

CLINICAL REPORT

To Follow Dermatological Treatment Regimens – Patients' and Providers' Views

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Adherence to long-term therapy for chronic illness is on average 50%. However, regarding adherence to dermatological treatment the existing literature is limited. The aim of the study was to acquire an understanding of issues associated with adherence to dermatological therapy. Focus group interviews were used in two types of fora: patients with chronic dermatological diseases and health care providers, including doctors, nurses and pharmacists working in dermatological care. Results reveal the providers' view of a suboptimal rate of adherence. According to both providers and patients, factors affecting adherence were patients' expectations and experiences of therapeutic effect, possibilities for the patient to take active part in treatment decisions, as well as mode of administration and type of medication. Suggested strategies for improvement are individualized patient education, continuous treatment support with assessment of medication-taking behaviour and enhanced communication skills among the providers. Key words: patient adherence; compliance; concordance; dermatology; focus groups.

(Accepted May 28, 2004.)

Acta Derm Venereol 2004; 84: 445–450.

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Adherence to long-term therapy in chronic illness is on average 50% (1). However, for lifestyle changes and other more behaviourally demanding regimens adherence is much lower, with long-term success rates less than 10% (2–4). Under-use is more common than over-use and it has been shown that drug holidays, i.e. skipping medications for 5–7 days, are present in about 20% of patients once every month (5). Since the 1970s, several studies have shown that up to 10% of all in-hospital visits are due to drug-related problems, e.g. adverse reactions and insufficient adherence (6). As many as 50% of these problems might have been prevented if drug use had been optimal (7). Adherence

data specific for dermatological treatment are lacking; however, it has been shown that disproportionately many drug-related problems detected at the pharmacy are associated with use of over-the-counter dermatological products (8).

Topical skin treatment raises specific problems that might affect adherence, e.g. related to time spent on daily rubbing, greasiness of applied ointments and creams, and local variation in the surface distribution of the applied formulation resulting in uneven and irregular dosaging. The aim of this study was to acquire a deeper understanding of the issues regarding adherence to dermatological treatment, by asking patients and providers in dermatological care for their perceptions of impediment of adherence to treatment, as well as possible strategies to increase adherence.

MATERIALS AND METHODS

The focus group interview method was used in two fora: 1) patients with chronic dermatological diseases and 2) providers of pharmacological treatment including doctors, nurses and pharmacists working in dermatological care. Focus group methodology can be defined as group discussions in which persons representing the target group discuss different aspects of a topic (9–11). The discussions are led by an experienced group leader and are aimed at exploring people's experiences, wishes, opinions and concerns regarding the chosen topic. It elucidates the participants' framework of understanding and provides insight into their knowledge.

Study population

Four focus groups, each with six participants, were established: one group of patients (Pat 1) and one group of providers (Pro 1), at a Swedish University Hospital, and another group of patients (Pat 2) and group of providers (Pro 2), at a Swedish County Hospital (Table I).

Heterogeneity guided the selection to cover the diversity within the target group of participants. A nomination strategy was chosen to obtain a sample consisting of individuals who had long experience of dermatology care, either as a provider or a patient. For the focus groups of providers (Pro 1 and 2), two doctors at the respective involved clinics nominated experienced dermatologists, dermatology nurses and local pharmacists with special interest in dermatological treatments. The physicians also identified patients with various chronic skin diseases for the focus groups of patients (Pat 1 and 2). Among the patients recruited at the County Hospital, four suffered from atopic dermatitis and two from psoriasis. At the

Table I. Background data on patients' and health care providers' age and number of years having chronic dermatological disease/experiences of dermatological care as specialist

	Age (years)		Years ^a	
	Mean	Range	Mean	Range
<i>Patients</i>				
<i>County hospital</i>				
Women (n=4)	54	41–60	41	9–60
Men (n=2)	28	24–32	18	4–31
<i>University hospital</i>				
Women (n=5)	56	34–72	30	1–61
Men (n=1)	46		29	
<i>Providers</i>				
<i>County hospital</i>				
Women (n=5)	52	48–63	21	4–33
Men (n=1)	34		8	
<i>University hospital</i>				
Women (n=5)	47	32–58	19	7–35
Men (n=1)	56		27	

^aYears of experiences of dermatological care.

University Hospital three patients suffered from psoriasis, one from palmo-plantar pustulosis and two from atopic dermatitis. This study was approved by the regional ethics committee for human research.

Validation, data collection and analysis

Validation of the procedure was based on a pilot focus group conducted with four practising dermatologists as participants and the same moderator and assistants as in the main study. In the main study, each focus group session lasted approximately 1.5 hours. K.K. served as moderator of all sessions. Assistant moderators L.R. and Å.K.L. observed the discussion, took notes and audio-taped the sessions. The moderator clarified the purpose of the study, before the members were asked to share their experiences of dermatological treatment. Questions were directed towards the group as a whole and tailored towards starting or maintaining the discussion within the scope of the study. An interview guide with pre-defined open-ended questions was used to ensure that all relevant topics were systematically covered in all interviews.

All four focus group sessions were transcribed verbatim, using Hill et al.'s Consensual Qualitative Research (CQR)

method to analyse the focus group data (11). The analysis team (K.K., L.R. and Å.K.L.) independently analysed the interviews. In accordance with inductive analysis process, *themes (domains)* from the transcripts were identified (12). Consensus on the domains was reached within the analysis team, before two external auditors, (J.S. and M.M.), both experienced dermatologists, checked the bearing of the domains in the raw data. Then, *core ideas* (short summaries of every theme/domain) were identified by the analysis team. Consensus on the core ideas was also checked by the auditors. The focus group data were analysed using the software QSR NUD*IST VIVO[®] (version 1.3.146, Qualitative Solutions & Research Pty Ltd) for qualitative data analysis.

RESULTS

This study reports on the domain of adherence and the domain of perceptions of communication about drug information. Presentation of other domains identified is found elsewhere and available upon request from authors.

Domain of adherence

Three categories were identified within the domain of adherence: *Level of adherence* [1]; *Factors affecting adherence* [2], and *Strategies to improve adherence* [3]. In the following, categories [1–3] and subcategories (name given in italics in the text) within this domain are described, and examples given as quotations are indicated by quotation marks. The information within square brackets refers to the category as presented in Table II.

Level of adherence. Most providers commented on a *sub-optimal rate of adherence* [1A], e.g. a nurse estimates the level of adherence as 25%, and a doctor hopes for 40–50% at best. When asked a direct question about the level of adherence, only one patient stated that he was not adherent. The rest said that they were adherent, although they reported various reasons for not taking their medication as prescribed.

“Sometimes the patient tells us [that he/she is non-adherent], but most of the time they say nothing at

Table II. Domain of adherence challenges encountered by patients (n=12) and providers (n=12) in dermatological care

1. Level of adherence	
A. Unsatisfactory, in most cases low [Pat=1; Pro=7]	
2. Factors affecting adherence	
A. Experiences and expectations of the therapeutic effect [Pat=5; Pro=8]	
B. Degree of active participation in choice of treatment [Pat=3; Pro=2]	
C. Type of drug (corticosteroids/emollients, etc.) and mode of administration (oral/topical) [Pat=2; Pro=6]	
D. Patient-related factors [Pat=0; Pro=4]	
E. The patients' attitudes to drugs [Pat=8; Pro=8]	
3. Strategies to improve adherence	
A. Information about medications, thereby increasing patient knowledge [Pat=0; Pro=3]	
B. Treatment support [Pat=0; Pro=5]	
C. New drugs and smaller packages [Pat=0; Pro=2]	

The figures within square brackets after each category refer to the number of core ideas within that category. Pat=patient-generated ideas; Pro=provider-generated ideas.

all. Patients usually accept the physician's view at the visit, but then do their own thing at home. Non-adherence usually shows in that the patient does not improve." (Pro 2)

Factors affecting adherence. Both patients and providers claim that *experiences and expectations of the therapeutic effect* [2A] affect adherence. Many patients adjust their treatment in relation to their current topical condition. When patients no longer experience any symptoms they stop their treatment, since it is demanding and interferes with everyday living.

"I grease whenever I want to ... I cannot be bothered with a treatment schedule. I have no time for that. So I use it when I feel the need for it. – If it is a lot [of redness and scaling], then you might grease somewhat more. If it isn't that much, then you might get a bit lazy and grease less. I don't follow [the treatment] that exact, maybe one should, but ..." (Pat 1)

The providers emphasize that such individual adjustments are often appropriate, but also that the risk of under-use is evident. Both patients and providers claim that the patients' expectations and experiences of treatment impact on the motivation to adhere. Patients expecting immediate effects might give up treatment too early. On the other hand, experiences of a successful treatment in comparison with negative consequences of treatment holidays tend to increase the motivation to be adherent.

Another factor that impacts on adherence is the *degree of active participation in choice of treatment* [2B]. All groups emphasized the importance of a shared decision-making process.

"You see, I don't take any [medication], I mean, I don't get any medication prescribed [that I don't want]. Because I say no ... [When I have accepted a treatment] I follow it to 100%. And there is no reason to cheat, because it's you, yourself, who will suffer when not following the prescription – it's so obvious." (Pat 2)

Type of drug (corticosteroids/emollients, etc.) and mode of administration (oral/topical) [2C] were other factors of importance to adherence. Patients adhere better to oral than to topical treatment. It is easier to take a tablet a day than to follow a demanding everyday procedure of applying topicals. Adherence to corticosteroids varies, sometimes due to negative attitudes towards these drugs.

According to some providers, *patient-related factors* [2D] such as age, gender, cultural differences and acceptance of the disease also affect adherence. For example, several providers claimed that the application technique varies considerably between patients.

"– I think that it is very much dependent on generation and gender. It is much more difficult for men to take care of their body this way than for women. It's more feminine

[to do that] in a way. Nowadays, young women are used to take care of their skin in a completely different manner than middle-aged men. So you are facing a very broad spectrum [of patients as a provider]." (Pro 1)

The patients' *attitude towards drugs* [2E] was deemed to influence adherence by both patients and providers. It was evident that the *estimation of risks and benefits of the medication vary between patients*. Some patients focus mainly on the effect and tolerate more adverse effects, while others are focused on minimizing adverse effects, even if that would mean a poor effect. *Fear of side effects* was referred to as a cause of low adherence by all groups. This was especially the case for corticosteroids, where patients mentioned, for example, bruises, thin skin and brittleness of the bones. Hair loss was mentioned in relation to cytotoxins. Some patients do everything to avoid these drugs, while others appreciate their good effect and are willing to accept some side effects. Some patients reason that there is a maximal dose of these drugs that you can take during your lifetime without jeopardizing your health. Some believe immunization against drugs to be possible. Alternative medicines serve as a complement to prescription drugs and are perceived to have less side effects. Patients initiate treatment with alternative medicines, without consulting the health care personnel.

Strategies to improve adherence. Measures to improve adherence include *giving information about medications, thereby increasing patient knowledge* [3A] and *treatment support* [3B]. Providers emphasized the importance of treatment support, especially support during periods of inpatient treatment at a dermatology clinic. They also suggested that adherence might be improved by more effective *new drugs* and by *smaller packages* [3C] that allow for a more feasible individualization and optimal use of differing treatments. For example, new, less sticky topicals were demanded.

Domain of perceptions of communication about drug information

The participants' perceptions of communication about information on drugs were classified into a second domain. Four categories were identified within the domain: *Patient's attitudes to information about medicines* [4], *Important information about medicines* [5], *Good methods for communication/information about medicines* [6] and *Sources used by patients in addition to health care providers and pharmacists* [7]. In the following text, categories [4–7] and subcategories (name given in italics in the text) within this domain are described, and examples given as quotations indicated by quotation marks. The information

Table III. Domain of patients' and providers' perceptions of communication about/information on drugs in dermatological care

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4. Patients' attitudes to information about medicines
 - A. Active and self-directed [Pat=1; Pro=0]
 - B. Rely on the provider to select and provide necessary information [Pat=1; Pro=0]
 5. Important information about medicines
 - A. How to use the medication and why it should be used [Pat=3; Pro=4]
 - B. About side effects [Pat=1; Pro=0]
 - C. About new drugs [Pat=2; Pro=0]
 - D. Patient's own responsibility for treatment [Pat=0; Pro=1]
 - E. Most drugs don't cure the disease but alleviate symptoms [Pat=0; Pro=1]
 6. Good methods for communication/information about medicines
 - A. Patients appreciate talking about their disease, with providers and with other patients in a group setting [Pat=3; Pro=0]
 - B. Combination of written and oral information [Pat=2; Pro=1]
 7. Sources used by patients in addition to health care providers and pharmacists
 - A. Internet [Pat=1; Pro=0]
 - B. Medical textbooks and magazines [Pat=1; Pro=0]
 - C. Friends and relatives [Pat=2; Pro=0]
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The figures within square brackets after each category refer to the number of core ideas within that category. Pat=patient-generated ideas; Pro=provider-generated ideas.

within brackets refers to the category as presented in Table III.

Patient's attitudes to information about medicines. Some patients emphasized the importance of being *active and self-directed* [4A] in seeking information about, for example, new treatments. Other patients delegated this responsibility to the expert, i.e. they *relied on the provider to select and provide the necessary information* [4B] and to suggest new treatments.

"I'm not active, not at all, no. – I trust my doctor to help me and that we can discuss something and that I can try something. I don't live life with my disease on my mind. I have it – I know that – but I don't."

Important information about medicines. Information about *how to use the medication and why it should be used* [5A], was deemed important information by both patients and providers. Patients found information about *side effects* [5B] and *new drugs* [5C] important. They also wanted to know more about their skin disease and how to reduce symptoms like itching. Providers, however, mentioned none of these aspects, but thought information about *patients' own responsibility for the treatment* [5D] and the fact that *most drugs don't cure the disease but alleviate symptoms* [5E] to be essential.

Good methods for communication/information about medicines. Patients emphasized the importance of effective communication. They would *appreciate talking about their disease with providers and with other patients in a group setting* [6A], like the ongoing focus group discussion. Treatment periods abroad (climate care) were also mentioned as a good way of meeting other patients in the same situation. A *combination of written and oral information* [6B] was preferred by both patients and providers.

Sources used by patients in addition to health care providers and pharmacists. The *Internet, medical textbooks/magazines and friends/relatives* [7A–C] were used by the patients as sources of information in addition to receiving it from providers.

DISCUSSION

Adherence to drug treatment is a complex issue and not easily explored by quantitative research tools alone. Therefore qualitative methods may be used initially to capture as many aspects of this matter as possible. To our knowledge, qualitative approaches have so far not been used to explore adherence to dermatological treatment. There was a striking pattern of similarity across patients, providers and geographic regions, suggesting that the domains presented in this paper capture some of the major adherence and communication issues that arise in dermatological care. The major themes were similar in the groups and the new information added by the last focus group was limited, indicating that saturation was reached.

This study has shed light on issues perceived by providers and patients to affect adherence to dermatological treatment. Although providers commented on a suboptimal rate of adherence, few patients reported that they were non-adherent. Instead, patients mentioned, what were for them, pragmatic and logical reasons for deviating from the recommended dosage regimen. Consequently, direct questions about adherence tend to generate answers that are biased due to social desirability. Or it might be that patients actually do not see conscious deviation from recommended regimens as non-adherence, but rather as a necessary adjustment. This observation may have a clinical implication. Instead of asking patients if they follow their prescribed regimen or not

it would be more useful to ask, 'During the past week, have you missed or changed your use of the ointments and creams prescribed to you?' (also suggested by Haynes et al. (2)). This simple question may trigger patients to talk about the reason for not taking their medication or changing their regimen, and a more optimal treatment regimen may be decided on in concordance with the patient. An even more approachable and neutral phrase would be: 'Most people find it demanding to adhere to this treatment regimen. In what situations do you experience difficulty in using your topicals as prescribed? Or, when do you feel a need to change the way you use your medications?'

The way in which patients take medicines varies widely and is strongly influenced by their beliefs and attitudes (13). There are also many therapy-related factors affecting adherence. Important ones include the access to medications, the complexity of the therapy, the immediacy of beneficial effects, side effects and the availability of medical support (4). This study further found factors such as patient expectations, attitudes to drugs and earlier experiences of the treatment to affect motivation to adherence. Consequently, the provider needs to take the patient perspective into account in order to achieve optimal adherence. Chren (14) states that patient treatment outcome improves when doctors are sensitive to patients' own disease experience, such as the effect on daily life and patients' perceptions of their medication. Providers may be able to give improved support for differing self-care practices to optimize patients' drug use, by gaining increased insights into patient management of complex drug regimens (15). Clinical use of patient-reported outcomes like quality of life (QoL) could be useful in the individualization of care and treatment (16).

Most patients in our study emphasized the importance of communication, and all groups stressed the importance of patient participation in choice of treatment. Some patients and providers did not even start a treatment unless the patient was fully on-board. Renzi et al. (17) show in a longitudinal study on dermatology patients that dissatisfaction with care and psychiatric morbidity are significantly and independently associated with poor medication adherence. They conclude that particular attention to doctors' interpersonal skills is necessary to improve patient adherence. Richards et al. (3) also stress the importance of working in partnership with patients to achieve a more collaborative model of self-management behaviour. Adherence and treatment outcome will benefit from an effective seamless care where all parties – patient and provider (doctor/nurse/pharmacist) – are communicating and concerned about optimal and individualized care to ensure the patient's possibility of following the recommended treatment. QoL

assessments may prove useful in improving patient–provider communication, especially regarding psychosocial issues (18).

It was evident that some patients turn to health information sources other than health care providers, e.g. the Internet, medical textbooks, magazines and friends/relatives. Research indicates that patients perceive Internet information as good or better than information from their doctors (19), even though Internet information is often incomplete and inaccurate (20). Although increased information and knowledge may empower patients and increase shared decision-making, most patients do not share this information with their doctor. Likewise, media coverage of medicines is often inaccurate and incomplete regarding benefits, potential adverse effects and costs (21). It is important for providers to be aware of differing sources of information used by patients, and to be up to date with this information, since it might influence patients' perceptions of disease and treatment and hence affect adherence.

This study indicates that there is some discrepancy between patients' and providers' perceptions of what constitutes the most important information about medicines. The patients stressed the importance of information on adverse events and new, promising drugs. The providers on the other hand, focused on the importance of raising the patients' awareness of their own responsibility for the treatment and making them realize that most drugs control, rather than cure, the disease. These differences in the agendas of patients and providers need to be addressed. In order to achieve concordance during the consultation, the providers' first priority has to be to identify and meet patients' concerns before delivering their own message. It is important that doctors, nurses and pharmacists are aware of patients' own disease experiences.

In conclusion, providers commented on a suboptimal rate of adherence, which patients did not do to the same degree. Strategies for improving adherence are individualized patient education, continuous treatment support with assessment of medication-taking behaviour and enhanced communication skills among providers.

ACKNOWLEDGEMENTS

We are indebted to patients and providers for their contribution to this research and to Elinor Sviberg Carlberg for transcriptions of the focus group interviews. This study was supported by the County of Östergötland (ALF). The following participants of the Adherence to Dermatological Therapy Study Group have also been involved in the preparation of this manuscript: J. Ahlner MD PhD, Linköping; S. Bejgrowicz MSc Pharm, Linköping; A-M. Hornmark MD, Örebro; E. Jörgensen MD, Kalmar;

E. Niklasson MD, Linköping; H. Overgård-Petersen MD, Västermik.

REFERENCES

- Haynes RB. Interventions for helping patients follow prescriptions for medications. *Cochrane Database of Systematic Reviews* 2001; Issue 1.
- Haynes RB, McDonalds HP, Garg AX. Helping patients follow prescribed treatment. *Clinical applications*. JAMA 2002; 288: 2880–2883.
- Richards HI, Fortune DG, O'Sullivan TM, Main CJ, Griffiths CEM. Patients with psoriasis and their compliance with medication. *J Am Acad Dermatol* 1999; 41: 581–583.
- Sabaté E, ed. Adherence to long-term therapies. Evidence for action. Geneva, Switzerland: World Health Organization, 2003.
- Leukflens HG, Urquhart J. Variability in patterns of drug usage. *J Pharm Pharmacol* 1994; 46 (Suppl): 433–437.
- Manasse HR. Toward defining and applying a higher standard of quality for medication use in the United States. *Am J Health-Syst Pharm* 1995; 52: 374–379.
- Escovitz A, Pathak DS. Health outcomes and pharmaceutical care: measurements, applications and initiatives. New York: Haworth Press, 1996.
- Westerlund T. Drug-related problems. Identification, characteristics and pharmacy interventions. Dissertation, Department of Social Medicine, Göteborg University, 2002.
- Kitzinger J. Qualitative research: introducing focus groups. *BMJ* 1995; 311: 299–302.
- Krueger RA. Focus groups: a practical guide for applied research, 2nd edn. Newbury Park, CA: Sage, 1994.
- Hill CE, Thompson BJ, Williams EN. A guide to conducting consensual qualitative research. *Counseling Psychologist* 1997; 25: 517–572.
- Patton MQ. Qualitative evaluation and research methods, 2nd edn. Newbury Park: Sage, 1990.
- Elwyn GA, Edwards A, Britten N. "Doing prescribing": how doctors can be more effective. *BMJ* 2003; 327: 864–867.
- Chren M-M. Doctor's orders. Rethinking compliance in dermatology. *Arch Dermatol* 2002; 138: 393–394.
- Townsend AK, Hunt K, Wyke S. Managing multiple morbidity in mid-life: a qualitative study of attitudes to drug use. *BMJ* 2003; 327: 837–841.
- Renzi C, Abeni D, Picardi A, Agostini E, Melchi CF, Pasquini P, et al. Factors associated with patient satisfaction with care among dermatological outpatients. *Br J Dermatol* 2001; 145: 617–623.
- Renzi C, Picardi A, Abeni D, Agostini E, Baliva G, Pasquini P, et al. Association of dissatisfaction with care and psychiatric morbidity with poor treatment compliance. *Arch Dermatol* 2002; 138: 337–342.
- Detmar SB, Muller MJ, Schornagel JH, Wever LDV, Aaronson NK. Health-related quality-of-life assessments and patient-physician communication: a randomized controlled trial. *JAMA* 2002; 288: 3027–3034.
- Diaz JA, Griffith RA, Ng JJ, Reinert SE, Friedmann PD, Moulton AW. Patients' use of the Internet for medical information. *J Gen Intern Med* 2002; 17: 180–185.
- Berland GK, Elliott MN, Morales LS, Algazy JI, Kravitz RL, Broder MS, et al. Health information on the Internet: accessibility, quality, and readability in English and Spanish. *JAMA* 2001; 285: 2612–2621.
- Moynihan R, Bero L, Ross-Degnan D, Henry D, Lee K, Watkins J, et al. Coverage by the news media of the benefits and risks of medications. *N Engl J Med* 2000; 342: 1645–1650.