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Dermatology patients' and their doctors' representations about adherence

Abstract: The aim of our study was to identify representations about patient adherence among dermatologists (N=40) and their patients (N=153). A combined qualitative-quantitative methodology was applied. Dermatologists identified good doctor-patient relationship, information from the doctor, and background information as the most important determinants of adherence. In patients' rankings, information from the doctor and understandable communication received the highest scores. Multidimensional scaling arranged patients' results into four content groups which helped to reveal the structure of the representations. Our results may contribute to the evidence-based confirmation that transparency of views and expectations in doctor-patient communication is a basic determinant of successful adherence.

Keywords: Patient adherence, representations, doctor-patient relations, dermatology, mixed methods design

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1 Introduction

Patient adherence is a challenging field of health behaviour research. Reviewers of the adherence literature argue that the causes of the relatively high number

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Márta Csabai, Institute of Psychology, University of Szeged, 6722 Szeged, Hungary of open questions might be due to the fragmented nature of the research, lack of appropriate qualitative methodologies, the neglect of patients' perspectives, and the lack of integrative models [1,2].

According to a widespread WHO definition, adherence may be described as 'the extent to which a person's behaviour-taking medication, following a diet and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider' [3, p. 17]. This definition applies the term 'agreed recommendations', which suggests that adherent behaviour should be based on a mutual agreement or common decision-making of practitioner and patient. The definition reflects the influence of those attempts which tried to re-conceptualise the problem of compliance, partly in the form of such concepts as 'concordance' [4], or 'informed adherence' [5]. These concepts grew from the recognition that patients and practitioners bring different illness and treatment beliefs to the consultation, and that their lack of knowledge about each other's expectations might easily lead to non-compliant behaviour and possibly to the failure of the relationship [6-7]. The terms 'adherence' and 'concordance' are often used as synonyms, but several authors emphasize that concordance has an additional reference to the relationship, and to the process of reaching an agreement or consensus [8].

In health care relationships, the parties' views about the other's roles, and their expectations towards each other are important factors in adherence [9]. If these expectations remain unclear, this might bring about a 'bogus contract' between professionals and their patients [10]. In other words, there may be different hidden expectations and concepts regarding the relationship in the minds of the doctor and the patient and some of their own representations may be unknown even to themselves.

There are relatively few studies which examine the differences in healthcare practitioners' and patients' representations about adherence. The research of Pollock [11] shows that the absence of knowledge about patient perspectives could limit effective cooperation and adherence.

Arbuthnott & Sharpe [12] also note that perspectives and preferences are of primary importance, and emphasize the importance of the reduction of asymmetry in information exchange and the facilitation of mutual decision-making. According to our hypothesis, an important precondition of asymmetry reduction may be the transparency of expectations in the given consultation. These expectations might be affected by representations about adherence itself.

2 Aim of the study

Our study aimed to explore representations and their differences among practitioners and patients. We thought it important to compare practitioner and patient groups whose experiences about professional-patient relationship originated in the same therapeutic environment and who also had personal experiences with each other. Thus, we chose professionals and patients from the same clinic as the study sample, similar to Gachoud, Albert, Kuper, Stroud and Reeves [13] in their study about social work, nursing, and medicine. As will be explained below, we applied a combined qualitative-quantitative methodology through which we could test and compare the representations of patients using a questionnaire with items created from content categories identified in the interviews with their doctors. A further advantage of the use of combined methodology was that we could interpret data from the different sub-samples of doctors and patients independently.

We chose the medical sub-speciality dermatology, since this is one of the fields in clinical care where treatment adherence has been reported as relatively low [14-16]. Another reason was the recent focus on the importance of the doctor-patient relationship in dermatological adherence research [16-21]. The quality of the doctor-patient relationship has been increasingly regarded as an essential factor in dermatological adherence [18, 22-25]. A further consideration was that there is relatively little qualitative research which connects patients' views about the management of their chronic illness with adherence/ concordance models [9, 26-27]. Dermatological diseases, being prevailingly chronic, long-term conditions, seemed appropriate targets for such examinations [20].

3 Methods

3.1 Questionnaire development and protocol

The complex nature of representations, and their often hidden components, are not always easily explored by quantitative research methods. The application of qualitative measures, on the other hand, is usually complicated and time-consuming. At the same time, many authors highlight their usefulness, emphasizing that new approaches are needed in this field [14, 20]. Based on these considerations, we applied a combination of qualitative and quantitative methods in our research, following the Mixed Methods paradigm [28-29]. We followed the steps of the process of thematic text analysis [30]. The first step was administering structured interviews with 40 dermatologists at the Clinical Department of Dermatology and Allergology at the University of Szeged in Hungary. The interview consisted of 11 questions about adherence and information dissemination to patients. Stem questions used by the interviewer to open the discussion concerned the information doctors gave to their patients about their treatments and medications, the factors they thought adherence depended on, and the ways doctors facilitated patient adherence. Interviews took place in the clinical department where the participating dermatologists worked. The doctors were interviewed by a psychologist with an MA degree. Interview length was 30-40 minutes. Transcripts were made from the answers and a text data file was created from them. Based on grounded theory methodology [31], content categories were not pre-prepared, but were created from the material of the dermatologists' interviews. Transcripts were coded into these categories by two independent coders, both of them graduate psychology students with Human Behaviour Analyst BA degrees. For further examination, and for the design of our questionnaire, we used those items which were mentioned by at least 10% of the doctors. A 12-item attitude scale was created from the most typical statements in each content category, and a 7-grade Likert-type scale (7 = fully agree; 1 = fully disagree) was added to each item (Table 1). In the next phase of the study, this questionnaire was completed by 153 patients of doctors in the interviews, all diagnosed with chronic skin diseases, most frequently psoriasis (N=82). Other diagnoses were atopic dermatitis and vitiligo. The average duration of their illness was 13.81±13.92 years. Patients' average age was 50.18±16.11 years (ranging from 18-87 years). The sample included both females (N=90) and males (N=63). The level of education varied among the patients of whom 31 had a primary

school certificate (1-8 years of education), 87 had a high school graduation certificate (9-12 years of education) and 32 of them had higher education qualifications (12+ years of education). Administration of the questionnaire always took place according to the same protocol: after their medical treatment in the outpatient department, a psychologist informed the patients about the aim of the study and requested their informed consent. The questionnaire administered after informed consent was obtained.

3.2 Statistical procedures

After analysing the content of the interviews, and defining the frequency of each content category, we calculated the interrater reliability coefficient, Krippendorff's alpha [32]. After recording the data from the questionnaires into data files, descriptive statistics and multidimensional scaling with SPSS 17.0 software were performed. We applied the multidimensional scaling method to the patients' questionnaire data to discover underlying factors that explain the similarities of certain items [33]. Multidimensional scaling (MDS), which creates a perceptual map, spatially represents the similarities and dissimilarities of a set of elements [34]. In our research, the goal of using MDS was to reveal the psychological dimensions in the data that can meaningfully describe the underlying cognitive constructs [35-36]. We conducted a hierarchical cluster analysis (Ward's method) for a further analysis of the dimensions of adherence representations of patients.

4 Results

4.1 Interviews with doctors

Based on the frequencies of content categories in dermatologists' interviews, we produced a hierarchy of factors which were considered the most important in establishing adherence (Table 1). Intercoder reliability was 0.68 using Krippendorff's alpha.

Table 1 indicates that dermatologists (N=40) found good doctor-patient relationship (37.5%), information from the doctor (37.5%), background information (37.5%) and the patient's financial state (32.5%) to be the most important factors for adherence. These factors were evaluated by the doctors as all being equally essential. Patient's personality (20%) was considered of moderate importance by doctors, and it was followed in the ranking

by the doctor's understandable communication (12.5%), written handouts (12.5%) and the doctor's personality (12.5%). Dermatologists mentioned the following factors least frequently, but with equal weight: time for consultation (10%), internet/telephone contact (with caregivers) (10%), comfortable medication (10%) and doctor's empathy (10%).

4.2 Patients' questionnaire results

The results of the patients' attitude scale questionnaire are shown in Figure 1. On a 7-point scale, patients (N=153) found the doctor's understandable communication (M=6.75, SD=0.58), information from the doctor (M=6.78, SD=0.58)SD=0.65) and patient's personality (M=6.24, SD=1.19) to be the most essential factors for adherence. These were followed by the importance of a good doctor-patient relationship (M=6.1, SD=1.65), the doctor's personality (M=5.91, SD=1.64) and the doctor's empathy (M=5.88, SD=1.6).

To determine whether a statistically significant relationship was present between patients' age and their results on the attitude scales, Pearson's correlation coefficients (r) were calculated. Patients' age correlated significantly with the following categories: good doctor-patient relationship (r=0.446, p<0.01), doctor's empathy (r=0.336, understandable communication (r=0.331, p<0.01), patient's financial state (r=0.288, p<0.01), and written handouts (r=0.217, p<0.05) (Table 2).

In the next step, multidimensional scaling was applied to the data from patients' questionnaires, to organize information and to understand group similarities. The result, a 'cognitive map,' is a spatial representation of how the ideas are considered to be similar to or different from each other. Points are positioned so that distances reflect the dissimilarities between the corresponding items (Figure 2).

As can be seen in Figure 2, items from the questionnaire (categories based on the doctors' interviews) can be grouped into four major content groups according to the patients' answers. The first content group labelled as 'External resources', contains the following categories: patient's financial state, background information, and internet/telephone contact. The second content group, which includes the categories of 'time for consultation', 'comfortable medication' and 'written handouts', was named 'Framework and aids of communication'. The next content group, 'Doctor's traits and the relationship' includes the categories 'doctor's personality', 'doctor's empathy' and 'good doctor-patient relationship'. Finally, the fourth major content group was where the content

Table 1: Content categories and their frequencies in the interviews with the doctors (N=40), and items of the attitude scale which were created from the most typical statements under the content categories.

| Content category (frequency in the physician interviews N=40) | Description of category / Item of attitude scale |
|---|--|
| Information from the doctor (37.5%) | The doctor can help his patient to be adherent mostly by giving detailed information about the patient's disease. |
| Background information (37.5%) | Information from family members, television, newspapers, and the internet can significantly affect the patient's adherence with the treatment. |
| Good doctor-patient relationship (37.5%) | Those patients are the most adherent with the treatment who have a trusting relationship with their doctors. |
| Financial state (32.5%) | Expensive drugs may be the main obstacle of adherence. |
| Patient's personality (20%) | Basically patients' adherence depends on their personalities. |
| Doctor's personality (12.5%) | Characteristics and personal traits of the doctor affect the adherence of patients. |
| Understandable communication (12.5%) | Doctor talking to patient in an understandable way would be best in improving adherence. |
| Written handouts (12.5%) | Written handouts and brochures given by the doctor are a great help in the healing process. |
| Comfortable medication (10%) | The ease of use of medication plays a role in adherence with the treatment. |
| Time for consultation (10%) | Adherence would mostly improve if there was more time for consultation between the doctor and the patient. |
| Telephone/Internet contact (10%) | There should be an internet or telephone service for giving information and maintaining contact between doctor and patient. |
| Doctor's empathy (10%) | The doctor's empathetic concern for the patient's problem would affect the healing process in a positive way. |

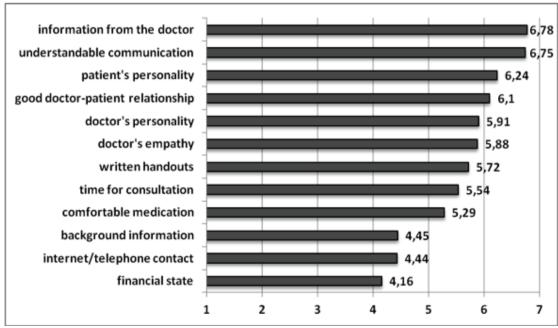


Figure 1. Patients' rankings of the most important aspects of adherence. Questionnaire (7-point attitude scale) results with means of the scores (N=153).

Table 2: Significant correlations between patient age and questionnaire results (Pearson correlation coefficients *p<0.05, **p<0.01).

| Questionnaire item categories | Patient age |
|----------------------------------|-------------|
| Written handouts | 0.217* |
| Financial state | 0.288** |
| Understandable communication | 0.331** |
| Doctor's empathy | 0.336** |
| Good doctor-patient relationship | 0.446** |

categories - 'patient's personality', 'understandable communication' and 'information from the doctor' - were the most intensely condensed. This was identified as 'Patient's personality and information.' The results of the multidimensional scaling are in accordance with the identified cluster structure of patients' answers based on hierarchical cluster analysis (Ward's method). Based on the cluster algorithm, a dendogram was generated for visual classification of similarity for grouping (Figure 3).

5 Discussion

As is reflected in the results of the interviews, dermatologists found good doctor-patient relationship, information from the doctor, background information, and the patient's financial state as the strongest determinants of patient adherence. Their patients found understandable communication and information from the doctor to be particularly essential in establishing adherence; however, in contrast to their doctors, they did not consider background information, and their financial state as strong determinants. The difference is very sharp, as patients ranked these 'external resource' items in last place. These results suggest that compared to the individual patient's subjective view of his or her own situation, dermatologists as professionals look at the problem through a different lens, based on their sociodemographic knowledge of many patients. Another explanation may be, and it has been strengthened by further results, that patients' representations about adherence are more focused on individual traits and the relationship than on contextual and social issues.

Also, it was interesting to see that in the patients' ranking, the importance of information from the doctor and personality factors preceded the doctor-patient relationship. We wanted to understand the deeper structure of these results, so we used multidimensional scaling, which is based on a principle that people make judgements based on their mind's hidden, or latent, inner processes. The spatial representation of the multidimensional

Euclidean distance model, 2 dimensional solution

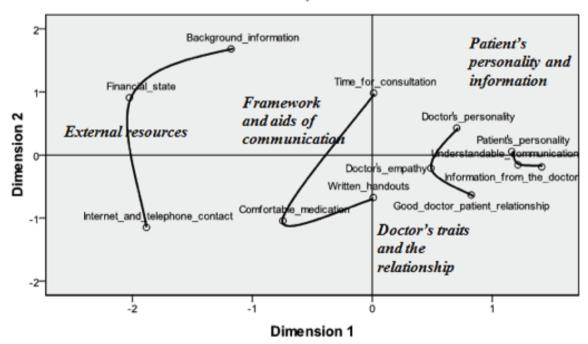


Figure 2: Results of the multidimensional scaling of chronic skin patients' answers to the questionnaire, with the four major content groups indicated (N=153).

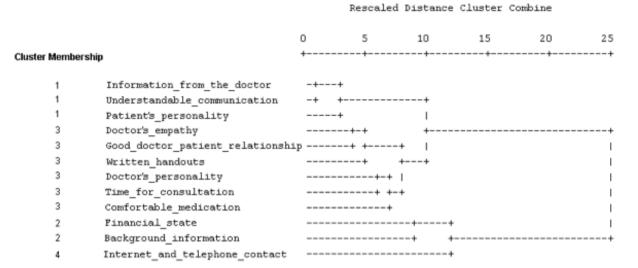


Figure 3: Dendogram from the cluster analysis of chronic skin patients' answers to the questionnaire, with cluster memberships indicated (N=153).

scaling method presents the possibility that these differences are not primarily disparities of how important these factors are, but rather indicate the role of these factors in adherence.

The proximal position and inner structure of the content group 'Doctor's personal traits and the relationship' suggest that in patients' representations, good doctor-patient relationship mostly depends on the doctor's personality and empathy. 'Patient's personality and information' as a distinct and highly condensed content group in its inner structure refers to the outstanding role of patient's personal characteristics and the support of clear-cut, easy-to follow information. It may suggest that patients need more information, but also that they think the doctor's main task is proper dissemination of information.

Older patients rated 'good doctor-patient relationship', 'doctor's empathy", and "understandable communication' on the attitude scales as more important factors of adherence than younger participants. This suggests that special attention is needed in communicating and building relationships with elderly patients [37]. Although there is no clear evidence that older people would be more nonadherent than members of other age groups [38], the relatively strong correlations of age with these categories imply that the improvement of communication and the relationship could help them in becoming more adherent.

From the standpoint of conditional complementarity, quantitizing seems to give additional value to qualitative data only when converting it into quantitative form (i.e., nominal-, ordinal-, interval-level data) allows more meaning to be extracted from it and that form allows

researchers to answer important questions or test hypotheses that could be convincingly answered or tested no other way. Maximizing the numerical precision of qualitative data and their compatibility with quantitative data seems to enhance the value of qualitative data [39].

6 Conclusion and implications for practice

The aim of our study and the choice of the mixed methods approach were to explore the similarities and discrepancies of the representations of doctors and patients. It is important to emphasize that the content groups we identified by multidimensional scaling represent conscious components of the cognitive structure of representations, but also refer to more hidden, unintentional belief systems or automatic thoughts. Therefore, it is important to further examine these representations of adherence, and to improve communication in order to make the 'contract' with the patient clear and fit the expectations of both sides. This may facilitate shared decision-making between doctors and patients. This is an especially important issue in making the best decisions and personally tailored treatment plans that will be reliably followed over the long term by patients with chronic conditions. It is worth applying such communication and intervention methods which help health-care providers and their patients to mutually recognize their views of adherence, together with the arising difficulties and expectations, which play an essential role in the establishment of adherence.

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