

## **Noncompliance: A Never-Ending Story. Understanding the Perspective of Patients with Rheumatoid Arthritis**

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**Key words:** (non) compliance; rheumatoid arthritis; patient perspectives; content analysis; grounded theory methodology

**Abstract:** For roughly the last 25 years there has been consensus in social science research that the term "compliance" in medical therapy research lacks clarity and may even be counter-productive. However, the medical world continues to be disconcerted and scandalized when patients take a critical attitude to doctors' instructions or indeed fail to comply with them. In order to explore this area, interviews were conducted with patients who have suffered for at least eight to ten years from rheumatoid arthritis, a chronic disease that often leads to disability and a decline in social status. The sample was created in cooperation with the German Rheumatism Research Center (DRFZ) at the Charité Berlin Hospital. The survey methodology comprised partially structured interviews with an initial narrative exploration. The interviews were analyzed both in terms of their content as well as with the use of elements of the framework concept of "grounded theory methodology." Our qualitative study has shown that patients take great efforts to manage their disease and that the important thing here is to provide professional support rather than to criticize patients' individual beliefs, preferences and decisions for or against therapeutic recommendations.

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"To write prescriptions is easy, but to come to an understanding with people is hard."  
(Franz KAFKA, 1952, p.152)

## 1. Introduction

According to traditional medical understanding, the success of treatment depends on the patient following the doctor's instructions. With the discovery of antibiotics medicine for the first time possessed medications with high patient benefit, so that it seemed justified to insist on *compliance* with prescribed treatments. For example, LERNER (1997) has shown how important the development of tuberculostatics, in particular, has been for the acceptance of the concept of compliance, since this treatment provides the public with effective protection from an infectious disease that previously had dramatic consequences. On the other hand, for decades there have been studies that have radically questioned the compliance concept. For instance, CONRAD in 1985 suggested, that noncompliance should be interpreted primarily as an expression of a striving for autonomy (see also more generally CONRAD, 1987). TROSTLE (1988) argued in a wider context that medical compliance should be seen as a fundamental ideology that assumes the need for medical control over patient behavior and in the industrialized world has been shaped to a considerable extent by the sales strategies of industry. A hermeneutic approach to patient behaviors has repeatedly shown that nonconformity with medical recommendations during the illness process only becomes interpretable when one views the patient as an active participant (CARR & DONOVAN, 1998; HUNT, JORDAN, IRWIN & BROWNER, 1989). This has not, though, seriously disrupted the search for more and more new ways to make patients compliant. Since the 1980s there have been repeated attempts to raise compliance rates by explaining the expected benefits to patients or by means of medication reminders to encourage the regular taking of medication (De ACHAVAL & SUAREZ-ALMAZOR, 2010; STOCKL et al., 2010). [1]

Although more sophisticated variants, for instance the concepts of adherence or concordance, claim a patient-centered approach, these "more modern" concepts still ultimately cling to the idea of the need to convince patients that there are clear medical guidelines that promise them maximum benefit (CARTER, TAYLOR & LEVENSON, 2003; CUSHING & METCALFE, 2007; NCCSDO, 2005; SEGAL, 2007; TREHARNE, LYONS, HALE, DOUGLAS & KITAS, 2006). Even though there was repeated well-founded criticism of the compliance concept (DONOVAN & BLAKE, 1992; PLAYLE & KEELEY, 1998; THORNE, 1990; TROSTLE, 1988) intense discussion of compliance has continued to the present day. In a recent editorial, APPLBAUM and OLDANI (2010) stated that compliance was embedded in the interests of the health and pharmaceutical industries. It is quite conceivable that economic incentives for doctors to follow guidelines still promote the idea of exerting pressure on patients to be "obedient" (OLDANI, 2010). [2]

The following results of a study, which is based on the interpretation of patient experiences, show why in the case of rheumatoid arthritis it is so important to

maintain the tradition of basic skepticism toward the concept of compliance. Section 2 highlights the importance of the compliance debate for the condition of rheumatoid arthritis. Section 3 explains the study design and sample recruitment. Section 4 contains the interpretations of patients' accounts of their experiences of the disease, side effects, self-perceptions, of compliance and the doctor-patient relationship. Section 5 places the research findings in the context of the prevailing compliance debate and shows the need for future research. [3]

## 2. Rheumatoid Arthritis

Rheumatoid arthritis is a disease of ultimately unknown origin that has an episodic nature and can cause severe pain and lead to massive disability as a result of progressive joint destruction; the individual course of the disease cannot be forecasted (LINDQVIST, SAXNE, GEBOREK & EBERHARD, 2002) and an unfavorable course can lead within a few years to a decline in social status (GEUSKENS, BURDORF & HAZES, 2007). Furthermore, it can often be months or even years before the diagnosis is made. The disease thus contains a host of elements that cause serious insecurity for the patient. Although a "drug-based basic therapy" (medical guidelines talk about Disease Modifying Antirheumatic Drugs [DMARDs], SMOLEN et al., 2010) can apparently slow down the course of the disease, no long-term results for this form of treatment have been published. Rheumatoid arthritis is one of those chronic diseases in which high levels of patient noncompliance are repeatedly reported. Empirical studies estimate compliance rates of about around 60% (VAN DEN BERNT, VAN DEN HOOGEN, BENRAAD, HEKSTER & VAN RIEL, 2009). This appears as a problem to doctors particularly since all international guidelines recommend the commencement of a basic therapy immediately following confirmation of the diagnosis (see e.g. NICE, 2009). The latest generation of these basic medications are the TNF-alpha inhibitors, also known as "biologics" (for the drugs mentioned see [Appendix 1](#)); for the last ten years or so great hope has been placed on their ability to halt joint destruction. The impression has been created for doctors and patients alike that this is a fundamental medical advance even though clinical studies have not yet shown that biologicals are superior over the long term to the previous basic therapy (DONAHUE et al., 2012; ROUNDTREE et al., 2009; SIEGEL, 2008). Specific attention needs to be paid to the question of whether biologicals have a more favorable effect on frequently raised mortality rates than has been reported for DMARDs (particularly MTX); a question that cannot currently be answered because of a lack of methodologically sound control studies (LISTING et al., 2012; WASKO, DASGUPTA, HUBERT, FRIES & WARD, 2013). Some groups of researchers indeed question whether, despite the benefit of modern medications, the lowered life expectancy of patients with severe rheumatoid arthritis has improved at all over the past decades (GONZALEZ et al., 2008). Although it is not the intention of this article to express an opinion on these research results from epidemiological studies, it should certainly be noted how complicated it is for patients as well as for doctors to obtain a clear picture regarding the state of therapeutic progress. [4]

The current debate about compliance in patients with rheumatoid arthritis is without question directly linked to the high profit expectations of the pharmaceutical industry, which for its part is currently developing the next phase of drug therapy for rheumatoid arthritis (MEDICAL NEWS TODAY, 2011). The strength of the influence of globally active pharmaceutical companies in informing the opinions of the medical profession and the extent to which this has shaped the medicalization of care concepts and health policy in general has been shown repeatedly within the medical anthropology field (BIEHL, 2007a, 2007b; HAYDEN, 2007; LAKOFF, 2004). Analysis of the perspective of patients on their disease and on the care process is therefore gaining increasingly in significance. Thoughts about and attitudes towards medical advice as well as the decisions of people with chronic conditions not automatically to follow doctors' recommendations in every situation, cannot be analyzed using the categories of "compliance" and "noncompliance." Instead, the medical profession should be more concerned with finding out about the patient's perspective and take this as a basis for their own actions. The usefulness of this type of understanding of chronic disease, based here on the example of rheumatoid arthritis, is the subject of the following study. [5]

### **3. Study Design**

At the center of our study is the question of how experiences of disease and healthcare provision appear from the perspective of individuals suffering from rheumatoid arthritis. In view of the research questions and objectives, a qualitative design was chosen for the project (FLICK, 2007; FLICK, VON KARDOFF & STEINKE, 2000 [1991]). The current article presents findings relating to the issue of the experience of healthcare provision from the view of rheumatoid arthritis patients. The findings are discussed in the light of existing knowledge of the "compliance concept." A publication with additional findings that focus on the experience of the disease can be found elsewhere (RICHTER, STAMER & SCHMACKE, 2012). [6]

#### **3.1 Sample**

The sample was recruited in cooperation with the Deutsches Rheuma-Forschungszentrum Berlin [German Rheumatism Research Center] (DRFZ) at the Charité Berlin Hospital. An early-stage (disease present for less than two years) cohort was established at the Epidemiology Research Unit of the DRFZ during 2000 and 2001 with the participation of various rheumatology institutions. Comprehensive data for over 900 patients is available relating to disease activity, severity of condition, comorbidity, quality of life, time off work for illness, type and frequency of physician care, hospital treatments, therapy and side effects. This data was collected over three years by means of a questionnaire survey. At the time of conducting the interviews in 2008 the patients in the early-stage cohort had been suffering from rheumatoid arthritis for eight to ten years on average. Creation of the sample on the basis of the early-stage cohort therefore enabled interviews to be conducted with patients who had many years of experience of healthcare provision. [7]

Because of the time and financial resources available within the project, the sample was based on those patients in the early-stage cohort who lived in the north of Germany. Inclusion was further restricted in terms of severity of the disease and age of the interviewee. The patients included in the sample had to have a medically attested disease severity level of moderate to severe. The assumption here was that in comparison with patients with mild conditions, patients with moderate to severe medical conditions would have illness-related problems that adversely affected their everyday lives and therefore would have regular contact with doctors. Because there was no patient assessment of the severity of the condition, assessments by doctors were used. In addition to the regional catchment area and the severity of the disease, age also represented an important criterion in sample recruitment. The interviewees had to be at least 18 years old, i.e. adults, and a maximum of 70 years old. This decision was made in order to try and avoid the combination of potential geriatric care problems with possible problems caused by a chronic condition. After applying the inclusion criteria described above, the size of the early-stage cohort was reduced from 900 to 103 patients who received letters from staff at the German Rheumatism Research Center. Altogether 29 of the 103 patients replied and expressed interest in an interview. This type of sampling is described as "opportunity sampling" within a previously defined total group (PATTON, 2002 [1980]). This opportunity sample was then reduced to a total of 22 participants based on aspects of maximum heterogeneity (FLICK, 2007; PATTON, 2002 [1980]). PATTON describes the process of developing maximum sample variation as follows:

"We maximized sample variation by creating a matrix in which each person in the sample was as different as possible from others using dimensions such as nature of work, stage in career, public visibility, institutional affiliation, age, gender, ethnicity, geographic location, mobility, health status, nationality, and field of endeavour" (2002 [1980], p.235). [8]

In terms of the present study, the following matrix criteria were used: gender, greatest possible age variation between 18 and 70, family status and occupational status. The extent to which the defined matrix criteria presuppose or imply (maximum) differences between the interviewees cannot be answered conclusively. However, it can be assumed that everyday life-world aspects are affected by the above criteria. Gender-specific behavior is seen particularly in terms of questions of compliance. In quantitative research there are differing statements regarding the influence of gender on compliance (MARADIT-KREMERS, NICOLA, CROWSON, O'FALLON & GABRIEL, 2006; VILLER et al., 1999). [9]

In conjunction with the analysis process described below, the sample was created based on the aim of uncovering emerging common themes that cut across the diverse sample profile taking into account maximum heterogeneity, i.e. the sample selection aimed at exploring "important shared patterns that cut across cases and derive their significance from having emerged out of heterogeneity" (PATTON, 2002 [1980], p.235). The sample on which this study is based is composed as follows:

- 13 women, ages ranging from 43 to 67; three in employment, one unemployed, two housewives, seven pensioners; seven living with partner, six not in partnership and
- nine men, ages ranging from 40 to 70; two in employment, seven pensioners; eight living with partner, one not in partnership. [10]

### 3.2 Survey/Interviews

The survey phase of our project involved conducting interviews with patients suffering from rheumatoid arthritis. The method of the interview was chosen because the project deals with the development of "personal narratives or themes that require a climate of trust for the discussions" (MEY & MRUCK, 2010, p.432; our translation). It was expected that aspects of the experience of the disease as well as aspects of the experience of healthcare provision should come up in the interviews. Against this background "a combination of elements from various interview methods" (p.428; our translation ) seemed to be appropriate. Elements of a theme-centered, guideline-based interview were combined with elements of a narrative interview. The method of the guideline-based expert interview as described by MEUSER and NAGEL (2005) was selected because of the wish to address the interview partners as user-oriented experts in relation to the healthcare system. According to MEUSER and NAGEL, one characteristic of experts—in relation to the methodology described here—is that they "themselves are part of the field of action" (p.73; our translation); they are not outsiders looking in on the field being investigated. The study design is based on the assumption that patients with a chronic disease are part of the field of action that is the healthcare system. In line with the choice of methodology, part of the interview was conducted based on a partially structured, semi-open interview guide (MAYRING, 2003 [1983], pp.66f.). The guide, in addition to the intensive preparation of the interviewer, guarantees a concentration on the selected range of themes and also ensures both in terms of language and content that the interviewee is recognized as an expert (MEUSER & NAGEL, 2005). [11]

Combined with the guide is an invitation to the interviewee to tell his or her own story at the start of the interview. The aim of this initial narrative at the start of the interview is to encourage spontaneous accounts, specifically in connection with the patient's experience of the disease. Following the invitation for the interviewee to tell his or her own story, the interview guide deals with the following themes: consequences of the illness in different areas of life, the role of information and explanation, experiences with the care system, therapy objectives and future perspectives (for the rationale of the themes see RICHTER, STAMER & SCHMACKE 2009). Following two pre-tests and a subsequent minor modification of individual guide questions, a start was made on the survey. The invitation for the interviewee to tell his or her own story and the interview guide can be found in [Appendix 2](#). [12]

The interviews, which lasted on average between 60 and 90 minutes, were conducted between April and August 2008. With two exceptions the interviews

took place in the living rooms of the interviewees (one took place in a cafe and one in an office). All interviews were transcribed word for word and in their entirety (for transcription rules, see [Appendix 3](#)) and pseudonyms were used. Informed consent for recording the discussion, an interview analysis and a presentation of the results exist for all interviews. The project design was submitted to the Data Protection Officer at the Legal Department of the University of Bremen. Written certification was obtained stating that there are no data protection concerns relating to the project. The Legal Department/Data Protection Officer did not feel the project needed to be submitted separately to the Ethics Commission. [13]

### 3.3 Analysis

A combination of summary qualitative content analysis and open coding (FLICK, 2007; MAYRING, 2003 [1983]; POPE, ZIEBLAND & MAYS, 2000) was chosen for the analysis of the data. Based on the individual interview the analysis started with paraphrasing of the relevant interview texts. Using various reduction steps, for instance the bundling of overlaps, a summary of the paraphrases according to groups of themes and therefore of the entire interview material was derived. The summary then led to the creation of a category system, which—in combination with the steps of explication and structuring—was analytically applied to all the interviews. The category system comprises two main categories, "experience of the disease" and "experiences of healthcare provision." The core of the present article consists of patients' experiences of healthcare provision, so the following text refers solely to the "experiences of healthcare" category. This main category includes the categories "experiences of medication" and "interactions between doctors and patients." Both categories also include various sub-categories (RICHTER et al., 2009) that in their totality cover the diversity of common themes emerging from the material. [14]

Building on the summary content analysis process, the sequences assigned to the categories and sub-categories are then openly coded. In this way it was possible to gain an understanding of the subjective perspectives of the patients, which is not feasible solely using a summary content analysis process. The codes were grouped together into inductive categories derived from the text sequences. Comparative analysis of the categories (FLICK, 2007; POPE et al., 2000) in turn enabled a description of the deductively formed content analysis categories by means of a detailed exposition of their internal differentiation. For example, the category "interactions between doctors and patients" covers a range of patient wishes for doctors' attitudes that span a spectrum from authoritarian to participatory. In other words, specific importance is placed on illustrating the variety of different perspectives grouped together in a category. In terms of open coding and comparative analysis, elements of the framework concept of grounded theory methodology developed by GLASER and STRAUSS (2010 [1967]) were used in addition to the use of qualitative content analysis. Although a more comprehensive application of the framework concept—specifically in relation to the analysis of all narrative interview sequences—would have been desirable, this was not feasible because project resources limited the amount of



time available for the analysis. This methodological restriction also marks a boundary of the study. [15]

To ensure the accuracy of the analysis process, interviews and interview sections were interpreted in interdisciplinary research groups. Part of the interviews was analyzed within the framework of an interpretation group specifically set up for the project, which was made up of staff in the project group as well as staff who were working at the University of Bremen on other qualitative healthcare research projects. Another part of the interviews was analyzed by individual project members working on their own. The interpretation of a third and last part of the interviews—primarily taking the form of selected interview sequences—was performed in an interdisciplinary research workshop based at the University of Bremen. Interpretation in groups is considered a quality criterion of qualitative research (STEINKE, 1999). [16]

In the following presentation of results all deductively and inductively formed categories are presented that relate to the healthcare experiences of patients and therefore to issues of compliance. [17]

## 4. Results

The interpretations presented are documented with quotes from the interviews. The information given after each quote includes the gender of the interviewee (F= female, M = male), the code (e.g. 30) and the page and line number from the interview. [18]

### 4.1 Adjustment of the medication: A burdensome search process

Immediately after receiving the diagnosis of "rheumatoid arthritis," a process of addressing issues of drug treatment begins for the affected individuals. The period following diagnosis is characterized by a phase of searching for a suitable medication, in other words one that is both well tolerated and effective for the individual; the length of this phase varies from person to person. One of the interviewees, for example, states:

"I really don't know what I started with. Well, I tried, the [doctor]<sup>1</sup> tried out a lot with drugs and and (...). But nevertheless I know that he tried a lot of things with me until I had the feeling that this one is working well for me, you know, until these ones that I mentioned early, these expensive infusions, [biologics]<sup>2</sup> infusions" (F30/10/309-320). [19]

The search for an effective drug therapy is experienced as a phase of high stress and strain: "Yes and that's what I meant by mental strain—no medication helped.

1 Additional text in square brackets represents comments by the researcher that aim to improve the comprehensibility of the quoted extract from the interview. For interview transcription notations see [Appendix 3](#).

2 Names of individual medications in square brackets may mean one of two things. Either they have been added to aid comprehensibility (see previous Footnote) or the interviewees have used in the interview a name that differs from the standard name for the medication. In addition, specifically named biologics are generally replaced by the term "biologic."



In fact, it became worse and worse. You have changed visually and mentally. In fact, everything has changed, you are. The environment has become smaller (...)" (F3/4/129-136). Concerned by the physical symptoms, which are the motivation for the search for an effective therapy, the fundamental question for the affected individuals is to what extent a helpful medication exists for them. The frequently unavoidable trying out of different medications becomes an even greater challenge the more dramatically and rapidly the disease process leads to disruptions in the individual's personal and professional life. The longer this search phase lasts, the greater the stress.

"Yes, that was the first year. At that time I was, I didn't feel very well. But good at the end when the basic medication started to work, and that was the second, MTX didn't work, it was [Arava]. And that was in combination with [Azulfidine]. Only at the end of the year they put me on that. You always have to wait an age, they first of all try out various things. MTX is normally given first, that's the way of it. Even if you don't respond to it, that is ba\_, that is standard" (M13/2/4-51). [20]

There was criticism of trying the so-called standard therapies (here MTX) for too long even though there was no improvement in the patient's condition and additional treatment with cortisone was needed for symptomatic relief. The following interview extract also highlights the length of the search phase in the initial adjustment of the medication:

"Simply, when now with, when someone now becomes ill, the more quickly it is determined which drug works for the specific person and can be used. I would have preferred that as I wouldn't then have had three or four years of such suffering. And perhaps I also wouldn't have had to even give up the job because of it. If the correct medication had been found for me at the start, perhaps I would still have it" (F3/38f./1288-1295). [21]

The burden identified in this quote is not just in terms of coping with the symptoms, it also relates to the growing uncertainty as to whether the search process would lead to a "correct" therapy at all. [22]

The men and women who took part in the study had on average suffered from rheumatoid arthritis for approximately eight to ten years. A spectrum of treatments was found that varied between exclusive control with "painkillers" (e.g. M23), use of basic therapeutic medications such as MTX (e.g. M5) and/or treatment with biologics (e.g. F4). [23]

On the one hand, we see the approach of selecting a medication immediately following diagnosis that has formed the basis for drug treatment for approximately ten years up to the present day.

"Yes, and then they identified it, rheumatoid arthritis. 45 percent was there already as I said. Yes, and then they started with MTX. In tablet form, which I couldn't cope with. Yes (sighs), as I said, they then said that it could be injected. That would be quite

good. My GP would be able to do that. And so then it's remained with MTX up till now" (M5/2/57-63). [24]

On the other hand, we see processes in which various medications are "tried out" one after the other. The reasons for switching could be side effects or lack of tolerance. In addition, a process of effectiveness, diminishing effectiveness and trying out another medication is described in the interviews.

"I then had various drugs, cortisone anyway and then basic therapy MTX. These were the first drugs. And then there was an improvement over time and then the me\_, the medications no longer worked. After that he [the doctor] then switched to [a biologic]. So I also had [the biologic] injected for a couple of years and [Arava], both drugs. And that also went well for some time, two or three years. And in the last year it was no longer enough. The effect got weaker and then he [the doctor] told me I've again got something new and then in the last year I started on this new thing, it's called [another biologic], the brand name ..." (M24/2/51-63). [25]

It is not possible to forecast which drugs will in the best-case scenario show the desired effect. It is possible that a "simple" combination of medications will be found to be sufficient:

"Well, how should I put it? We—the doctor—experimented with various painkillers. And again in different doses or dosages, that is. And now I've been put on this calcitriole, which has worked and I'm happy. Otherwise, as I said, I still don't have a th\_, I was supposed to have a sort of basic therapy, but it didn't happen somehow, I can't tell you exactly the reasons, I didn't ask at all, everything just petered out" (M23/7f./231-239). [26]

Alternatively, it may be that relief is only provided by a "modern" basic therapy:

"So, I take X mg of [biologic] per, per week and my IBO 800, they certainly relieve the pain and combat the inflammation. I get on well with them. So I take 1,600 mg a day. And I'm satisfied if I can maintain that as it is, I'm certainly satisfied with it" (F4/9/271-276). [27]

When one considers the search processes described, it becomes evident that the terms *compliance* and *noncompliance* are not able to encompass the situation of the patients. Particularly in the phase of development of an appropriate drug treatment regimen, patients are confronted by an array of questions and uncertainties that affect their entire private and professional lives. In this period of upheaval doubts inevitably arise as to how far the recommended medication is the best course of action and whether its use might not bring with it new burdens. Patients basically want to find their own space within the recommended drug therapy in the tension between despair and hope that they are experiencing in this time of radical change. [28]

## 4.2 Experiences of side effects: Weighing up the benefits and harms

In the interviews various side effects were mentioned, for instance diarrhea and inflammation of the intestinal mucosa following long-term use of certain painkillers (e.g. F30, F7).

"And yes I can say that these Voltaren drugs and this Ibuflam, I think it's called Ibuflam, well, for the most severe episodes, I mean when you have it so acutely and you have to or should or want to take it quickly, well, then it's probably quite good. Viewed long-term it's not good because the acute episode, at some point my gut couldn't cope any longer, it almost seemed to give up on me" (F7/4/121-129). [29]

Here medications are experienced as helpful for acute episodes, but extremely burdensome for chronic conditions. The experience of depressive phases (e.g. M13) in relation to the taking of painkillers is also mentioned. Side effects such as hair loss (e.g. F3, F8), skin rashes, exhaustion and tiredness (F8), feelings of drowsiness (e.g. F10), stomach problems and nausea (e.g. F2, F4), recurring infections (e.g. F9) and pulmonary inflammation (e.g. F3) are described as particularly burdensome in connection with the taking of basic therapy medications and biologic medications by individuals with rheumatoid arthritis. Furthermore, drugs can have a direct impact on the structure of daily life:

"With this one, I know that definitely, I had, before that I had gold, these gold injections. And then I'd think, today is Monday, you'll have to go for your gold injection, you do that in the evening, then really, really, really quickly back home, get the children ready and then just go to bed because of this gold for example, I felt so, I was, I got sick and there was. I could, don't know whether it didn't agree with me. In any case I felt, I knew that for certain, once I'd had the injection, two hours later I'd be feeling ill and I'd said that to the doctor" (F4/10/314-324). [30]

Side effects require a restructuring of the daily routine, they necessitate a balancing of effectiveness and side effects and they reflect that the process of searching for a suitable drug regimen is not yet complete. The burden associated with the ongoing search is made clear in the following interview extract:

"And they then switched to [Arava]. That one didn't agree with me at all. I was constantly feeling dizzy, everything was spinning round, I couldn't do anything properly any more. They stopped that, yes, they did. And then I had to take two. And I said, that won't work, I won't manage that. I was constantly feeling sick. And then you feel stupid when you go there and say: this one doesn't agree with me and that one doesn't agree with me, see what I mean?" (F2/15/486-493) [31]

The interviews do not show an aversion in principle to drugs, but they do reflect the—at times—deep distress in terms of the constant balancing of benefit and harm. These worries can take dramatic forms:

"And I still have the feeling that all the drugs I have to take, that the stuff is tearing me up from the inside. It was switched again two years ago, I was then given another one

and they then said in the pharmacy, this and that and if I was taking this against the other one. I said, if the same stuff is in it, yes, but if I don't get on with it I'll have to have the other one again. But I don't know, I'm not really satisfied. And of course when you read through the description, you get worried. In this disease I must say that there is a hell of a lot of anxiety involved" (F2/2f./66-77). [32]

This point once more demonstrates that the concepts of *compliance* and *noncompliance* do not cover the reality of the individual with the disease. The interviews show a highly stressful process of consideration of the benefits and risks of drug treatment and are also characterized by the attempt to actively find a way to cope with the burden of the disease. [33]

#### **4.3 Anxiety-producing associations: Rheumatoid arthritis and cancer**

Certain drugs generate particularly high levels of anxiety and aversion. The aversion to MTX is based on the fact that this drug is also used in the treatment of individuals with cancer. Such an aversion may exist even before having taken the drug (e.g. F8), or may also develop while taking the drug, irrespective of whether the drug proves to be ineffective (e.g. F3) or effective (e.g. F7).

"Yes, I have to say that with this MTX thing. I needed to have something effective, I'd still say that now. However, I wouldn't still say now that it has to be MTX. And I, from my experience I understand anyone who says: I reject it. Because as I said, I no longer had these sort of rheumatoid arthritis symptoms, not so strongly, instead I had these symptoms of chemo[therapy]. I hadn't read anything about it before then. I then just told my sister what I've got, on the phone, and what I take and so on. And my brother-in-law, he looked things up on the Internet and said: Did you know that MTX is actually used in breast cancer? And then I thought, that's why you always feel as if you've had chemo" (F7/8f./272-284). [34]

From the patient's point of view the basic therapy MTX can lose the character of an anti-rheumatic drug and be perceived as a cancer medication. It is a frequently used medication in "chemo" (a term that has now entered everyday language) therapy for cancer. The *cancer* association crops up a second time in connection with pain therapy. One interviewee mentions that there will be the need in future to resort to stronger painkillers, for example "opiates or morphines" (M11/8/269) —substances that are largely envisaged for the late stages of cancers. A similar significance is given to the issue of cortisone because of the feared consequences in terms of bone density, body weight and appearance. This could be because cortisone with its strong pain-relieving effect is viewed as a risky magic potion. Cortisone is repeatedly described as an important, rapid and effective medication in acute phases of the disease characterized by rheumatic exacerbations.

"(...) I also know about the long-term side effects and said then that I didn't want that. So for myself I ruled it out. I did it short-term at that time for six weeks because that was shortly before the holiday and I thought, I can either cancel the holiday or I take

some sort of medication that will help me to get through it all right. Because I couldn't have gone on holiday in that condition, you know" (M11/2/53-68). [35]

However, the effectiveness of cortisone as a medication is set against the side effects experienced, such as weight gain and associated consequences.

"As I said, at the beginning I received a fairly strong dosage of cortisone and I was, at one point I was 120 kilos. So then we reduced it gradually. Now I take 10 mg and calcitriole and I am now 96 kilos and also feel better physically. When I was so fat, I had respiratory problems (...)" (M23/2/49-59). [36]

Once again the reference to *compliance* and *noncompliance* does not appear relevant in relation to the felt impact of the drug substances. It is important to understand that medications for the treatment of rheumatoid arthritis (as with other chronic conditions) always also carry with them a symbolic meaning and this needs to be taken into account in addition to the described side effects of the medications which can be considerable. With their basic and pain therapy medications for rheumatoid arthritis patients may feel that they have entered the sphere of cancer diseases. This can have an extremely depressing effect and doctors must be aware of symbolic meanings of this type. Again, the analytical issue is manifestly not "obedience" but is instead a further hurdle for successful coping with the disease. [37]

#### 4.4 "Compliance" from the patient viewpoint

At least three basic viewpoints can be identified when one considers attitudes to drugs in the context of rheumatoid arthritis: strict compliance with medical treatment regimens, flexible compliance with medical treatment regimens and independent rejection of medical regimens. According to one viewpoint, treatment success is only achieved through the disciplined taking of medication, even if this may impose great strains. In response to the question as to what had helped most during the past years in terms of the disease, one interviewee gave the following answer, illustrating the perspective of strict compliance with medical treatment regimens:

"Most? Well, that's a good question. Overall, it's the drugs you know. I think if I stopped them, I'd go back to where I was at the beginning, certainly. You should, I mean, if they have set a dosage and it works, a bit, don't try it at all. You know, I think it's as it was all described in the leaflet, and if you do that, then you go back to where you were to begin with when nothing was right. If you go, now I'll take it, now I won't and now I'll start again and then stop again—that just won't work at all. That doesn't help you, does it" (F12/24/785-796). [38]

Another viewpoint is a flexible and therefore to some extent self-determined approach to the taking of medication based on the patient's own feeling of physical well-being.

"So, normally, I actually have the [biologic]. However I no longer have it (laughs) because I don't like being injected. At some point then I just no longer want to have something rammed into my gut and so I stop. Then, as I said, I simply start taking cortisone for a while till I get the next fungal infection and then I go back to the [biologic]. But then I simply leave it out for three or four months. And you can do that also with the [biologic], you know, you can do that" (F9/19/634-642). [39]

The approach just described implies a distinct striving for autonomy that finds its expression in flexible, non-standardized decisions regarding the taking of medication based on self-awareness. [40]

In a further viewpoint the desire or aim for complete independence from the taking of medication is formulated:

"My wish would actually be to come off the tablets again completely. No longer having this dependence, no longer having to swallow a certain number of tablets every day, you know. As I said, that was the reason four or five years ago why I stopped because I simply said that I'm deciding for myself now, that I don't want it any more and won't go along with it until I say for myself that there's no other option for me now. And I managed the whole thing for two years. And I'm proud about that, or at least pleased, because these were two years during which I—at least in terms of the tablets—had no restrictions because I wasn't taking any and in that respect could quote 'move about freely'. I can move about freely, that isn't the issue. Just when I now go somewhere, I need to think about these things. And if I don't have them with me, then I have a problem, you know. That's just how it is" (M11/9/277-294). [41]

Ultimately, there is a tension between the autonomy resulting from not taking drugs and the autonomy resulting from taking drugs, for example the reduction of pain and maintenance of mobility. Caught up in this field of tension, the interviewee decided against taking drugs for as long as possible. He informed his doctor of this decision, "after I stopped taking them [the drugs]" (M11/33/1097-1098). An independent rejection of the doctor's recommendation of drug therapy is illustrated here. [42]

This shows how actively patients with rheumatoid arthritis address the problem of *compliance* with doctors' prescriptions and that although they greatly value the possibilities of drug therapy, they look for an "appropriate" way for them. For instance, patients may stop taking their medication for periods of time or in extreme cases reject it completely. Decisions of this type can only ever be understood in the context of the development of the patient's specific personal circumstances. Patients are active participants and show a high degree of reflection and rationality in their processes of consideration. It provides further confirmation that there is a "logic of noncompliance" (TROSTLE, HAUSER & SUSSER, 1983) which admittedly can only be understood if one listens to the history of the patient. [43]

#### 4.5 Significance of the doctor-patient relationship for treatment decisions

A typical feature of rheumatoid arthritis is that confirmation of the diagnosis may take quite a long time. After notification of the diagnosis, the issue of time then changes from the patient viewpoint. They are now confronted with the problem that all modern guidelines specify the immediate prescription of a so-called basic therapy that is supposed to halt the progress of the arthritic changes but may also entail significant side effects. During this phase patients above all need time to comprehend the physical and social processes associated with the disease. Obviously in this situation the importance of the doctor-patient relationship becomes the actual basis for the joint discussion of potential treatment decisions. The following quotes illustrate the problems that patients have in understanding that from now on they will have to live with a chronic disease:

"That was right at the beginning, the stay at the rehabilitation center. Yes, but what they told you there, I saw all these leaflets, you know you had to process so much and the disease was still then at such an early stage. I didn't understand a single word they told me" (F3/25/818-823). [44]

And in another interview:

"Not just like the first orthopedic surgeon who discovered it, who asked me if I'd thought about incapacity to work, 50 percent disabled. Crash, crash, crash. Before I'd even understood that I'd got rheumatoid arthritis, that was. Yes, first of all then I was hostile. I thought: You asshole, you can tell me anything. Nothing's going to happen. But it did happen. Apart from that, I can't think of anything else" (F30/19f./636-643). [45]

In the light of extreme experiences of this type it is clear that patients attach great significance to the time devoted to them in the doctor-patient relationship. However, time is not just viewed in terms of the actual minutes and hours elapsed or invested, but more importantly it is interpreted in relation to the possibilities and limits of the expected medical care options offered:

"And what I find extremely good is that they [GP and rheumatologist] have time. You know, it wasn't like you're on a conveyor belt. However, one time I was with the rheumatologist, he had so many, I almost said customers, so many patients. I said: You know, doctor, I feel as if I'm on a conveyor belt. And he really took that to heart and since then he's had more time for me. You know, I was a bit annoyed" (F22/12/382-389). [46]

Conversely, the interviews show that a lack of interest in the patient on the part of the doctor is criticized and is seen as unacceptable. In another interview:

"Then I went to the rheumatologist in X-town. Was there for a few years, but saw no progress, the stiffness in the fingers was getting worse and worse. The joints in themselves, that was OK. And I always had the feeling that it can't be. It was a rheumatologist, a doctor, a rheumatologist or whatever, sitting like a crazy professor and I'm sitting in front of him and he taps about on his machine for hours and then I



say to him: 'Have you got a question now or am I finished?' 'No, stay there' "  
(M25/1/16-24). [47]

This sort of exercise of physician's power in the context of medical consultations and the associated lack of interest in the condition of the patient are experienced as extremely unpleasant. [48]

Empathy, sensitivity, a friendly manner and helpful support are what are wanted from doctors, particularly in relation to phases of high disease activity. A realization of these patient concerns in turn represents a fundamental basis for the joint negotiation of future treatment methods:

"But there [in a rheumatology clinic] I must say you were built up again. In X-town [rheumatology clinic] you know, they treat the patient as an individual. And that's how it should be as I see it. And not always in general, always according to the procedure, always working through the table" (F3/9f./325-338). [49]

Joint negotiation of conceivable treatment methods and objectives for the individual are at the heart of the following quote, which also illustrates the need for forward-looking discussions between patient and doctor:

"Yes, that's what I talked about briefly earlier on, looking at things as a whole you know. The person as a rheumatoid patient. But also then looking at the whole. And that includes this working things out. These are objectives that the patient has or where the doctor needs to say, you know, the objective is no longer possible, we won't achieve that. But working things out together, I think that's really important you know. And not at the end of the day as it's still done today, from the internal medicine specialist I get this or that drug and from the orthopedic surgeon I get this one and injections in the joint or these orthopedic devices or whatever and that's that, you know. That's the most important thing in general. Because this disease isn't curable. And because it affects all areas of the affected person. Professionally, personally for your own condition, everything. And that's a really important point, you know" (F6/29/964-979). [50]

The interviewee forcefully states the need for jointly working out or negotiating the treatment pathway that appears the best possible for the individual person. Conversely, a quasi-standardized dispensing of medications is seen as not appropriate, particularly in view of the long-term nature of the disease. There is a clear desire for participation in the decision-making process, which enables a connection between the patient and the "prescribed" therapy to develop. [51]

The following quote shows how diverse the character of doctor-patient meetings can be in terms of agreement on treatment decisions:

"I gradually cut down on them [all rheumatoid arthritis medication] and at my next quarterly visit to the rheumatologist I informed him that I'd stopped taking everything. Yes, and he said that's OK. Ultimately, and here we're at this point again, no-one can force anyone to take medication, he said. And if I'm getting on all right with that, then

that's OK and if I don't get on all right, then we'll both see. In other words, he is not the sort who stands up and says: Oh my God, and then: Find another doctor. Instead he says: OK, try it and if it works, we're both happy and if it doesn't work, then at least it was an attempt. So, and that's why I think, or that's the point where I say this is a doctor who I feel in good hands with, who, you know, doesn't block everything from the outset, in terms of alternatives that I perhaps, even if they may be wrong, but that I perhaps have found for myself, whether they are good or bad is another matter, but he then responds and says that if you are of the opinion that they'll do you good, then try them out. And if it's something useful, then we can talk about it further. And if it does nothing, we can also talk about it and then we'll see whether there's another possibility, yes. And because of that I'm very happy with the doctor, you know" (M11/33/1103-1126). [52]

The interviewee values empathy on the part of the doctor that finds its expression in a willingness to support the patient, irrespective of whether medical recommendations are completely accepted or not. The interviewee feels accepted by the doctor in the role of patient since his decisions are supported by the doctor, but not judged. There is no mention of attempts by the doctor to change the mind of the patient in his decision. Rather, the interviewee feels encouraged by the doctor and receives the assurance that, if necessary, they will look for new pathways of action and treatment together. This type of "relaxed" basic medical attitude underlines ultimately how unnecessary the concept of *compliance* is in the care of patients with rheumatoid arthritis and that what is important is to help the affected individuals find their way to deal with a disease that frequently entails severe physical and psychosocial restrictions. [53]

## 5. Final Observations

It is striking that the decades-long debate about and research into compliance in medicine has achieved only one objective, namely continually to fuel the uncomfortable feeling among patients that they are behaving disobediently. Even if one sets aside a not infrequently justified mistrust of non-evidence-based medical recommendations, the term *noncompliance* signifies nothing other than that patients—particularly in the case of chronic illnesses—understand doctors' recommendations as part of their search for an appropriate way to live with the disease, nothing more, nothing less. Where, from a medical viewpoint, there is actually "important" advice that affects the doctor's mission to heal, it is of particular importance to take patients' sensitivities and questions seriously and build up a strong relationship with them. The task of finding out more about patients' ideas regarding living "normally" with illness remains a research priority (AHLMÉN et al., 2005; McPHERSON, BRANDER, TAYLOR & McNAUGHTON, 2001; SINCLAIR & BLACKBURN, 2008). Here it is necessary, amongst other things, to look systematically for patient-relevant results, above all patient reported outcomes, for clinical studies (CARR et al., 2003; SANDERSON, MORRIS, CALNAN, RICHARDS & HEWLETT, 2010; SHARPE & CURRAN, 2006). Certainly, in extremely medicalized societies it is also important to reduce the dependence on professional helpers and to give space for the development of new patterns of living (SHARIFF et al., 2009; STAMM et al., 2008). It seems to be

particularly difficult for many doctors to see patients not as the object of medicine but as the experts in their disease. One of the pioneers of evidence-based medicine, David SACKETT, went further in his thinking than many present-day practitioners by linking the discussion of noncompliance to three prerequisites: "First, the diagnosis must be correct ... Second, the therapy must do more good than harm ... Finally, it must be established that the patient is an informed, willing partner in the execution of a maneuver designed to alter compliance behavior" (1979, p.3). However, SACKETT may here have massively underestimated the fact that a change in the attitudes of doctors is also required. This includes consideration of the information and communication needs of patients in the doctor-patient relationship, which has also been repeatedly demanded in relation to the treatment of individuals with rheumatoid arthritis, from DALTRY (1993) through to KJEKEN et al. (2006) and LEMPP, SCOTT and KINGSLEY (2006). Finally, the poignant question must be envisioned of whether or not the doctor's surgery will ever be the best place to understand the particular importance of the patient's perspective. The question cannot be circumvented of whether or not in democratic societies far more creative ways need to be sought to empower the patient in order to develop a counterweight to the "passivizing" effect of physician dominance (PLAYLE & KEELEY, 1998). Currently there seems to be no "prescription" for banishing the concept of compliance from the doctor-patient relationship. But qualitative health research can—here in the case of rheumatoid arthritis—still illuminate the extent to which the compliance construct is at odds with the life situation of individuals suffering from rheumatoid arthritis. Since the call by KLEINMAN, EISENBERG & GOOD, (1978) for a clinical social science, the road has not become easier. Indeed, medicine today is perhaps even further away from the orientation of medical anthropology, "which insists that the only valid grounds for understanding illness and treatment are the microcultural worlds in which patients and families engage in everyday social activities" (KLEINMAN, 1995, p.151). Future research projects should particularly focus on how the importance of a deepened understanding of the patient perspective in chronic diseases can be incorporated into the self-image of the medical professions. The question as to why many doctors are still finding it difficult to apply and practice this shift in perspective remains largely unclear despite encouraging visions (GIGERENZER & GRAY, 2011) and all efforts to implement informed and shared decision (COULTER, 2010). [54]

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## Appendix 1: List of Drugs (in alphabetical order)

ARAVA (LEFLUNOMIDE): DMARDs

AZULFIDINE (SULFASALAZINE): DMARDs

CALCITRIOLE (used in conjunction with calcium in the management and prevention of primary or corticosteroid-induced osteoporosis)

IBO (IBUPROFEN): NSAIDs

IBUFLAM (IBUPROFEN): NSAIDs

MTX (METHOTREXAT): Immunosuppressants

VOLTAREN (DICLOFENAC): NSAIDs

Patient information about drug treatment of rheumatoid arthritis

(<http://www.mayoclinic.com/health/rheumatoid-arthritis/DS00020/DSECTION=treatments-and-drugs>):

- *NSAIDs*: Nonsteroidal anti-inflammatory drugs (NSAIDs) can relieve pain and reduce inflammation. Over-the-counter NSAIDs include ibuprofen (Advil, Motrin, others) and naproxen (Aleve). Stronger NSAIDs are available by prescription. Side effects may include ringing in the ears, stomach irritation, heart problems and liver and kidney damage.
- *Steroids*: Corticosteroid medications, such as prednisone, reduce inflammation and pain and slow joint damage. Side effects may include thinning of bones, cataracts, weight gain and diabetes. Doctors often prescribe a corticosteroid to relieve acute symptoms, with the goal of gradually tapering off the medication.
- *Disease-modifying antirheumatic drugs (DMARDs)*: These drugs can slow the progression of rheumatoid arthritis and save the joints and other tissues from permanent damage. Common DMARDs include methotrexate (Trexall), leflunomide (Arava), hydroxychloroquine (Plaquenil), sulfasalazine (Azulfidine) and minocycline (Dynacin, Minocin, others). Side effects vary but may include liver damage, bone marrow suppression and severe lung infections.
- *Immunosuppressants*: These medications act to tame your immune system, which is out of control in rheumatoid arthritis. Examples include azathioprine (Imuran, Azasan), cyclosporine (Neoral, Sandimmune, Gengraf) and cyclophosphamide (Cytoxan). These medications can increase your susceptibility to infection.
- *TNF-alpha inhibitors*: Tumor necrosis factor-alpha (TNF-alpha) is an inflammatory substance produced by your body. TNF-alpha inhibitors can help reduce pain, morning stiffness, and tender or swollen joints. Examples include etanercept (Enbrel), infliximab (Remicade), adalimumab (Humira), golimumab (Simponi) and certolizumab (Cimzia). Potential side effects include increased risk of serious infections, congestive heart failure and certain cancers.
- *Other drugs*: Several other rheumatoid arthritis drugs target a variety of processes involved with inflammation in your body. These drugs include

anakinra (Kineret), abatacept (Orencia), rituximab (Rituxan) and tocilizumab (Actemra). Side effects vary but may include itching, severe abdominal pain, headache, runny nose or sore throat.

## **Appendix 2: Initiation of the Narrative Part of the Interview and Guide Questions in the Rheumatoid Arthritis Project**

### **Initiation of the narrative part of the interview**

"I'd like you to think back to the time when your illness began, what sort of life you were leading and how you then gradually became aware of the signs of the disease. Perhaps you remember particular events. You can take as much time as you like to go into detail as I'm interested in everything that is important to you."

### **Guide questions**

The sequence of the groups of questions should be determined flexibly and adapted in terms of content to the initial narrative of the interviewee. In relation to each group of questions, the interviewer should start with a less structured question (A/B) and then assess to what extent additional questions (C) should be asked.

#### *1. Understanding / significance of the disease*

A) What are the most important features of rheumatoid arthritis (or: your rheumatic condition) for you?

B) What has changed for you because of the disease?

C) Possible supplementary questions relating to:

- possible changes in personal life (e.g. relationship with partner, children, parents, friends)
- possible changes in professional life

#### *2. Role of information and explanation*

A) How well informed about the disease do you feel? And how well was it explained to you?

B) What does "well informed" / "well explained" mean to you?

C) Possible supplementary questions:

- What other topics would you like information about? (This also includes topics other than the disease itself.)
- Who do you trust in terms of providing information / explanations?
- What have you done to find additional information?
- To what extent are, for instance, self-help groups important to you?

### *3. Experiences with / in the healthcare system*

A) I'd like you to tell me about your experiences of the treatment of your disease

B1) Looking back, what has helped you the most?

B2) What did you feel, for instance, about your encounters with (your GP ...)?

C) Possible supplementary questions relating to:

- GP/rheumatologist care
- physiotherapy, occupational therapy
- communication and continuity in the treatment process
- experience of medications and side effects
- experience with alternative therapies
- reasons for possible discontinuation of the treatment

### *4. Treatment objectives*

A) I'd like you (once more) to tell me what are the key objectives for you (today) in the treatment of your disease.

B1) To what extent during the course of your illness have there been changes in terms of what are for you the most important treatment objectives?

B2) Today there is a lot of talk about doctors and their patients defining treatment objectives together. What is your opinion about this?

C) Possible supplementary questions relating to:

- To what extent has there been joint discussion of treatment objectives in your meetings with your doctor?
- What do you want/expect from your doctor?

### *5. Final phase*

A) When you think about the future, what is most important to you?

B) We have discussed a lot of topics and you have told me in detail about a wide range of things. We are now coming to the end of the interview. Is there anything that we haven't so far discussed that is of particular importance to you?

### Appendix 3: Interview Transcription Notations

Underlining	Emphasized word/phrase
[Unintelligible]	Unintelligible speech
[The therapist]	Explanation by the author
Word unfini_	Denotes where a word was broken off
(Laughing)	Denotes non-verbal elements of communication
(been[?])	Hard to make out word because of e.g. background noise
[Telephone ringing]	Interruption, e.g. doorbell, phone ringing, background noises etc.
(- -)	Short pause (up to approx. 5 seconds)
(Longer pause)	Longer pause (approx. 5 seconds or more)
, (Comma)	Brief pause between parts of a sentence
. (Period)	Falling intonation (end of sentence)
? (Question mark)	Interrogative intonation

Transcription was word for word. Everyday expressions such as "yeah" or fillers such as "mhm" and "oh" were also transcribed. The transcription of the speech of the interviewer was also word for word. With colloquial phrases apostrophes were used where necessary, e.g. "they're coming" or "he ain't here."

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