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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, having 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

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Table 1 Participant demographics and medical history in focus group held for men

Name[a] (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)	Apprentice electrician	10	C		Betamethasone dipropionate/calcipotriol ointment and hydrocortisone butyrate cream	NB-UVB		6	11	5
Romeo (36)	Medical doctor	4	M		Clobetasol propionate ointment and betamethasone valerate and clioquinol cream			8	3	2
Mike (40)	Logistics and distribution manager	15	M		Clobetasol propionate cream, betamethasone valerate cream, betamethasone valerate liniment, and betamethasone dipropionate/calcipotriol gel		NB-UVB and methotrexate	5	11	15
Jonah (56)	Joiner	12	M	Actinic keratosis	Hydrocortisone butyrate cream and betamethasone dipropionate/salicylic acid ointment		Acitretin	7	16	2
Jake (66)	Retired warehouse worker	30	M	Hypertension	Clobetasol propionate cream, hydrocortisone butyrate cream, and mometasone furoate cream	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[a] (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)	Ethnology student	16	C		Betamethasone dipropionate/calcipotriol ointment, betamethasone dipropionate liniment, and calcipotriol cream	NB-UVB	Coal tar	8	12	4
Kimberly (47)	Accountant	19	M	Insulin-dependent diabetes mellitus and colitis ulcerosa	Betamethasone dipropionate/calcipotriol gel dispensed in a gel applicator		Methotrexate and NB-UVB	8	5	12
Charlotte (58)	Nurse	53	C	Psoriatic arthritis, hypertension, and hypothyroidism	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.

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

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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 topical antipsoriatics. 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)[9] 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.

Ethics

Ethical approval was not required for this study according to Danish law. A signed consent was obtained from all participants before the focus groups were held.

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,[10] but improved by receiving support from their partner.[3] Considering treatment factors, adherence was limited when patients experienced the treatment as greasy,[5] but improved when treatment was easy to apply.[5,11] 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 "My wife checks my skin for flare-ups, because I don't." Jake
	Apply treatment before major social events	"I apply the gel more carefully if I need to go somewhere." Kimberly "It's more comfortable if I look good when we're going out." Jake "When I'm going on a date, I'm concerned about my psoriasis." Romeo
	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 "I worked on an oil rig; it was a daily routine. As long as I was there, I used the cream every day." Charlotte
	Not paying for medication	"I get a lot of prescription subsidies so it's not expensive." Mike "My parents pay for the cream." Arthur "I get so much prescribed medication that I actually get the expenses covered by the health insurance." Kimberly
	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
	The prescriber takes time to listen	"They ask." Jake "It seems that the doctors have time for their patients […] maybe it takes half an hour per patient." Jonah
	Writing down questions for the consultations	"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
	Duration of disease	"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
	Psoriasis affected visible areas	"I use more cream if my psoriasis starts to flake […] I use more cream where the skin can be peeled off in flakes." Jake
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
	Use equipment that eases topical application	"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
	Uncertain if the doctor's treatment plan is not followed	"The treatment plan from the doctor says 'follow your doctor's instructions' […] It doesn't say what happens if you don't follow it." Jonah
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 "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
	Being at work	"I treat my skin in the morning before I leave and in the evening when I get home." Mike "It's not possible to put the cream on at work […] There are no toilets in a lot of the places I work." Jonah
	Treatment influences on sexual life	"I don't feel so attractive when I'm all greased in ointment." Charlotte
	Price of treatment	"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
		"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
	Lack of confidence in prescriber	"I realized that the doctors were not open to other treatment options." Charlotte
	Need for a patient-centered treatment	"I started to doubt the doctors." Mike
	Lack of immediate access to the dermatologist	"The doctor's treatment plans are too similar compared to the diversity of the disease." Jake
		"You cannot contact the dermatologist by phone, unless you have time to wait an hour for someone to pick up the phone." Jonah
		"It's difficult to get in touch with the dermatologists." Kimberly
		"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
	Lack of uniform information from prescribers, pharmacologists, and Patient's Information Leaflet	"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
Disease-related	Little extent of disease	"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
	Psoriasis being a chronic disease	"I tend to give up when I experience a new flare-up." Romeo
		"It's something that never disappears completely […] You won't suddenly become cured." Jonah
	Affected areas difficult to reach by hand	"If I can't reach the parts of my body that are affected, then I won't get it treated." Mike
		"Sometimes I don't treat the small areas in the back, because it's difficult to reach." Jonah
		"It's difficult to reach the psoriasis on my back, flexor side of my lower legs and scalp." Charlotte
Treatment-related	Side effects	"I'm aware of the scary side-effect that causes the skin to get thinner." Jake
		"A week has gone by and my skin has been treated; now my skin has gone thinner." Mike
		"I have used ointments containing cortisone for 25-30 years and now I have skin atrophy." Charlotte
	Greasiness	"For me it's a constrain to be all creamed up; I stain everything with cream all over the place." Arthur
		"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
	Drug formulation in ointment	"My skin itches a lot under the occluding ointment […] Sometimes it's worse when I apply a thick layer of ointment." Kimberly
		"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
		"If it works well, I lose my motivation." Charlotte
		"If it goes well, I tend to stop." Jonah
Patient-related	Negative attitude toward corticosteroids	"There are no healthy ingredients in those creams." Mike
		"They're definitely not good for the body." Arthur
	Forgetfulness	"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
	Intentionally rejecting treatment	"I intentionally refused to follow the doctor's treatment plan." Jake
		"I would rather not have it […] I prefer my moisturizers." Jonah
	Pregnancy and lactation	"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
		"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
		"It's probably just me who doesn't have patience." Kimberly

Table 6 Complementary treatments used

Complementary treatments used	Property code (characteristics)	Illustrative data extracts
Outdoor tanning	Travels to the south	"Sun and sea […] I bought a small apartment in Spain close to the beach." Charlotte
Using moisturizers (developed by nonmedical personnel)	Cream from ostrich feathers	"I used a cream derived from ostrich feathers. It stank terribly." Kimberly
Food supplements	Aloe vera juice	"I've been drinking Aloe Vera juice every day for half a year." Charlotte
	Vitamin extracts oral	"I take some vitamins […] it helps." Jonah
	Omega-3 fish oil oral	"My skin has become smoother after I started taking fish oil." Charlotte
	Flaxseed oil oral	"I moisturize myself from within with flaxseed oil." Jonah
		"Yes flaxseed oil should be good for many things. I also use it." Kimberly
Healthy food	Avoiding meat products	"I live healthy. Everything I eat is organic and I rarely eat meat." Jonah
	Vegetable juice	"I drink juice, carrot juice." Jonah
Salt baths		"Usually I sit and wash my legs in a bowl of salt water." Charlotte
Products with silica mud		"I went to the Blue Lagoon in Iceland and bought Silica Mud." Charlotte

behind the treatment plan,[6,7,12] but improved from confidence in the prescriber.[6] In relation to the disease, adherence was limited by having areas difficult to reach,[6] but improved when suffering from widespread disease.[6] In relation to the patients themselves, adherence was limited by patients terminating treatment when initial positive treatment results were reached,[5] but improved by establishing routines in their everyday life.[5,12] 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[13] or use of technical support on adherence. Technical support could include sending mobile phone reminders[14] 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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