

Supplementary Materials

Patients' Needs Concerning Patient Education in Axial Spondyloarthritis: A Qualitative Study

Yvonne M. van der Kraan, BSc¹, Davy Paap, PhD^{1,2}, Niels Lennips, BSc¹, Else C.A. Veenstra, BSc¹, Freke R. Wink, MD³, Stan C. Keskamp, MD¹, Anneke Spoorenberg, MD/PhD¹

Affiliations:

¹Department of Rheumatology and Clinical Immunology, University Medical Center

Groningen, University of Groningen, Groningen, NL

²School of health, Department of physiotherapy, Saxion University of Applied Sciences,

Enschede, NL

³Department of Rheumatology, Medical Center Leeuwarden, Leeuwarden, NL

Corresponding author:

University Medical Center Groningen

Department of Rheumatology and Clinical Immunology

T.a.v. Y.M. van der Kraan

P.O. box 30 001
9700 RB Groningen

The Netherlands

E-mail address: y.m.van.der.kraan@umcg.nl

Interview Guide:

Opening

Introduction, small talk and explanation of the interview procedure.

1. Could you describe how you ended up at the rheumatology department in the UMCG?

PROBE: symptoms

- Age
- Which symptoms did you experience?
- How did they influence your daily life?
- How did you cope with that?

PROBE: diagnosis

- How did you receive the diagnosis?
- What kind of patient education did you get at the moment of the diagnosis?
- What feelings did you experience when receiving the diagnosis?
- Were you alone or together with someone when you received patient education?
- Was the patient education sufficient?
- Why was it (in)sufficient?

2. Could you tell me what kind of patient education you received during your disease process?

PROBE: attraction

- Have you searched for information yourself?
 - When did you do this?
 - Are you now searching in a different way than you did before?

- Do you always understand the information and patient education that you get?
- Does the patient education match your needs?
- Which topics do you find important and would you prefer to see in patient education?
- What would you like to learn from patient education?

PROBE: fashion

- You have just told me that you have received patient education from various healthcare providers, can you tell me if you received any other form of patient education since you were diagnosed? (patient association, flyer)
- Was this offered to you or did you search for it yourself?
- What form of patient education do you prefer? And why?
- Is there a form of patient education that you did not receive but that you would still like to receive? And why?
- Are you affiliated with a patient association?
- Would you like to tell me more about it?
 - Ambiance
 - Purpose
 - Appointments
 - Contact

PROBE: moment

- In your opinion, at which moment was the patient education most useful? And why?
- Do you still prefer to receive patient education?
 - About what?

3. How do you experience the contact with the healthcare providers?

PROBE: patient-healthcare provider relationship

- Who is/was involved in your disease process?
- What is/was their function?
- How did you experience the contact with them?
- Do you feel that you can discuss everything with your healthcare provider?
- Do you feel that you have an influence on the decisions that are made regarding your disease process?
 - Can you explain why you feel you (do not) have an influence?
- Have these healthcare providers also provided patient education on your disease?

4. If you were a healthcare provider, what kind of patient education would you offer to new patients with axSpA?

Suggestions:

- *Face-to-face contact with a healthcare provider*
- *group sessions / patient day*
- *videos*
- *writing / folder*

Closing statement:

Is there anything you would like to add?

What did you think about the interview?

Do you have any more questions?

COREQ (COnsolidated criteria for REporting Qualitative research) Checklist

A checklist of items that should be included in reports of qualitative research. You must report the page number in your manuscript where you consider each of the items listed in this checklist. If you have not included this information, either revise your manuscript accordingly before submitting or note N/A.

Topic	Item No.	Guide Questions/Description	Reported on Page No.
Domain 1: Research team and reflexivity			
<i>Personal characteristics</i>			
Interviewer/facilitator	1	Which author/s conducted the interview or focus group?	7
Credentials	2	What were the researcher's credentials? E.g. PhD, MD	1
Occupation	3	What was their occupation at the time of the study?	1
Gender	4	Was the researcher male or female?	N/A
Experience and training	5	What experience or training did the researcher have?	7
<i>Relationship with participants</i>			
Relationship established	6	Was a relationship established prior to study commencement?	7
Participant knowledge of the interviewer	7	What did the participants know about the researcher? e.g. personal goals, reasons for doing the research	7
Interviewer characteristics	8	What characteristics were reported about the interviewer/facilitator? e.g. Bias, assumptions, reasons and interests in the research topic	7
Domain 2: Study design			
<i>Theoretical framework</i>			
Methodological orientation and Theory	9	What methodological orientation was stated to underpin the study? e.g. grounded theory, discourse analysis, ethnography, phenomenology, content analysis	6
<i>Participant selection</i>			
Sampling	10	How were participants selected? e.g. purposive, convenience, consecutive, snowball	7
Method of approach	11	How were participants approached? e.g. face-to-face, telephone, mail, email	7
Sample size	12	How many participants were in the study?	9
Non-participation	13	How many people refused to participate or dropped out? Reasons?	9
<i>Setting</i>			
Setting of data collection	14	Where was the data collected? e.g. home, clinic, workplace	9
Presence of non-participants	15	Was anyone else present besides the participants and researchers?	9
Description of sample	16	What are the important characteristics of the sample? e.g. demographic data, date	9,10
<i>Data collection</i>			
Interview guide	17	Were questions, prompts, guides provided by the authors? Was it pilot tested?	8
Repeat interviews	18	Were repeat interviews carried out? If yes, how many?	N/A
Audio/visual recording	19	Did the research use audio or visual recording to collect the data?	8
Field notes	20	Were field notes made during and/or after the interview or focus group?	9
Duration	21	What was the duration of the interviews or focus group?	8
Data saturation	22	Was data saturation discussed?	8,10
Transcripts returned	23	Were transcripts returned to participants for comment and/or	9

Topic	Item No.	Guide Questions/Description	Reported on Page No.
		correction?	
Domain 3: analysis and findings			
<i>Data analysis</i>			
Number of data coders	24	How many data coders coded the data?	8
Description of the coding tree	25	Did authors provide a description of the coding tree?	8,9
Derivation of themes	26	Were themes identified in advance or derived from the data?	8,9
Software	27	What software, if applicable, was used to manage the data?	8
Participant checking	28	Did participants provide feedback on the findings?	8
<i>Reporting</i>			
Quotations presented	29	Were participant quotations presented to illustrate the themes/findings? Was each quotation identified? e.g. participant number	11
Data and findings consistent	30	Was there consistency between the data presented and the findings?	9-15
Clarity of major themes	31	Were major themes clearly presented in the findings?	9-15
Clarity of minor themes	32	Is there a description of diverse cases or discussion of minor themes?	9-15

Developed from: Tong A, Sainsbury P, Craig J. Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups. *International Journal for Quality in Health Care*. 2007. Volume 19, Number 6: pp. 349 – 357

Once you have completed this checklist, please save a copy and upload it as part of your submission. DO NOT include this checklist as part of the main manuscript document. It must be uploaded as a separate file.