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Psoriasis patients’ experiences concerning medical adherence to treatment with topical corticosteroids

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Abstract: Nonadherence to topical treatment of psoriasis is a common cause of treatment failure. This focus group study was conducted to obtain the patients’ own experiences and explanations regarding medical adherence. The participants consisted of eight primary adherent patients with moderate psoriasis treated with corticosteroid or corticosteroid–calcipotriol combinations, purposefully sampled by age and sex at a dermatology outpatient clinic. Secondary medical adherence was supported by accessibility of the prescribing physician, the prescriber taking time to listen, a more manageable disease, using a nonstaining product, and establishing routines around treatment at home. Secondary medical adherence was affected negatively by changes in daily routines, if the treatment influenced the patient’s sexual life, having too little time in the consultation room, lack of confidence in the prescriber, diverging information from health care personnel, experiencing side effects, having fear of side effects, impractical formulations of topical products, and impatience regarding time before an effect of the treatment was observed. From this study, the recommendations for the prescribing doctor to improve medical adherence are, the doctor needs to take time to listen to the patient, prescribe a topical product that is easy to apply and less greasy, inform the patients about benefits from treatments, and explain the rationale behind the treatment plan.

Keywords: psoriasis, adherence, corticosteroids, calcipotriol, focus groups

Introduction
Psoriasis is a chronic disease with a prevalence rate of 2%–4% in the Western population.1 Topical corticosteroids and corticosteroid–calcipotriol combinations constitute first line of treatment. In chronic diseases, one of the main causes of treatment failure is medical nonadherence.2 In patients with psoriasis, the rate of medical nonadherence to topically prescribed corticosteroids or corticosteroid combinations is reported to range from 8% to 88%,3,4 addressed in studies using heterogeneous study designs. The multifactorial determinants of medical nonadherence to topical corticosteroids and corticosteroid/calcipotriol combinations have mainly been investigated in survey studies,5,6 while only briefly described in qualitative studies.7,8 This led us to conduct this study, to get the patients’ own experiences and explanations on medical adherence.

Participants and methods
In January 2016, we led two semistructured focus groups using open-ended questions in patients diagnosed with psoriasis and treated with topical corticosteroid and/or corticosteroid–calcipotriol combinations. Participants were purposefully sampled by age and sex at the outpatient clinic at the Department of Dermatology and Allergy Centre, Odense, in
### Table 1: Participant demographics and medical history in focus group held for men

| Name               | Age (years) | Occupation              | Duration of psoriasis (years) | Married (M) | Cohabitation (C) | Comorbidities                                      | Topical corticosteroids and corticosteroid–calcipotriol combinations used last year | Other types of currently prescribed antipsoriatics | Previously used antipsoriatics (corticosteroids excluded) | Self-reported adherence\(^b\) last 6 months (0–10) | DLQI | PASI |
|--------------------|-------------|-------------------------|-------------------------------|-------------|------------------|--------------------------------------------------|----------------------------------------------------------------------------------|----------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------|---------------------------------------------------------------|-------|------|
| Arthur (20)        | 10          | Apprentice electrician  | 10                            | C           |                  |                                                  | Betamethasone dipropionate/calcipotriol ointment and hydrocortisone butyrate cream | Clobetasol propionate ointment and betamethasone valerate and ciclopirox ointment | NB-UVB                                                                                     | 6                                             | 11    | 5    |
| Romeo (36)         | 4           | Medical doctor          | 4                             | M           |                  |                                                  | Clobetasol propionate cream and betamethasone valerate and ciclopirox ointment | Betamethasone propionate cream, betamethasone valerate cream, betamethasone valerate liniment, and betamethasone dipropionate/calcipotriol gel | NB-UVB and methotrexate                                                                   | 8                                             | 3     | 2    |
| Mike (40)          | 15          | Logistics and distribution manager | 15            | M           |                  |                                                  | Hydrocortisone butyrate cream and betamethasone dipropionate/salicylic acid ointment | Betamethasone propionate cream, hydrocortisone butyrate cream, and mometasone furoate cream | Methotrexate                                                                                     | 5                                             | 11    | 15   |
| Jonah (56)         | 12          | Joiner                  | 12                            | M           |                  | Actinic keratosis                                 | Hydrocortisone butyrate cream and betamethasone dipropionate/salicylic acid ointment | Acitretin                                                                                   | 7                                             | 16    | 2    |
| Jake (66)          | 30          | Retired warehouse worker | 30                            | M           |                  | Hypertension                                     | Betamethasone propionate cream, hydrocortisone butyrate cream, and mometasone furoate cream | Hydrocortisone butyrate cream and betamethasone dipropionate/salicylic acid ointment | Methotrexate                                                                                     | 2                                             | 4     | 3    |

**Notes:**
\(^a\) All patients are given a fictional name.
\(^b\) In addition, all patients reported being primary adherent 6 months prior to the study.

**Abbreviation:** DLQI, Dermatology Life Quality Index; PASI, Psoriasis Area Severity Index; NB-UVB, narrowband ultraviolet B phototherapy.

### Table 2: Participant demographics and medical history in focus group held for women

| Name            | Age (years) | Occupation         | Duration of psoriasis (years) | Married (M) | Cohabitation (C) | Comorbidities                                      | Topical corticosteroids and corticosteroid–calcipotriol combinations used last year | Other types of currently prescribed antipsoriatics | Other priorly prescribed noncorticosteroidal antipsoriatics | Self-reported adherence\(^b\) last 6 months (0–10) | DLQI | PASI |
|-----------------|-------------|--------------------|-------------------------------|-------------|------------------|--------------------------------------------------|----------------------------------------------------------------------------------|----------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------|---------------------------------------------------------------|-------|------|
| Melinda (24)    | 16          | Ethnology student  | 16                            | C           |                  |                                                  | Betamethasone dipropionate/calcipotriol ointment, betamethasone dipropionate liniment, and calcipotriol cream | NB-UVB                                                                                     | Coal tar                                                                                 | 8                                             | 12    | 4    |
| Kimberly (47)   | 19          | Accountant         | 19                            | M           |                  |                                                  | Betamethasone dipropionate/calcipotriol ointment, betamethasone dipropionate liniment, and calcipotriol cream | Betamethasone dipropionate/calcipotriol gel dispensed in a gel applicator         | Methotrexate and NB-UVB                                                                  | 8                                             | 5     | 12   |
| Charlotte (58)  | 53          | Nurse              | 53                            | C           |                  |                                                  | Betamethasone cream, betamethasone dipropionate/calcipotriol ointment             | Betamethasone cream, betamethasone dipropionate/calcipotriol ointment             | NB-UVB, PUVA, and ustekinumab                                                           | 7                                             | 8     | 15   |

**Notes:**
\(^a\) All patients are given a fictional name.
\(^b\) In addition, all patients reported being primary adherent 6 months prior to the study.

**Abbreviations:** DLQI, Dermatology Life Quality Index; PASI, Psoriasis Area Severity Index; NB-UVB, narrowband ultraviolet B phototherapy; PUVA, psoralen combined with ultraviolet A therapy.
December 2015. Upon recruitment, a Psoriasis Area Severity Index score and a Dermatology Life Quality Index score were obtained for each patient. Furthermore, patients were asked if they were primary adherent, ie, having filled their prescription, and provided a measure of self-reported secondary adherence, ie, not applying medication from filled prescription, on a visual analog scale. Finally, patients were asked open questions regarding their living health conditions and use of antipsoriatic treatments (medical history and sociodemographic characteristics of patients are presented in Tables 1 and 2).

One focus group was held for men and another for women. The study was conducted in accordance with the World Medical Association’s Declaration of Helsinki. Eight primary adherent patients suffering from psoriasis took part in the study, five men and three women. The age range was 20–66 years, with a median age of 43.5 years. The focus groups were led by MTS and HJ in a conference room at the hospital. To demonstrate primary adherence, the patients were asked to bring all the packages of corticosteroids and corticosteroid–calcipotriol combinations they had at home. Initially, while placing the packages on the table in front of them, the patients were briefly asked to introduce themselves and tell about their disease and use of antipsoriatic treatments. After this, we continued to discuss reasons for medical nonadherence. The discussions were grouped in five consecutive sections according to the determinants of nonadherence defined by the World Health Organization (WHO) listed in Table 3. We used audio recording and continued until all points were discussed. Each focus group lasted ~100 minutes.

The audio records were transcribed and thereafter manually coded by MTS. In the evaluation, we used deductive qualitative content analyses based on WHO’s five categories for determinants affecting adherence. Codes were grouped into larger categories. Uniformities and variations were revealed by MTS and HJ in a comparative process.

**Table 3** Determinants of nonadherence defined by the World Health Organization (WHO)⁹

| 1. Social-economic                           |
| 2. Health care-related                      |
| 3. Disease-related                          |
| 4. Treatment-related                        |
| 5. Patient-related                          |

*Note:* Reprinted by permission from WHO [Report No: WHO/MNC/03.01]. Sabate E. Adherence to Long-Term Therapies: Evidence for Action. World Health Organization; 2003. © 2003 WHO.⁹

**Results**

All reported determinants influencing medical adherence are given in Tables 4 and 5. Medical adherence was supported by living with a partner, accessibility of the prescribing physician, the prescriber taking time to listen, having a more manageable disease, using a nonstaining product, and establishing routines around treatment at home (Table 4). In contrast, medical adherence was negatively affected by changes in daily routines, if the treatment influenced the patient’s sexual life, having too little time in the consultation room, lack of confidence in the prescriber, diverging information from health care personnel, experiencing side effects, having fear of side effects, impractical formulations of topical products, and impatience regarding time before an effect of the treatment was observed (Table 5). The price of medication was considered high, but the participants prioritized to buy the medication or had the medication paid for by health insurance or family members. Although some of the patients expressed a wish for an effective treatment, they also reported discontinuing treatment when it worked. Six out of eight patients used complementary approaches as a supplement to prescribed treatments; most commonly sun bathing and vitamin supplements (Table 6).

**Discussion**

This study adds information on important aspects of living with psoriasis, a disease requiring topical treatment that is both time consuming and impractical for the patient. Using a qualitative research design helped us to provide insight into the nonmeasurable aspects of the patient’s perceptions on medical drugs and daily life. The results from our study may not be representative of all patients with psoriasis. This is stressed by the patients described in this study all being primary adherent and having regular checkups at the hospital clinic. To identify differences in determinants of nonadherence between primary versus secondary nonadherent patients, we recommend future studies to be conducted among topically treated primary nonadherent psoriasis patients. Potentially, participants could also be sampled from other settings, ie, general practice or private dermatologists. The study findings align with those reported in the international literature. In relation to social/economic factors, adherence was limited when patients experienced the disease influencing on their intimate life, but improved by receiving support from their partner. Considering treatment factors, adherence was limited when patients experienced the treatment as greasy, but improved when treatment was easy to apply. In relation to the health care system, adherence was limited when patients experienced uncertainty regarding the rationale...
### Table 4: Key categories and property codes relevant to being adherent to prescribed topical corticosteroids and corticosteroid–calcipotriol combinations

| Key category | Property code (characteristics) | Illustrative data extract |
|--------------|---------------------------------|---------------------------|
| Social/economic | Being married/cohabitation | “My wife encourages me to apply the cream.” Jonah |
| | Apply treatment before major social events | “I apply the gel more carefully if I need to go somewhere.” Kimberly |
| | Routines of everyday life | “Habits and rituals help me […] If I bring the gel with me to the swimming pool I will remember to use it.” Kimberly |
| | Not paying for medication | “I get a lot of prescription subsidies so it’s not expensive.” Mike |
| | Reducing stress | “I try to relax and have less to think of […] stressing less reduces my flare-ups.” Melinda |
| | Health care-related | Confidence in prescriber |
| | | “When a doctor writes a prescription, I’m confident in the medical authorities; I redeem the prescription and use the medication.” Jake |
| | | “I have good confidence in doctors […] there must be good reasons why the doctors say what they say.” Arthur |
| | | “They ask.” Jake |
| | | “It seems that the doctors have time for their patients […] maybe it takes half an hour per patient.” Jonah |
| | | “It’s important to write down a list of questions to bring to the consultation […] If I have any questions, I always write them down.” Kimberly |
| | Disease-related | Severity of disease |
| | | “If I get a flare-up, then I’ll do something about it.” Jake |
| | | “I will apply more cream if it gets really bad.” Melinda |
| | | “The worse it gets, the more you follow the treatment plan.” Jonah |
| | | “I’m not afraid of the side effects, because I’ve used the cream for many years […] when I was a child, my mother used to apply steroid creams on me.” Charlotte |
| | Treatment-related | Drug formulation in liniment |
| | | “It’s amazing how the liniment doesn’t grease and it works well […] Liniment… it’s the one I prefer to use, because it doesn’t turn my hair greasy.” Mike |
| | | “The radiator brush is very good. The angle makes it easier to apply.” Kimberly |
| | | “The gel applicator is amazing and easy to put in my toilet bag […] I started using a bath brush to help apply the cream.” Charlotte |
| | Patient-related | Setting routines around home treatments |
| | | “I make it part of my daily routine.” Melinda |
| | | “In the bathroom, I have a small closet and a shelf with all my remedies.” Charlotte |
| | Vanity | “It’s my vanity.” Melinda |

### Table 5: Key categories and property codes relevant to being nonadherent to prescribed topical corticosteroids and corticosteroid–calcipotriol combinations

| Key category | Property code (characteristics) | Illustrative data extract |
|--------------|---------------------------------|---------------------------|
| Social/economic | Changing routines | “I occasionally forget to put the cream on in the weekends.” Charlotte |
| | Being at work | “If I’m out visiting a mate, I sometimes forget to put the cream on.” Arthur |
| | | “In the weekends I tend to forget, because other events occur.” Kimberly |
| | | “I treat my skin in the morning before I leave and in the evening when I get home.” Mike |
| | Treatment influences on sexual life | “It’s not possible to put the cream on at work […] There are no toilets in a lot of the places I work.” Jonah |
| | Price of treatment | “I don’t feel so attractive when I’m all greased in ointment.” Charlotte |
| | | “I couldn’t have bought the ointment if my parents didn’t pay for it […] It had become so expensive.” Melinda |

(Continued)
### Table 5 (Continued)

| Key category                      | Property code (characteristics)                                                                 | Illustrative data extract                                                                                                                                                                                                 |
|-----------------------------------|------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Health care-related               | Lack of information from prescriber                                                              | “After I got handed a bunch of cream with no details on how to use them I totally lost the trust in doctors.” Arthur                                                                                                           |
|                                   | Lack of confidence in prescriber                                                                | “So regarding the ointment, I was just told it was the only one available […] Liniments work better for me, but I’m always prescribed an ointment or a cream.” Melinda                                                      |
|                                   | Need for a patient-centered treatment                                                            | “I realized that the doctors were not open to other treatment options.” Charlotte                                                                                                                                          |
|                                   | Lack of access to the dermatologist                                                             | “I started to doubt the doctors.” Mike                                                                                                                                                                                   |
|                                   | Lack of uniform information from prescribers, pharmacologists, and Patient’s Information Leaflet | “The doctor’s treatment plans are too similar compared to the diversity of the disease.” Jake                                                                                                                           |
|                                   | Little extent of disease                                                                        | “You cannot contact the dermatologist by phone, unless you have time to wait an hour for someone to pick up the phone.” Jonah                                                                                                  |
| Disease-related                   | Psoriasis being a chronic disease                                                               | “It’s difficult to get in touch with the dermatologists.” Kimberly                                                                                                                                                        |
|                                   | Affected areas difficult to reach by hand                                                        | “If there’s a month left till your next check-up is due, you may end up not following the doctor’s treatment plan.” Melinda                                                                                                   |
| Treatment-related                 | Side effects                                                                                     | “The pharmacologist told me to put a thin layer whilst the dermatologist told me to apply a thick layer […] If you read the Patient’s Information Leaflet, you’ll get different information than what you’ll get informed from the dermatologist.” Melinda |
|                                   | Greasiness                                                                                       | “I don’t necessarily use the cream if I don’t have a psoriasis flare-up […] If I’m not bothered, then why should I apply the cream? […] If it doesn’t itch, then why should I treat it!” Jake |
|                                   | Drug formulation in ointment                                                                    | “I tend to give up when I experience a new flare-up.” Romeo                                                                                                                                                              |
|                                   | Stop treatment when there has been effect from treatment                                         | “It’s something that never disappears completely […] You won’t suddenly become cured.” Romeo                                                                                                                             |
|                                   | Stop treatment when there has been effect from treatment                                         | “If I can’t reach the parts of my body that are affected, then I won’t get it treated.” Mike                                                                                                                               |
|                                   | Stop treatment when there has been effect from treatment                                         | “Sometimes I don’t treat the small areas in the back, because it’s difficult to reach.” Jonh                                                                                                                             |
|                                   | Stop treatment when there has been effect from treatment                                         | “It’s difficult to reach the psoriasis on my back, flexor side of my lower legs and scalp.” Charlotte                                                                                                                   |
|                                   | Stop treatment when there has been effect from treatment                                         | “I’m aware of the scary side-effect that causes the skin to get thinner.” Jake                                                                                                                                              |
|                                   | Stop treatment when there has been effect from treatment                                         | “A week has gone by and my skin has been treated; now my skin has gone thinner.” Mike                                                                                                                                     |
|                                   | Stop treatment when there has been effect from treatment                                         | “I have used ointments containing cortisone for 25-30 years and now I have skin atrophy.” Charlotte                                                                                                                       |
|                                   | Stop treatment when there has been effect from treatment                                         | “For me it’s a constrains to be all creamed up; I stain everything with cream all over the place.” Arthur                                                                                                                   |
|                                   | Stop treatment when there has been effect from treatment                                         | “When I apply the ointment it greases a lot […] You can clearly see when I have the ointment on; it greases a lot and I leave stains.” Romeo                                                                                   |
|                                   | Stop treatment when there has been effect from treatment                                         | “My skin itches a lot under the occluding ointment […] Sometimes it’s worse when I apply a thick layer of ointment.” Kimberly                                                                                                 |
|                                   | Stop treatment when there has been effect from treatment                                         | “The ointment doesn’t absorb into the skin.” Charlotte                                                                                                                                                                    |
|                                   | Stop treatment when there has been effect from treatment                                         | “If I apply the ointment two times and the psoriasis is gone, I don’t apply it again.” Jake                                                                                                                                     |
|                                   | Stop treatment when there has been effect from treatment                                         | “If it works well, I lose my motivation.” Charlotte                                                                                                                                                                       |
|                                   | Stop treatment when there has been effect from treatment                                         | “If it goes well, I tend to stop.” Jonah                                                                                                                                                                                  |
| Patient-related                   | Negative attitude toward corticosteroids                                                          | “There are no healthy ingredients in those creams.” Mike                                                                                                                                                                   |
|                                   | Forgetfulness                                                                                   | “They’re definitely not good for the body.” Arthur                                                                                                                                                                         |
|                                   | Intentionally rejecting treatment                                                               | “Once in a while I forget to apply the cream […] Even when I decide to treat my skin for a period of time, I still forget.” Romeo                                                                                           |
|                                   | Pregnancy and lactation                                                                         | “I intentionally refused to follow the doctor’s treatment plan.” Jake                                                                                                                                                      |
|                                   | Fearful of side effects                                                                         | “I would rather not have it […] I prefer my moisturizers.” Jonah                                                                                                                                                         |
|                                   | Fearful of side effects                                                                         | “I didn’t apply the cream to be on the safe side […] When I was pregnant and breastfeeding, I didn’t apply the cream.” Kimberly                                                                                              |
|                                   | Fearful of side effects                                                                         | “I’m seriously scared of the side effects.” Jonah                                                                                                                                                                          |
|                                   | Fearful of side effects                                                                         | “I’m aware that it has an effect on my body.” Arthur                                                                                                                                                                     |
|                                   | Impatient regarding time before treatment works                                                  | “As time goes by, I lose my patience.” Arthur                                                                                                                                                                             |
|                                   | Impatient regarding time before treatment works                                                  | “It’s probably just me who doesn’t have patience.” Kimberly                                                                                                                                                                |
behind the treatment plan, but improved from confidence in the prescriber. In relation to the disease, adherence was limited by having areas difficult to reach, but improved when suffering from widespread disease. In relation to the patients themselves, adherence was limited by patients terminating treatment when initial positive treatment results were reached, but improved by establishing routines in their everyday life. In addition to previous research, this study showed that the patients received help from their partner in checking the skin for flare-ups and assisting in greasing.

Treatments need to be continued after they have shown an initial beneficial effect. Further research is needed to elucidate the effect of, eg, early follow-up visits or use of technical support on adherence. Technical support could include sending mobile phone reminders or use of patient-supporting apps delivered by smartphones. For the prescriber to help improve adherence, the recommendations from this study are the doctor needs to take time to listen to the patient, prescribe a topical product that is easy to apply and less greasy, inform the patients about benefits from treatments, and explain the rationale behind the treatment plan.

Disclosure

The authors report no conflicts of interest in this work.

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