

Supplementary Material

Cover page

Treatment preferences in young adults with moderate to severe psoriasis – a qualitative study from the Nordic countries

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Semi-structured interview guide

Introduction

Thank you for participating in this study. As we spoke about earlier, this interview is part of a research project in which we examine what is important to patients regarding biologics of psoriasis.

Before we begin, I should remind you that the interview is recorded for the analysis. When I transcribe the recording, you will be anonymized, meaning that any personally identifiable information is veiled, and you will appear with a code instead of your name. This anonymized transcript and the information I received from your doctor on the consent form (your age, diagnosis, PASI and DLQI scores, but not your name and contact details) will then be passed on to our project lead, Gitte Lee Mortensen, for analysis. Can you please confirm for the record that you consent to participating in this interview? You still have the right to end the interview at any time.

Thank you. To gain in-depth knowledge about the *background* of patients' treatment needs and priorities, we ask about how psoriasis has affected people's lives. Therefore, some of my questions are rather personal. I hope that you are up to being open about such issues today, but if you think it's getting too personal, just let me know and we will skip that. I will begin by asking a few basic questions and then ask about your experiences with having psoriasis. After that, we will talk about what is most important to you with respect to biologics. But this is not an exam. If it's unclear what I mean or you don't know what to answer, just say so. There are no right or wrong answers. I would just like to gain insights about what is important to you.

Do you have any questions before we start?

Opening background questions

1. Could you please begin by telling approximately how long you have had psoriasis (time of diagnosis)?
2. What is your private situation? Are you single or do you live with a partner? Any children (age)?
3. What kind of area do you live in?
 - a. Rural area/village
 - b. Small town: under 20.000 inhabitants
 - c. Medium sized town: between 20-100.000 inhabitants (incl. suburbs)
 - d. Larger city: above 100.000 inhabitants (incl. suburbs)
4. Are you currently employed or studying?
 - a. Approximately how many hours per week are you working/studying?
 - b. If reduced hours/no occupation:
 - i. Is that due to psoriasis?
 - ii. How long have you been working or studying on reduced hours/ been without occupation?

Thank you. I would now like to hear about how psoriasis may have affected your quality of life

5. To begin with, would you describe your psoriasis as mild, moderate, or severe?
 - a. Previously versus today
 - b. Can you please describe why you consider your psoriasis to be mild/moderate/ severe today?
6. Please describe which psoriasis symptoms you currently have
 - a. Do you have small or larger spots and on which parts of the body?
 - b. Are there any parts of the body that particularly bother you?
 - c. Do you have problems with itching?
 - d. Do you experience any pain?
 - e. Do you have any problems with your joints (PsA diagnosis)?
 - f. Does psoriasis affect your sleep?

7. Which of these symptoms do you feel have the largest impact on your quality of life?

a. Can you tell a bit more about why and how that particular symptom affects your quality of life?

b. Could you provide any examples of that, please?

8. Looking back on the years you've had psoriasis, which areas of your life have been affected by the disease? I'm thinking of areas such as your occupation, your social life or your love life, for instance (PROBE for each: Please describe how it has been affected)?

a. Has your psoriasis affected you work/studies?

i. Your choice of occupation?

ii. Absence or reduced capability of work/study?

iii. Career opportunities?

b. Your social life, relations with other people?

c. Your leisure activities?

d. Your family life?

i. Are there any other members of your family who has psoriasis (parents, siblings, etc.)?

e. Your love life (relationships and intimacy/sex life)?

f. Your psychological well-being?

Thank you. I would like now to talk about your experiences with psoriasis treatment

9. Do you feel that the psoriasis treatments you have received so far have affected your quality of life?

a. Which treatments and how have they affected your QoL?

10. Which treatments(s) are you currently receiving for your psoriasis – and for how long have you received this (PROBE until saturation)?

a. Products/treatments

i. How is this taken (topical, UV treatment, tablet, syringe, infusion)

ii. How often is this taken?

11. Have you been satisfied with your current (systemic) treatment – PROBE why/who not?
- a. Has it been efficient in reducing your plaques (NB! Use the best lay concept in the local vernacular)?
 - b. Has it been efficient with regard to specifically bothersome body parts (which)?
 - c. How long did it approximately take for the treatment effect to set in?
 - i. Did you consider that a rather rapid or slow response?
 - ii. What would you say constitute a rapid response (days/weeks)?
 - iii. Is speed of response important to you – why?
 - d. For how long have you considered the effect to be satisfactory, if at all?
 - e. Have you found it rather easy or bothersome to take your medicine?
 - i. Please describe if and how this may be important to you

12. Have you mostly taken your medication as recommended by your doctor?

- a. Why or what may have led you not to (e.g., forgetfulness, interference with activity, lacking time, appearance, side effects ...)?

Thank you. I would now like to focus on what is most important to you regarding your coming biologics

13. I understand that you are about to begin biologic treatment – how do you feel about that?

- a. Do you happen to know the name of the treatment?
- b. Do you know how it should be taken?

14. What are your expectations for biologics compared to your previous treatments?

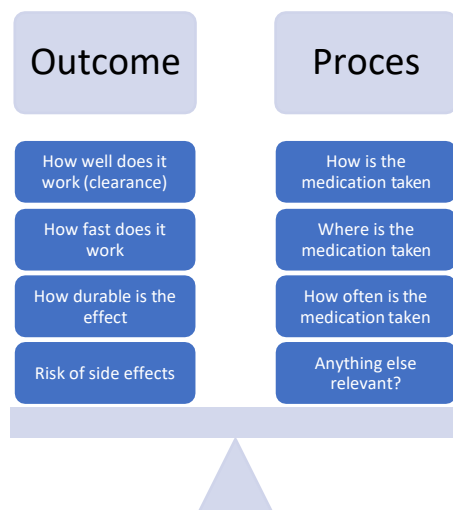
- a. Do you expect it to be more efficient in clearing plaques compared to previous treatments?
- b. How fast do you expect the effect to set in?
- c. Is that slow, fast, and acceptable?

- d. Do you expect the effect to be durable (how durable)?
- e. Do you have any concerns about side effects?
- f. Do you expect it to be convenient to take?

15. If you were to describe your overall goal with psoriasis treatment, what would that be?

I would like to try engaging you in a small exercise, where I will start by giving a brief information. I will show you a figure to help us (show the figure using 'share screen' and slowly describe the content):

Visual presentation of treatment attributes for the treatment preference exercise



Today, different kinds of biologics exist. When comparing them, we often talk about their slightly different *properties*. In the first column, you see aspects related to outcome. For instance, how effective a treatment is at clearing spots, how quickly it starts to work, how long the effect lasts, or the risk of side effects. In the other column, we have different practical aspects of the treatments such as how, where, and how often they should be taken (tablet/ injection, at home/clinic). Each country has guidelines about which ones are offered to patients, so it's not so that one can decide

for oneself. But if you were to describe which treatment aspects are most important to *you*, what would you say?

16. Which treatment properties would you say are most important to you? Please try to describe why a certain property is particularly important (and potential dilemmas).

- a. How efficient it is at clearing spots (overall body surface area or specific body areas)
- b. How quickly the effect sets in – what is a fast response to you (days/weeks)?
- c. How durable the effect is
- d. Potential (mild/severe) side effects
- e. How the product is taken (tablet/or injection/infusion)
- f. How often it should be taken
- g. Where it should be taken?
- h. Anything else?

PROBE carefully! Consider it an exercise. If you were to weigh x and x, what is the most important?

17. Has the Covid-19 pandemic in any way affected your thoughts about treatment?

Outro: Thank you. I just have a few final questions

18. Do you feel you have the knowledge about psoriasis and treatment that you need?

19. Where from have you gained knowledge about psoriasis and treatment options

20. Do you feel you can talk with your dermatologist about your treatment needs and preferences?

21. Before we end, is there anything you would like to add that is important to your treatment needs?

Thank you very much for participating and sharing your experiences with having psoriasis and your priorities regarding treatment. It is our hope that, after the analysis of interviews with patients across all the Nordic countries, we will be able to publish a scientific article in an international medical journal that reports the results. These processes take a long time, but would you be interested in receiving a copy of the article if we succeed? Also, I would like to send you a gift card 30,00 Euros to show our appreciation if you allow me to use your telephone number or email for this purpose only?