

ELECTRONIC SUPPLEMENTARY MATERIAL

Quality of life and contact with healthcare systems among patients with psoriasis and psoriatic arthritis: results from the NORdic PATient survey of Psoriasis and Psoriatic arthritis (NORPAPP)

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Authors: A Duvetorp^{1,2}, M Østergaard³, L Skov⁴, O Seifert^{2,5}, KS Tveit⁶, K Danielsen^{7,8} L Iversen⁹

Corresponding author: Lars Iversen, Department of Dermatology, Aarhus University Hospital, Aarhus, Denmark; lars.iversen@clin.au.dk

Online Resource 1: Full questionnaire

Note that only those questions relevant to each individual were presented to them.

Question 1: Do you have any type of psoriasis or psoriatic arthritis?

- i) Yes, and I'm diagnosed by a physician
- ii) Yes, but I'm not diagnosed by a physician
- iii) No, I do not have any type of psoriasis
- iv) Do not know/do not wish to answer

Question 2: Which type of psoriasis have you been diagnosed with by a physician?

- i) Psoriasis on the skin, on nails or the scalp
- ii) Psoriatic arthritis
- iii) Both psoriasis (on skin, nails or scalp) and psoriatic arthritis
- iv) Do not know/do not wish to answer

Question 3: How long after your first symptoms were you diagnosed by a physician?

Separate answers for "Psoriasis (on skin, nails or scalp)" and "Psoriatic arthritis"

- i) Within one year
- ii) One year after

- iii) 2–4 years after
- iv) 5–9 years after
- v) 10–14 years after
- vi) 15–19 years after
- vii) 20–29 years after
- viii) 30 years after or more
- ix) Do not know/do not wish to answer

Question 4: If you think about the past 12 months, how would you rate the severity of your ... ?

Separate answers for “Psoriasis (on skin, nails or scalp)” and “Psoriatic arthritis”

- i) Not severe at all
- ii) Not particularly severe
- iii) Quite severe
- iv) Very severe
- v) Extremely severe
- vi) Do not know/do not wish to answer

Question 5: Please describe in which way your psoriasis (on skin, nails or scalp) is quite, very or extremely severe

- *Free text answer*

Question 6: Please describe in which way your psoriatic arthritis is quite, very or extremely severe

- *Free text answer*

Question 7: Which symptoms or troubles due to your psoriasis (on skin, nails or scalp) have you experienced in the past 12 months?

- i) Bleeding
- ii) Burning
- iii) Depression or anxiety
- iv) Fatigue

- v) Flaking/scales
- vi) Itching
- vii) Pain
- viii) Plaque
- ix) Pustules (pus-filled blisters)
- x) Redness
- xi) Swollen fingers or toes (e.g. sausage digits, so called dactylitis)
- xii) Tender or swollen tendons (e.g. on the heel, so called enthesitis)
- xiii) Nail psoriasis
- xiv) Other symptoms
- xv) I have not experienced any symptoms in the past 12 months
- xvi) Do not know/do not wish to answer

Question 8: Where on the body have you had symptoms of psoriasis (on skin, nails or scalp) in the past 12 months?

- i) Ankles
- ii) Arm pit
- iii) Back/spine
- iv) Chest
- v) Elbow
- vi) Fingers
- vii) Genitals
- viii) Heels
- ix) Hips
- x) In skin folds (inverse psoriasis)
- xi) Knees
- xii) Nails
- xiii) Neck
- xiv) Scalp
- xv) Shoulders

- xvi) The bend of the arm
- xvii) Palm of hands or sole of feet
- xviii) Toes
- xix) Ears
- xx) Wrist
- xxi) Other body location
- xxii) I have not experienced any symptoms in the past 12 months
- xxiii) Do not know/do not wish to answer

Question 9: Based on the amount of psoriasis that could be covered by the palm of your hand, about how many palms would you say that you currently have across your entire body?

- i) None
- ii) Less than 1 palm
- iii) 1–3 palms
- iv) 4–9 palms
- v) 10–19 palms
- vi) 20 palms or more
- vii) Do not know/do not wish to answer

Question 10: How often have you had relapses or flare-ups of your psoriasis (on the skin, nails or scalp) in the past three years? With relapse or flare-up, we mean periods when symptoms have worsened.

- i) I've had constant symptoms, with no remission
- ii) Every week
- iii) Every month
- iv) Every quarter
- v) Every six months
- vi) Every year
- vii) Every two years
- viii) Every three years (once in the past three years)

- ix) I haven't had any flare-up or relapses in the past three years
- x) Do not know/do not wish to answer

Question 11: Have you experienced pain or soreness in any of your joints?

- i) Yes
- ii) Yes, I have it currently
- iii) Yes, in the past 12 months
- iv) Yes, more than one year ago
- v) No, never
- vi) Do not know/do not wish to answer

Question 12: In which location is/were your joint pain or soreness most bothersome?

- i) Ankles
- ii) Back/spine
- iii) Elbow
- iv) Fingers/hands
- v) Heel
- vi) Sole of foot
- vii) Hips
- viii) Knees
- ix) Neck
- x) Shoulders
- xi) Toes
- xii) Wrist
- xiii) Other body location
- xiv) Do not know/do not wish to answer

Question 13: To what extent do you agree that you have experienced the following in the past 12 months due to your psoriasis?

Each statement scored from 1 (do not agree at all) to 5 (totally agree)

- i) I've felt embarrassed or self-conscious because of my skin symptoms
- ii) The topical treatment (such as ointments or creams) of my skin has been taking up too much time
- i) The topical treatment (such as ointments or creams) of my skin has been inconvenient or messy

Question 14: To which extent do you agree that you have experienced the following in the past 12 months due to your psoriasis/psoriatic arthritis?

Each statement scored from 1 (do not agree at all) to 5 (totally agree)

My disease has ...

- i) ... caused sleeping disorders/lack of sleep
- ii) ... prevented me from maintaining good hygiene (e.g. showering or brushing the teeth)
- iii) ... interfered with my daily routines such as getting out of bed, eating, cleaning, shopping or cooking
- iv) ... prevented me from wearing specific clothes/shoes
- v) ... prevented me from participating in a social activity
- vi) ... prevented me from doing sports or a leisure activity
- vii) ... made me feel depressed or anxious
- viii) ... prevented me from having an active sex life
- ix) ... created difficulties in the relationship with my partner, family, close friends or relative
- x) ... created difficulties in the relationship with acquaintances such as new friends or colleagues

Question 15: Have you experienced any trouble doing different activities in the past 12 months due to your psoriatic arthritis?

- i) Yes, getting dressed, including tying shoelaces and doing buttons
- ii) Yes, getting in and out of bed
- iii) Yes, lifting a full cup or glass to my mouth
- iv) Yes, walking outdoors on flat ground
- v) Yes, washing and drying my body
- vi) Yes, bending down to pick up something up from the floor

- vii) Yes, turning faucets on and off
- viii) Yes, getting in and out of a car
- ix) Yes, having sex
- x) Yes, other difficulties, what? - *Free text answer*
- xi) No, I haven't had any trouble
- xii) Do not know/do not wish to answer

Question 16: Have you been absent from work or school in the past 12 months due to your psoriasis/psoriatic arthritis?

- i) Yes, I've been on a long-term sick leave
- ii) Yes, a couple of days per week
- iii) Yes, a couple of days per month
- iv) Yes, a couple of days in the past year
- v) Yes, only once in the past 12 months
- vi) No
- vii) I did not work or go to school in the past 12 months
- viii) Do not know/do not wish to answer

Question 17: To what extent has your psoriasis/psoriatic arthritis had a negative impact on your work/career or education since you first developed symptoms?

- i) No impact at all
- ii) Quite low impact
- iii) Impact

Question 18: Which types of healthcare professionals have you seen in the past three years for your ... ?

Separate answers for "Psoriasis (on skin, nails or scalp)" and "Psoriatic arthritis"

- i) Allergist
- ii) General practitioner
- iii) Dermatologist

- iv) Rheumatologist
- v) Nurse
- vi) Physiotherapist
- vii) Orthopaedist
- viii) Other healthcare professional
- ix) I haven't seen any healthcare professionals
- x) Do not know/do not wish to answer

Question 19: What is the medical specialty of the healthcare professional that you see most often for your ...
?

Separate answers for "Psoriasis (on skin, nails or scalp)" and "Psoriatic arthritis"

- i) Allergist
- ii) General practitioner
- iii) Dermatologist
- iv) Rheumatologist
- v) Nurse
- vi) Physiotherapist
- vii) Orthopaedist
- viii) Other healthcare professional
- ix) I Do not have a specific healthcare professional that I see most often
- x) Do not know/do not wish to answer
- i) Do not know/do not wish to answer

Question 20: When did you last see a dermatologist for your psoriasis (on skin, nails or scalp)?

- i) In the past week
- ii) In the past month
- iii) In the past quarter
- iv) In the past six months
- v) In the past year

- vi) In the past two years
- vii) Three years ago or more
- viii) I have never seen a dermatologist
- ix) Do not know/do not wish to answer

Question 21: When did you last see a rheumatologist for your psoriatic arthritis?

- i) In the past week
- ii) In the past month
- iii) In the past quarter
- iv) In the past six months
- v) In the past year
- vi) In the past two years
- vii) Three years ago or more
- viii) I have never seen a rheumatologist
- ix) Do not know/do not wish to answer

Question 22: If you think about the last time you were in contact with a physician for your psoriasis (on skin, nails or scalp). What were the main reasons that you were in contact with the physician? You may choose several options below.

- i) Renewal of a prescription
- ii) My symptoms had worsened
- iii) General follow-up
- iv) To talk about possible side-effects from medication
- v) I had side-effects from a medication
- vi) To discuss treatment options
- vii) To discuss test results
- viii) To take tests (such as a blood test)
- ix) To receive light therapy
- x) Psychological reasons (e.g. depression or anxiety)
- xi) Other reason, what? - *Free text answer*

xii) Do not know/do not wish to answer

Question 23: If you think about the last time you were in contact with a physician for your psoriatic arthritis.

What were the main reasons that you were in contact with the physician? You may choose several options below.

- i) Renewal of a prescription
- ii) My symptoms had worsened
- iii) General follow-up
- iv) To talk about possible side-effects from medication
- v) I had side-effects from a medication
- vi) To discuss treatment options
- vii) To discuss test results
- viii) To take tests (such as a blood test)
- ix) Psychological reasons (e.g. depression or anxiety)
- x) Other reason, what? - *Free text answer*
- xi) Do not know/do not wish to answer

Question 24: Overall, how satisfied or dissatisfied are you with the healthcare system and treatment of your ... ?

Separate answers for "Psoriasis (on skin, nails or scalp)" and "Psoriatic arthritis"

- i) Very dissatisfied
- ii) Neither dissatisfied nor satisfied
- iii) Quite satisfied
- iv) Very satisfied
- v) Do not know/do not wish to answer

Question 25a: Why are you dissatisfied with the healthcare system or treatment of your psoriasis (on skin, nails or scalp)?

- *Free text answer*

Question 25b: Why are you satisfied with the healthcare's system or treatment of your psoriasis (on skin, nails or scalp)?

- *Free text answer*

Question 26a: Why are you dissatisfied with the healthcare's system or treatment of your psoriatic arthritis?

- *Free text answer*

Question 26b: Why are you satisfied with the health care's system or treatment of your psoriatic arthritis?

- *Free text answer*

Question 27: Have you ever changed physician because you were dissatisfied with the management or treatment of your ...?

Separate answers for "Psoriasis (on skin, nails or scalp)" and "Psoriatic arthritis"

- i) Yes, once
- ii) Yes, several times
- iii) No, I never had the reason to change
- iv) No, I never had the option to change
- v) Do not know/do not wish to answer

Question 28: Have you had a dialogue with your physician about using any of the below treatment options for your psoriasis/psoriatic arthritis?

Treatment options:

- Oral (tablet) or injectable methotrexate
- Oral (tablet) medications (other than methotrexate)
- Injectable or intravenous biologic medication

- i) We discussed it but I never used it
- ii) We discussed it and I used it/will use it
- iii) We never discussed it
- iv) Do not know/do not wish to answer

Question 29: Why did you decide not to use oral (tablet) or injectable methotrexate?

- *Free text answer*

Question 30: Why did you decide not to use an oral (tablet) medication (other than methotrexate)?

- *Free text answer*

Question 31: Why did you decide not to use an injectable or intravenous biologic medication?

- *Free text answer*

Question 32: Are you using any of the following treatments for your psoriasis/psoriatic arthritis?

Treatment options:

- Emollients (such as creams or ointments without cortisone)
- Topical cortisone treatments (topical steroids)
- Alternative treatments (e.g. from health food stores)
- Light treatment (e.g. UV treatment)
- Oral (tablet) or injectable methotrexate
- Oral (tablet) medications (other than methotrexate)
- Injectable or intravenous biologic medication
- Other treatment

- i) Yes, I'm currently using it
- ii) No, I used it but stopped
- iii) No, I never used it
- iv) Do not know/do not wish to answer

Question 33: How long did you take the oral (tablet) or injectable methotrexate for before you stopped?

- i) A week or less
- ii) Two to three weeks

- iii) A month
- iv) A quarter (three months)
- v) Half a year
- vi) One year
- vii) Two years
- viii) More than two years
- ix) Do not know/do not wish to answer

Question 34: In general, how satisfied or dissatisfied are/were you with using oral (tablet) or injectable methotrexate?

- i) Very dissatisfied
- ii) Quite dissatisfied
- iii) Neither dissatisfied nor satisfied
- iv) Quite satisfied
- v) Very satisfied
- vi) Do not know/do not wish to answer

Question 35: Why are/were you dissatisfied with oral (tablet) or injectable methotrexate?

- i) I experienced side-effects, e.g. nausea, vomiting, diarrhoea or fever
- ii) I currently have/had problems with my liver
- iii) I have/had to change my lifestyle too much, e.g. limit the alcohol intake or follow a specific diet
- iv) I Do not/did not get enough effect
- v) I Do not/did not get any effect at all
- vi) I'm not/I wasn't able to keep up with my daily activities (e.g. missed work; missed family/personal time)
- vii) I am/was concerned about the long-term safety
- viii) It's too difficult to remember to take the medication
- ix) Other
- x) Do not know/do not wish to answer

Question 36: For how long did you take the injectable or intravenous biologic medication before you stopped?

- i) A week or less
- ii) Two to three weeks
- iii) A month
- iv) A quarter (three months)
- v) Half a year
- vi) One year
- vii) Two years
- viii) More than two years
- ix) Do not know/do not wish to answer

Question 37: When you first were prescribed the biologic medication, was it mainly yourself requesting the treatment or was it the doctor's suggestion?

- i) The doctor first suggested that I use the treatment
- ii) I was the one who first suggested that I use the treatment
- iii) Both the doctor and I suggested that I use the treatment
- iv) None of the above
- v) Do not know/do not wish to answer

Question 38: How satisfied or dissatisfied are/were you with using the biologic medication?

- i) Very dissatisfied
- ii) Quite dissatisfied
- iii) Neither dissatisfied nor satisfied
- iv) Quite satisfied
- v) Very satisfied
- vi) Do not know/do not wish to answer

Question 39: Why are/were you dissatisfied with the biologic medication?

- i) I experienced side-effects, e.g. nausea, vomiting, diarrhoea or fever

- ii) I have/ had to change my lifestyle too much, e.g. limit the alcohol intake or follow a specific diet
- iii) I Do not/did not get enough effect
- iv) I Do not/did not get any effect at all
- v) I'm not/I wasn't able to keep up with my daily activities (e.g. missed work; missed family/personal time)
- vi) I Do not like to self-inject
- vii) I am/was concerned about the long-term safety
- viii) It's too difficult to remember to take the medication
- ix) I get/got injection-site reactions
- x) Other
- xi) Do not know/do not wish to answer

Question 40: How would you evaluate the following treatment types in regards to health risks of long-term use?

Treatment types

- Topical steroids, e.g. cortisone salves or creams
- Oral (tablet) or injectable methotrexate
- Oral (tablet) medications (other than methotrexate)
- Injectable or intravenous biologic medication

- i) No health risks at all
- ii) Quite low health risks
- iii) Some health risks
- iv) Quite large health risks
- v) Very large health risks
- vi) Do not know

Question 41: Do you think there is a good or bad range of treatment options available today for your ... ?

Separate answers for "Psoriasis (on skin, nails or scalp)" and "Psoriatic arthritis"

- i) Very bad range

- ii) Quite bad range
- iii) Neither good nor bad range
- iv) Quite good range
- v) Very good range
- vi) Do not know

Question 42: If you think about your psoriasis/psoriatic arthritis as a whole, what is most important to you in terms of support or treatment?

- *Free text answer*

Question 43: Where do you get most of your information about psoriasis/psoriatic arthritis? You may choose a maximum of three options below.

- i) Doctors
- ii) Nurses
- iii) Other health professionals
- iv) Other patients
- v) Family or friends
- vi) Patient organisations
- vii) Books
- viii) Library
- ix) Internet – search engines (such as Google)
- x) Internet – specific disease-related sites
- xi) Internet – forums
- xii) Internet – other
- xiii) Television
- xiv) Radio
- xv) Newspapers
- xvi) Magazines
- xvii) Other, what? - *Free text answer*
- xviii) Do not know

Question 44: Are you a member of any patient organisation for psoriasis or psoriatic arthritis?

Sweden

- i) Yes, Psoriasisförbundet
- ii) Yes, Reumatikerförbundet
- iii) Yes, another organisation
- iv) No
- v) Do not know/do not wish to answer

Norway

- i) Yes, Psoriasis- og eksemforbundet
- ii) Yes, Norsk Revmatikerforbund
- iii) Yes, another organisation
- iv) No
- v) Do not know/do not wish to answer

Denmark

- i) Yes, Danmarks Psoriasis Forening
- ii) Yes, Gigtforeningen
- iii) Yes, another organisation
- iv) No
- v) Do not know/do not wish to answer