowska, 2005). Following hospitalization, patients have insufficient knowledge about their medications. Many do not know the names of their drugs the recommended dose, how they should be taken, the side effects and when they should seek medical advice (Holloway, 1996). Rycroft-Malone et al. (2001) reported that nurses appear to have a mental list of what they should inform the patient about when introducing a new medication. It is difficult to know whether nurses make an individual assessment of the patient before providing him/her with information. In general, nurses give information about the name of the medication, its purpose, its colour and the number of tablets to be taken, as well as how often they should be taken. The information is provided with little consideration for what the patient already knows or wishes to know about his/her medications. Nevertheless, it has been revealed that patients are generally satisfied with their level of participation in their encounter with nurses (Rycroft-Malone et al., 2001). Nurses spend a great deal of time with patients and explain or translate medical terms. They often use informational leaflets in order to explain the information orally. The design of written drug information is of major importance to enable the reader to understand it and obtain knowledge (Hill and Bird, 2003; Mumford, 1997). Patients have a great need for information about their medication and prefer to receive it from a doctor or nurse, rather than from other sources (Naeme et al., 2005). A combination of oral and written information is the most effective way of increasing a patient's knowledge about his/her medication. Patients who only receive oral information consider that they require additional knowledge (Arthur and Clifford, 1998). Fraenkel et al. (2001) reported that patients have a great need for information about their medications and wish to be fully informed, in particular about side effects and alternatives. A pilot study indicated that drug information given by a rheumatology nurse to patients in a group was more effective than that provided individually (Homer et al., 2009). Three-quarters of rheumatology nurses ($n = 80$) gave patients information about anti-rheumatic drugs and only 15% of the nurses also gave information about non-steroidal anti-inflammatory drugs (NSAIDs) (Mäkeläinen et al., 2007). Patients with rheumatoid arthritis (RA) were found to have a moderate knowledge of how to use anti-rheumatic drugs and NSAIDs (Mäkeläinen et al., 2009a) and

about half of the patients ($n = 173$) were satisfied with patient education given by rheumatology nurses. The patients who were dissatisfied felt that the rheumatology nurses had not tailored the information to their needs (Mäkeläinen et al., 2009b). Nearly a third of the patients with RA ($n = 86$) who received therapy with anti-rheumatic drugs, corticosteroids and NSAIDs were consistently compliant. Older age is associated with better compliance, but this is not the case for gender, disease duration and total number of pills taken for RA or any other reason (Tuncay et al., 2007). Adherence was found to be greater among patients who received drug information from a nurse at the start of treatment, followed by patient education on an ongoing basis, compared with patients provided with a drug information leaflet alone (Hill et al., 2001). Information and support from the nurse should enable every patient to have a level of knowledge that allows him/her an opportunity to make conscious decisions about his/her medication (Hill, 2007).

In clinical practice, doctors and nurses have noticed that some patients with rheumatic diseases know little about their medication, even in cases where they have been using it for several years. The question has been raised as to whether nurses should allocate more time to planning and structuring information about all kind of medication in order to enhance the patient's self-care ability and adherence. Jacobi et al. (2004) highlighted the value of emphasizing the patient perspective in order to improve care in the area of rheumatic diseases and adapt it to the needs of patients. The importance of considering patients' experiences has been emphasized in the development of rheumatology care. There is a lack of knowledge in this area. A phenomenographic study can contribute to such knowledge, as the results represent variations in patients' perceptions of the drug information they received from a nurse at the start of treatment. The aim of this study was to describe variations in how inpatients with rheumatic diseases perceive drug information provided by a rheumatology nurse.

Methods

Design

The study had a descriptive qualitative design with a phenomenographic approach, which is used to describe different ways in which individuals experience a phenomenon. Within phenomenography, the analysis focuses on the 'how' aspect. The main interest is the

description of differences – that is, variations in perceptions. The objective was to describe qualitatively different perceptions that encompass the majority of variations in the population and to capture thoughts that have not been the subject of conscious reflection. In other words categories of description that are the result of a phenomenographic study describe how the phenomenon in question is experienced. The experiences are not mental or physical entities but concern the internal relationship between the subject and the phenomenon. A descriptive category comprises a number of aspects that express a person's experiences of the phenomenon in question (Marton and Booth, 1997).

Subjects

Fifteen subjects who had been prescribed one or several new drugs during their period of hospitalization were approached, agreed to take part in the study and were interviewed. Strategic sampling was carried out in order to achieve variation in the perceptions of the phenomenon in terms of gender, age, marital status, education, type of rheumatic disease, disease duration and type of new drug (see Table 1).

Three inclusion criteria were formulated. The patient should:

- have been diagnosed with one or more rheumatic diseases
- have been prescribed one or several new drugs for his/her rheumatic disease or the disease impact, during the period of hospitalization.
- have taken the new drug for a minimum of four days.

Data collection

The data collection took place at a rheumatology hospital in the south-west of Sweden during February and March 2004. During the period of hospitalization, the doctor prescribed and gave the first oral information about the new drug to the patients, then a rheumatology nurse gave further information. The patient could receive oral and/or written information, and the time allocated varied. At the time of the study there were only guidelines for anti-rheumatic drugs, regarding what patient information should be provided and how, when a new medication is prescribed, but none for other medications such as NSAIDs, anti-hypertensive medication or iron tablets.

In order to recruit patients who met the inclusion criteria, the researchers (I.L. and S.A.) contacted nurses in six wards. These nurses asked the patients if they would be interested in participating and provided them with oral and written information about the aim and method of the study. When a patient had agreed to participate and given his/her written consent, it was sent directly to the researchers or placed in the envelope provided and handed to the ward nurses. The time and place for the interview was then decided together with the patient. Confidentiality was guaranteed and patients were informed that they could withdraw from the study at any time without the need to give a reason, and that it would have no impact on their care.

Each interview lasted between 30 and 60 minutes and was audio-taped. The interviews began with the researcher explaining the aim of the study and giving the patients an opportunity to withdraw. Patients were also encouraged to ask questions before, during and after the interview. The study was based on an open interview guide, in line with the phenomenographic tradition (Marton and Booth, 1997). The focus of the interviews was to achieve an open conversation in order to increase the understanding of how inpatients with rheumatic diseases perceive drug information provided by a rheumatology nurse. The following opening questions aimed at ensuring similar data from all patients:

- What information did you receive about your new medication?
- What do you think about the information you received about your new medication?
- How were you influenced by the information you received about your new medication?

In order to probe certain aspects, patients were requested to 'provide more details', or follow-up questions were posed such as: 'How do you mean?' or 'What do you have in mind when you say...?'. Two pilot interviews were conducted to test whether the answers to the interview questions were in accordance with the aim of the study; this was found to be the case, and these interviews were therefore included in the study data.

Data analysis

The interviews were transcribed verbatim by the researchers, who were familiar with the research method. The analysis was performed in relation to two

Table 1. Socio-demographic and clinical data of patients who received drug information ($n = 15$)

Patient	Gender	Age	Married/ co-habiting	Education	Rheumatic disease	Disease duration (years)	New drug (generic name)
1	Female	67	Yes	Primary school	RA	15	Hydroxyzine
2	Male	39	No	Secondary school	Polyarthritis	0.5	Amitriptyline
3	Male	59	Yes	Tertiary education	Polyarthritis	7	Hydroxychloroquine sulphate
4	Female	40	Yes	Secondary school	RA	3	Alendronate sodium
5	Female	38	Yes	Tertiary education	SLE RA	9	Cyclophosphamide
6	Female	43	Yes	Secondary school	RA	6	Amitriptyline
7	Male	79	No	Tertiary education	RA OA	11	Calcium carbonate
8	Female	57	Yes	Secondary school	Fibromyalgia Sjögren's syndrome	5	Propiomazine
9	Male	52	Yes	Secondary school	Polyarthritis OA	0	Prednisolone
10	Male	35	Yes	Secondary school	RA	1.5	Rofecoxib
11	Female	74	No	Primary school	Spondyloarthritis	42	Dextropropoxifen, flunitrazepam, zopiclone
12	Female	54	Yes	Primary school	RA	36	Tramadol
13	Female	72	No	Tertiary education	Sjögren's syndrome OA	0	Celecoxib
14	Female	65	No	Secondary school	RA	0.5	Tramadol
15	Female	62	Yes	Secondary school	Fibromyalgia OA Sjögren's syndrome	16	Hydroxychloroquine sulphate Prednisolone
Mean value		56				10	

Abbreviations: RA, rheumatoid arthritis; SLE, systemic lupus erythematosus; OA, osteoarthritis.

different contexts: the individual interviews and extracts from all the interviews dealing with the same or related areas (Marton and Booth, 1997). The data analysis comprised seven different steps (Dahlgren and Fallsberg, 1991; Sjöström and Dahlgren, 2002). The researchers carried out each step of the analysis independently and then compared and discussed the results until consensus was reached.

1. Familiarization

Each interview was listened to and read on several occasions in order to become familiar with it and gain an overall impression of the material. The focus was on the aim of the study.

2. Condensation

Each interview was searched for statements that corresponded to the aim of the study. These statements were inserted into tables in a data file, with a clear

indication as to the respondent from whom the statement originated. A total of 484 statements emerged.

3. Comparison

The identified statements were analysed in order to find similarities and differences. Those with similar content were grouped together and variations emerged, resulting in 17 preliminary perceptions.

4. Grouping

The statements were grouped according to their characteristic features in order to obtain a more comprehensive understanding of how they were connected with each other and formed perceptions. The 17 preliminary perceptions resulted in seven perceptions. The amalgamation concerned, for example, 'Being aware of one's own responsibility' and 'Acting on one's own initiative', which were amalgamated into the perception 'Own responsibility'.

5. Articulating

The seven perceptions were compared and grouped on the basis of similarities and differences. The analysis moved back and forth between the fourth and the fifth step until three different descriptive categories emerged.

6. Labelling

The perceptions that formed the descriptive categories were discussed by the authors, after which they were labelled to reflect their meaning.

7. Contrasting

The descriptive categories that emerged were compared in terms of similarities and differences in order to ensure that each of them had a unique character and that they were on the same level of description.

Ethical aspects

The operations manager at the hospital approved the study. The local Ethics Committee at the Spenshult R&D Centre issued an advisory statement with the registration number Sp.001-04. The study adhered to the four main ethical research demands: information, consent, confidentiality and utility (Swedish Research Council, 2002). Immediately after the interviews, the informants were given an opportunity to discuss any feelings or thoughts that might have arisen as a result of the questions. In view of the nature of the topic under investigation, the data collection took place in units where the researchers had no professional contact.

Results

Three descriptive categories, comprising seven perceptions, emerged and revealed how patients perceived the information about new medication provided by a nurse. Drug information led to autonomy, power and security. Quotations were used to describe and illustrate both the uniqueness and the variation within the different perceptions.

Autonomy

This descriptive category contained two perceptions: own responsibility and participation. Autonomy implied that the patient assumed responsibility and took the initiative, as well as playing an active role in the provision of information about the medication. Patients wanted to be independent, have control over

their situation and participate in decision-making about their own medication.

Own responsibility

This perception described patients' own responsibility in relation to drug information. There was a variation, in that some patients stated that they themselves were responsible for finding the information, while others were of the opinion that it was the duty of the doctor or nurse to inform them. Patients related how they took the initiative and asked the nurse if they were unsure about their medications. They assumed responsibility by searching for information about them. One patient stated:

'Yes, I think that it is my responsibility to read the information on the box or on the enclosed leaflet about side effects, as then one is aware of them if they should occur. That is definitely my responsibility.'(P:5).

Another patient remarked:

'The doctor is responsible for saying that, in the light of my background knowledge, I think you should take this one.' (P:13).

Participation

This perception described patients' experience of autonomy and participation in the area of medication, which was strengthened when the new medication was introduced in a consultation between the patient, doctor and nurse. The patients perceived that they had received information, were able to reflect on it and then discuss it again with the doctor and/or nurse; they had a choice and could, and did, dare to say 'no'. There was a variation, in that some patients did not experience participation in the decision about starting the new medication. These patients considered that they had received no information about the medication or whether there were alternatives. One patient who experienced participation described it as follows:

'I feel that I am the one who has made the decision. Nobody insisted upon it and I was given some time to think.' (P:6).

Another patient expressed:

'They thought that I should take it, there was sort of no discussion, just that I should take it.' (P:4).

Power

This descriptive category contained two perceptions: knowledge and motivation. Obtaining knowledge strengthened patients' self-esteem, and made them feel satisfied with the drug information, as well as motivated.

Knowledge

This perception described how patients were allowed time to assimilate the information at their own pace. After receiving the oral information, they could read the written information in peace and quiet and return with any questions that had arisen. The repetition of information by the nurse during the period of hospitalization facilitated the assimilation of knowledge. A variation existed, in that some patients described that there was insufficient time or that the information was routine. They had been given the medication without any information other than its name and the time at which they should take it. Limited drug information was perceived as either adequate or as giving rise to uncertainty and anxiety. One patient explained:

'That the nurses followed up and asked questions and suchlike and watched the developments the whole time felt really nice and very reassuring. All three nurses were aware of what I had taken and how much and the effect it had, which felt really good.' (P: 2).

Another commented:

'They just give you tablets and then that's it.' (P:11).

Motivation

This perception revealed how well-informed patients were often motivated and not afraid to try new medications. The information inspired hope that the drug would have an effect and ease the symptoms. The patients dared to try it in order to see if it would have the desired effect. They described the fact that information motivated them and strengthened their resolve to start a new course of drug treatment. One patient said:

'A hope that it can do something. But then you have to try it to find out if it works.' (P:3).

Another stated:

'The explanation I received about how it works seemed positive and made me think that it might have a good effect on me. So I thought that it would be worth a try.' (P:15).

Security

This descriptive category comprised three perceptions: trust, care and accessibility. Getting to know the nurse and being able to rely on his/her knowledge of the medication led to a basic sense of security about the drug treatment. This comprised trust on the part of the patient, as well as care and accessibility on the part of the nurse.

Trust

This perception described how the patient relied on the nurse, and his/her knowledge of the medication and ability to communicate information, all of which led to trust in the drug treatment. The fact that all members of the team (nurse, doctor, physiotherapist and occupational therapist) were aware of the patient's situation and treatment led to the perception of trust and faith in the medication, and thus security. One patient stated:

'It is clear that they know what they are talking about and the nurses here really knew, which made it feel really safe.' (P:2).

Another patient reported:

'I really have great trust (in the nurses) and I know that they work as a team. She (the nurse) is just as well informed about my situation as all the others, it's quite logical. At first I perhaps imagined that it would be the doctor who would inform me, but it does not necessarily have to be the doctor.' (P:6).

Care

This perception described patients' experiences of being shown care. They were well cared for and treated in a kindly fashion by the nurse during their hospital stay. It highlighted the importance of someone caring about whether the drug treatment had worked by providing follow up after initial information and treatment had taken place. One patient explained:

'When she came it was already prepared. She had arranged everything beforehand, so there was a great deal of care behind it. It also makes you feel important in some way.' (P:15).

Another patient remarked:

'Yes, it almost feels as if they care more when you are an inpatient but maybe it's because one feels better taken care of in hospital.' (P:8).

Accessibility

This perception described how patients experienced security during their hospital stay owing to the closeness and accessibility of nurses. The daily contact and communication were uncomplicated and simple. Knowledge was increased when information was provided gradually and could be assimilated before further information was given. The nurse had time for conversation, which led to a feeling of security. One patient said:

'That one can talk to the nurse. That one can come at any time and knock on the door and pose questions. It feels really good here.' (P:1).

Another patient stated:

'It can sometimes be easier to talk to the nurse. Because they have a bit more time.' (P:9).

Discussion

The study revealed that patient participation and responsibility in decision-making concerning medication can have an impact on the motivation to take the medication and thus on adherence. The closeness and accessibility of the nurse, as well as the possibility of having the information repeated on several occasions, led to a sense of security for patients.

A vital aspect is the patient's *own responsibility* for obtaining and reading information about the medication. Patients stated that drug treatment was their *own responsibility* and commented that, as long as they were in good mental health, they wished to be responsible for such decisions. This is in agreement with Arvidsson et al. (2005), who revealed that inpatients relied on their own ability to assume responsibility for decisions about medication. However, some patients in the present

study stated that it was the duty of healthcare professionals to inform them about the medication prescribed. Whyte (1994) holds that the quality of care is affected by the way in which drug information is communicated by healthcare staff to patients. The information must go two ways. The patients in the present study expressed that they had to take the initiative in order to obtain information, whereas they would have preferred the nurse to have taken the initiative and discussed the medication with them on repeated occasions during their hospitalization.

The result indicates that patients require both autonomy and *participation* in terms of drug treatment. The decision about starting a new medication was easier if it was made in consultation with the patient, doctor and/or nurse. Patients expressed a desire to be involved in the decision pertaining to their drug treatment (Donovan, 1991; Larsson et al., 2009). Åström et al. (2000) highlighted patients' wish to be given information about the drug, as well as alternatives to the recommended medication. Nurses have expressed that patients need information to be able to participate in the decision about treatment. Lack of participation can mean that patients do not follow instructions (Eldh, 2006). Horne and Weinman (1999) reported that patients who participate in the decision about their medications are more motivated in terms of adherence. In our study, patients who were involved in the decision about a new medication exhibited optimism and happiness at starting a medication that could help them. This meant that they were *motivated* to take the medication.

The result highlighted the value of repeating information and providing it gradually. The drug information provided increased patients' *knowledge* and *motivation* and gave them an inner power. Every patient has a legal, ethical and moral right to information about his/her medication, and nurses are the most suitable professional category to provide it (Byrne, 1999; Hill, 2006). Adherence is increased when patients receive more personalized information about their disease and its treatment (Viller et al., 1999). Well-informed patients experienced a higher quality of care than those who knew less about their medication (Mahmud et al., 1995). The result also revealed that even inpatients can experience a lack of information from nurses, which is in agreement with the findings of Arvidsson et al. (2005). There is a need for more flexible and patient-centred information, where patients have more of a role

in deciding the information they want and how it should be provided (Kjeken et al., 2006). Rankin and Stallings (2001) hold that the most important factor in patient education in order successfully to influence patients to make desired changes – for example, adherence in the area of medication – is to attempt to identify what motivates each individual patient. Motivational factors can vary between patients.

The patients in our study described security in terms of their medication as *trust* in the nurse's knowledge and receiving essential information, and that the medication is prescribed in their best interests. This is supported by Larsson et al. (2009), who demonstrated that the encounter with a competent nurse who is knowledgeable, efficient and engaged creates trust and reliance, both of which lead to security. Whyte (1994) described how patients want more information about their medication, but that there is a discrepancy between their wishes and what they receive from healthcare professionals, which can lead to a lack of trust in the medication. The result indicates that *access* to the nurse is important and creates trust, as well as an opportunity to have the information repeated and questions clarified. The opportunity to be able to contact nurses easily is of great value to the patient. The knowledge that the nurse who is responsible for the medication is accessible creates a sense of calmness in the patient. The nurse can obtain personal advice, as well as having contact with a doctor or other healthcare professional, when required. Patients have emphasized the nurse's role in coordinating the other team members (Arvidsson et al., 2006; Larsson et al., 2009). Eldh (2006) revealed that patients have a need to be listened to and to serve as a resource in the dialogue with the nurse. This indicates the need for greater respect towards the patient as a unique individual and as a resource for the members of the healthcare team. Every nurse should have a holistic perspective in the encounter with each individual patient (Ryan and Oliver, 2002). The holistic care model aims to provide the patient with information about his/her disease and its treatment and the ability to practise self-care and maintain social contacts, as well as handle the demands of the environment (Hill and Hale, 2004). The result of this study demonstrates that patients who encounter this holistic perspective experience improved well-being. The importance of the nurse devoting time to each individual patient, showing consideration and providing support has been illuminated and was also highlighted by Arvidsson (2006).

According to Rycroft-Malone et al. (2001), the key to a good relationship between the patient and the nurse is patient-centred care with continuity of contact. These authors underlined the importance of nurses posing open questions in order to identify the patient's need for knowledge. The basis of good patient education is ensuring that the level of education is tailored to the patient, which in turn makes him/her feel well cared for. The result of this study reveals that the patients expressed satisfaction at the nurses' concern for them, which is in agreement with the study by Ryan et al. (2003), who demonstrated that patients find it easier to manage their life situation when they experience support from nurses.

A limitation of the present study may be the fact that the subjects were recruited from only one hospital in Sweden. The results might have been different if subjects from other hospitals had taken part, as it is unlikely that all units are structured in the same way and that they provide standardized drug information. This result might also have been different if the study had not recruited only patients receiving anti-rheumatic drug information according to guidelines, but had also recruited patients receiving other types of drug for which no guidelines were available. In order to be able to deal with the material in a phenomenographic study, only a small number of subjects can be included. Provided that the strategic selection in the present study represents the variation in the group, and that the drug information provided by nurses in other hospitals is not rigidly structured, the results of this study could be extrapolated to a wider group of patients.

Conclusion

The results revealed that drug information provided by a nurse led to autonomy, power and security. This was due to the fact that patients conceived autonomy when they assumed responsibility and took the initiative and were involved in the drug information. Patients wanted to be independent and in control of their situation, and described the importance of being involved in decisions about their medication. Drug information provided knowledge and increased motivation, which patients perceived as giving them power. Access, care and being treated kindly meant that the patients had confidence in the nurse, which was perceived as security, and in turn is likely to enhance adherence. It would be of interest to investigate how patients perceive their

participation in a follow-up of their continued drug treatment.

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