All statements divided in concepts from the AXIAL SPONDYLOARTHRITIS workshops

				f rat	ing*		ement		icept
Statements	1	2	3	4	5	Mean	Median	Mean	Median
Consequences/Limitations i	in w	ork	-life						
I use my energy wrong. I use it all on work.		1			2	4,0	5		
I have felt compelled to tell colleagues that I have some limitations due to							-		
Bechterew's disease		1	1	1		3,0	3		
I had to tell and be very open about my disease at work			3			3,0	3		
Openness at work has been necessary to be understood			3	1		3,3	3		
I have to decline jobs because of my disease		1	1	1		3,0	3		
It limits me with regard to new work		1		1	1	3,7	4		
Is there anyone who wants to hire me, if they know about my disease?			2		1	3,7	3		
I never told I had Bechterew's disease at work. I want to be judged for my			2				2		
work and not my disease			3			3,0	3		
I will always tell my employer about my disease		1	2			2,7	3		
I arrange my work-life so that I can keep up with it and recharge			1	2		3,7	4		
I have worked part-time to prioritize my disease and family life in order to					2	10	-		
have enough energy		1			2	4,0	5		
I have reduced my work hours and thus my salary, so it costs money to be		1	1	1		3,0	3	3.7	4
		1		Т		3,0	3	3.7	-
The options for pension and flexjob are very limited in relation to				2	1	4,3	4		
knowledge about disease in the public sector					1		-		
I have gone from 110 per cent to 90 per cent because of my disease			1	1	1	4,0	4		
All treatment and physiotherapy take place during the day, which then			1	1	1	4,0	4		
affects my workday			-	-	-	4,0	-		
I have made a conscious career change from "fast pace" in the private		1			2	4,0	5		
sector to a position in the public sector to take my disease into account		-			-	1,0			
Home working days due to covid have given increased flexibility in				2	1	4,3	4		
everyday life									
Can I work and be active in the future or will I have to live differently?				1	2	4,7	5		
I had to arrange my work-life so that I could rest		1			1	3,5	4		
Due to my disease, I retired earlier than expected		1			1	3,5	4		
The first three months of my early retirement were the longest of my life				1	1	4,5	5		
My work-life stopped very abruptly				1	1	4,5	5		
Worries now and in the	fut	ure							
Worry about whether I can keep up with my work-life	<u> </u>		1		2	4,3	5		
Uncertainty about the future			3		2	3,0	3		
Will I be able to start a family?			1	1	1	4,0	4		
Uncertainty with the new unpredictability in my life		1		2	-	3,3	4		
I am worried about passing it on to my children		1	1	2	1	3,3	3		
I am worried about getting diseases related to Bechterew's disease		-	2	1	-	3,3	3		
What does the medicine do to my body in the long run?			1	1	1	4,0	4		
It is unpredictable who will have effect of the medicine and how long it			-	-	-	1,0			
works			3			3,0	3		
Worried that my back is growing together			2		1	3,7	3		
Concerned about the development of the disease over time			-	2	1	4,3	4	3.6	4
Does fatigue increase over time?				2	1	4,3	4		
Do back and joint stiffness increase?				2	1	4,3	4		
I am worried whether I can continue my sport if the disease develops			2	-	1	3,7	3		
I am worried whether my daughter will inherit the disease	1		-	1	1	3,3	4		
I am worried that my stiff neck will result in me losing my driver's licens	1			1	1	3,3	4		
I am worried about the biological medicine stop working and I have a	<u> </u>			-					
relapse		1			2	4,0	5		
Those who are close to me do not need to worry. I leave that to the healthcare professionals	2				1	2,3	1		
							1		
Take responsibility for your o	wn	situ	atio	n					

Openness to family and friends about the diseaseYou must take responsibility for your own situation and not sit backYou can do something yourselfRecreation and interests are very important so that the disease does not take up so muchYou have to get input, e.g., socially and culturally, so that the disease gets less spaceMental health becomes charged with positive thingsNow that there is limited medical treatment available, positive distractions are even more importantIt is important to set goals including sub-goalsI ride my bike a lot and I am really happy about that. I would be sad if I could not do thatBeing able to run every day makes me really happy. It gives me a boost in everyday lifeIt is important to be open to yourself, also in relation to alternative treatmentAm I doing enough myself to manage my disease?Can I counteract the development of my disease myself?Quality of life and content are very importantShould I be patient-ignorant or take responsibility and thus be an expert?I ti solve the challenges I face with my disease		1 1 1 1 1 1 1 1 1 1 1	2 3 2 1 1 1 1 1 1 2 2 2 2 2	2 1 2 2 1 1 1 1	4,3 3,7 4,0 4,3 4,7 4,7 3,7 3,7 4,0 4,0 4,0 3,0 3,7	5 4 4 5 5 4 4 4 4 4 4 4 4	3.8	4
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I solve the challenges I face with my disease	1		2	1	4,3	4		
	1 I I	1			2,5	3		
Identity/recognition/acce	cept							
I cannot do everything I would like to and have a hard time accepting that			1	2	4,7	5		
My disease does not matter much. Has become a part of my life		2	1		3,3	3		
The disease affects social life. Makes it awkward	1	1	1		3,0	3		
It has been a process to tell others I don't know, that I have a disease		1	2		3,7	4		
When you are not ill, you have the privilege of being normal	1	1		1	3,3	3		
When you are ill, you are both ill and have to put yourself in a vulnerable								
situation of having to tell colleagues about it		3			3,0	3		
I work full time so no one will say I am sick		1	2		3,7	4		
At times you can feel a little self-pity		1	1	1	4,0	4		
Why me?		1	2		3,7	4		
I have opted out of being part of patient associations in order not to be a patient	2	1			1,7	1		
My identity is not to be a patient, on the other hand, I am 100 per cent something else	1	1		1	3,0	3		
It has always been my trademark to be physically strong and the disease will not change that	1		1	1	3,7	4	3.2	3
I have said no to paid physiotherapy because then I am not a patient and	2	1			1,7	1	5.2	
have chosen private physiotherapy instead		_						
I have learned more about myself - for better or for worse		2		1	3,7	3		
I have gained insight into what is important for me to be able to do and			3		4,0	4		
what matters	2 1	-			1.2	1		
My sister didn't want to take medicine because she then felt ill 2	2 1	+			1,3	1		
I have not felt a deprivation due to my disease because I do not know what I have missed out on	1	2			2,7	3		
My boyfriend got another package 1	1	1		1	3,0	3		
My boyfriend gets involved in the treatment by, for example, having to 2	2			1	2,3	1		
tape a shoulder and he should not have to	-							
I see my wife's concern as support more than a worry		1	1	1	4,0	4		
The heredity of the disease has played a role in having children, but not	1		1	1	3,3	4		
decisively			Ē		-,-			
Surrounding's/relatives understanding a	and '	ʻgoo	d" a	advio	e			
People find it difficult to accept my situation and its limitations	1	1		1	3,3	3		
People have considered me to be a hypochondriac		1	2		3,7	4	3.2	3

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I find it scary how dependent I am on that medicine114,04Five days before I have to get my medicine, I can feel my disease1113,54I have experienced worse treatment in outer Denmark1113,03Lack of understanding/to be heard and seen by healthcare professionalsNo one listened to me when my symptoms started1114,04There is a lack of openness and recognition regarding alternative treatment options in the healthcare system11113,03In the time before my diagnosis, I have lost trust in the health care professionals11114,554.04				1	1		3,5	4		
I find it scary how dependent I am on that medicine114,04Five days before I have to get my medicine, I can feel my disease1113,54I have experienced worse treatment in outer Denmark1113,03Lack of understanding/to be heard and seen by healthcare professionalsNo one listened to me when my symptoms started1114,04There is a lack of openness and recognition regarding alternative treatment options in the healthcare system11113,03In the time before my diagnosis, I have lost trust in the health care professionals11114,554.04	I am incredibly happy to go to the hospital to receive my medicine	1		1			2,0	2	1	
Five days before I have to get my medicine, I can feel my disease 1 1 3,5 4 I have experienced worse treatment in outer Denmark 1 1 1 3,0 3 Lack of understanding/to be heard and seen by healthcare professionals No one listened to me when my symptoms started 1 1 1 4,0 4 There is a lack of openness and recognition regarding alternative treatment options in the healthcare system 1 1 1 3,0 3 In the time before my diagnosis, I have lost trust in the health care professionals 1 1 1 4,5 5 4.0 4				1		1		4	1	
I have experienced worse treatment in outer Denmark113,03Lack of understanding/to be heard and seen by healthcare professionalsNo one listened to me when my symptoms started1114,04There is a lack of openness and recognition regarding alternative treatment options in the healthcare system11113,03In the time before my diagnosis, I have lost trust in the health care professionals11114,554.04				-	1				1	
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No one listened to me when my symptoms started1114,04There is a lack of openness and recognition regarding alternative treatment options in the healthcare system11113,03In the time before my diagnosis, I have lost trust in the health care professionals11114,554.04		1	1		1		•	1	1	
There is a lack of openness and recognition regarding alternative treatment options in the healthcare system1113,03In the time before my diagnosis, I have lost trust in the health care professionals1114,554.04		by l	neal	1	1	-		1		
treatment options in the healthcare system1113,03In the time before my diagnosis, I have lost trust in the health care professionals1114,554.04				1	1	<u> </u>	4,0	4	{	
In the time before my diagnosis, I have lost trust in the health care professionals 1 1 1 4,5 5 4.0 4			1	1	1		3,0	3		
professionals			-							
professionals					1	1	4,5	5	4.0	4
		-	-		-			-	-	
I did not feel heard or seen until I was diagnosed 1 1 4,5 5	-				1	-				
I was asked to exercise more even though I was already exercising 1 4,0 4	I was asked to exercise more even though I was already exercising			1	1	1	4,0	4		

I did not fool I got holp to coluc my ob-llarase			4		1	4.0	4		
I did not feel I got help to solve my challenges			1		1	4,0	4		
You just need to take some painkillers (symptom treatment)			T	1	1	4,0 4,5	4	-	
I was not examined when I came with my pain		1		T	1		4	-	
I had the feeling that others thought it was something I was imagining		1			<u> </u>	3,5	4		
Everyday life with Bechterey	w's c	dise	ase						
There are many things I would like to do. And sometimes I push myself				_					
too much				3		4,0	4		
Wish I had more energy in my spare time				2	1	4,3	4	1	
Fatigue is paramount for me			1	2		3,7	4		
Træthed har været årsag til at jeg har skiftet job	1			1	1	3,3	4	1	
I have had to put myself aside		1	1	1		3,0	3		
I have to spend a lot of time on mobility exercises and physiotherapy that							_	1	
others don't have to		1	2			2,7	3		
I have to opt out because my disease takes time		1	1		1	3,3	3	1	
It is not fair that I have to spend time on e.g. exercises when others don't				-				1	
have to		1		2		3,3	4		
My spare time is filled with disease obligations instead of what I want to								1	
do		1		1	1	3,7	4		
If I don't exercise, I don't have the energy to do what I have to do. It is		4	4	4		2.0	2	1	
unfair		1	1	1		3,0	3		
I limit myself in terms of hard physical work in everyday life due to the		1	2			2 7	2	3.5	4
disease		1	2			2,7	3		
For me, cold means inactivity due to joint pain	1	1		1		2,3	2		
If I am too active, it costs me energy the next day		1	1	1		3,0	3		
Definitely, a need to rest in the afternoon to function well					3	5,0	5		
I had to constantly balance the things I wanted to do with my pain		1			1	3,5	4		
What does it cost in terms of pain to do what I want to do?		1		1		3,0	3		
You only have a certain amount of energy to spend each day				1	1	4,5	5		
I cannot do housework				1	1	4,5	5		
It annoys me endlessly that I cannot do work at home				1	1	4,5	5		
Things in everyday life are challenging for me due to Bechterew's disease			1		1	4,0	4		
It annoys me that I am not so flexible in my body				1	1	4,5	5		
I am stiff in the body and that limits me in terms of swimming			1		1	4,0	4		
I do not worry about my disease		2				2,0	2		
Sometimes there is too much focus on my situation/Bechterew's disease		1	1			2,5	3		
I can no longer tolerate alcohol as a result of my disease		1		1		3,0	3		
Meeting the hospital/health	care	svs	sten	n					
		-,-	r	1				1	1
You must not let yourself be taken over by the system			2	1	1	3,3	3	-	
Rheumatologists also considered me to be a hypochondriac			2		1	3,7	3	-	
There are unrealistic expectations of what the doctor thinks I can achieve		1	2			2,7	3		
in my everyday life in terms of exercise								-	
If you have Bechterew's disease, it is almost a guarantee that you will not	1		1	1		2,7	3		
get Crohn's disease			2			2.0	2	-	
Much focus is placed on pain in relation to the disease			3	2		3,0	3	-	
Lack of information about what the consequence of the medicine is			1	2	1	3,7	4	-	
I feel seen and heard by my doctor			4	2	1	4,3	4	-	
At the doctor's, it is a lot about medicine			1	2	1	3,7	4	-	
Danbio is a good tool in the meeting with the doctor			1	2	1	4,3	4	-	
Especially the nurses see and hear me			1	1	1	4,0	4	-	
Exchange of your regular doctor can be a challenge			1	2	2	3,7		-	
It is a good thing to be able to write directly to the doctor if in doubt			<u> </u>	1	2	4,7	5		
I have generally felt really well taken care of and met by competent			2		1	3,7	3		
healthcare professionals My strategy is to let the doctor worry about the disease and not me		1	1		1	2.2	2	{	
		1	1		1	3,3	3	3.3	3
I have confidence in healthcare professionals in general regarding my disease			1	2		3,7	4		
I have experienced a shift in confidence - felt alone with the disease	1	1			1	27	2	1	
I stopped at the physiotherapist as I did not feel he could do anything for	T	T			T	2,7	۷		
me that I could not do myself	2		1			1,7	1		
		I	I	I	I	l	i	I	

I think it is reasonable after paying taxes for forty years, that I use the	1		1		1	3,0	3		
healthcare system	-		-		-	3,0	5		
I feel I am burdening the public sector because of a banality	2		1			1,7	1		
I cost the public sector a lot of money	1	1	1			2,0	2		
I feel that I inconvenience the public system unnecessarily	2		1			1,7	1		
I have great chemistry with my doctor and that makes me feel safe			1		1	4,0	4		
I feel my doctor sincerely listens and hears what I say				1	1	4,5	5		
It is important that my doctor continues		1			1	3,5	4		
My doctor made me aware of my rights			1		1	4,0	4		
It is important that you, as a patient, feel free to speak up against the			1	1		3,5	4		
system you have become a part of			Т	1		3,5	4		
Life with Bechterew's c	lisea	se							
Difficult to plan your life for the long term			3			3,0	3		
It gives me less confidence that the disease can suddenly overwhelm me			2	1		3,3	3		
The mind and the physical are connected			1		2	4,3	5		
The unpredictability can lead to worries which can lead to a depressive		1			2	10	5		
state		T			2	4,0	Э	3.6	4
Being ill offers the opportunity to seek financial compensation, but it			2	1		3,3	3		
costs energy			2			3,5	3		
I have joined the patient association to meet others with the disease		1		2		3,3	4		
Stress has a big impact on my disease				-		0.7	4		1
			1	2		3,7	4		l
*Rating - 1: 'Not important at all', 2: 'A little important', 3: 'Somewhat important',	 4: 'Ve	 ery ir	-		' and	,		nce'.	

All statements divided in concepts from the PSORIATIC ARTHRITIS workshops

	Fre	quer	ncy o	f rat	ing*	State	ment	Con	cept
Statements	1	2	3	4	5	Mean	Median	Mean	Median
Concerns in relation to my illness/ur	Janc	_	od a						
	ans	wei	eut	lue		-	1		
What must I do? If I feel pain, must I stop what I'm doing?					3	3.0	3		
What makes my condition worse or better?				1	2	4.7	5		
I have many unanswered questions.				2	1	4.3	4		
I would like more information as regards what I can do myself			2		2	4.0	4		
Is my illness at a standstill, - should I resign myself to where I am now?			1	3		3.8	4		
It's hard to know whether I should continue when it hurts		2		2		3.0	3		
Thinking about whether I can stay in my apartment because my knees were so sore				1	1	4.5	5		
What are my prospects				2	2	4.5	5		
The pain has not improved after I took my medication (MTX)				1	1	4.5	5		
Concerned for the future				3	1	4.3	4		
Worried about experiencing more pain				3	1	4.3	4		
It worries me that my mobility may be reduced				3	1	4.3	4		
If it becomes worse - I will feel like I'm in deep trouble				4		4.0	4		
How bad will it become - will I end up in a wheelchair?			1	2	1	4.0	4	27	
Worries about my physical condition in general			1	2	1	4.0	4	3.7	4
What can it develop into	1			1	2	3.8	5		
I'm concerned about the limitations the illness forces on my everyday			2	1	1	3.8	4		
When I was diagnosed, I was afraid I would end up in a wheelchair	1	1		1	1	3.0	3		
Could not get a clear overview of the consequences the illness might			4			2.0			
possibly result in? Lose my apartment, be fired, etc?			1	1	1	3.0	4		
Worry about whether I can still be active with my kids, if I feel worse	2			1	1	2.8	3		
What worries me is not being able to interact with my children	2	1			1	2.3	2		
I'm concerned that I might need help getting out of bed for example	2		1	1		2.3	2		
The development of my illness - will it get worse?				1	3	4.8	5		
I could not return to the job I had before the illness				1	2	4.7	5		
What job opportunities are there if I do not have a job?			1	1	2	4.3	5		
Worry about whether my current job is too physically demanding	1			2		2.3	3		
Financial worries	1		1	1		2.0	2		
How long can I continue to work	1				2	2.8	3		
				~ 4	ممانية				
	subj	ect	euı	0, 1	eem	igs abot	it that		
Consequences of pain and fatigue, what I will be	1	1		1	3	4.8	5		
Worsening of pain					-		5		
Worsening of pain Before I had biological medication, I could not get up from the floor				1	2	4.7	5		
Worsening of pain Before I had biological medication, I could not get up from the floor Difficulty with cutting because of the pain				1 1	2		5 5		
Worsening of pain Before I had biological medication, I could not get up from the floor					2	4.7	5		
Worsening of pain Before I had biological medication, I could not get up from the floor Difficulty with cutting because of the pain Had a hard time getting up because of pain in fingers and wrist Wake up with severe pain at night				1	2	4.7 4.7	5 5		
Worsening of pain Before I had biological medication, I could not get up from the floor Difficulty with cutting because of the pain Had a hard time getting up because of pain in fingers and wrist	1		2	1 2	2 2 2	4.7 4.7 4.5	5 5 5		
Worsening of pain Before I had biological medication, I could not get up from the floor Difficulty with cutting because of the pain Had a hard time getting up because of pain in fingers and wrist Wake up with severe pain at night		1	2	1 2	2 2 2 1	4.7 4.7 4.5 4.3	5 5 5 4		
Worsening of pain Before I had biological medication, I could not get up from the floor Difficulty with cutting because of the pain Had a hard time getting up because of pain in fingers and wrist Wake up with severe pain at night Hurts a lot - dietary does not help	-	1		1 2 2	2 2 2 1	4.7 4.7 4.5 4.3 3.0	5 5 4 3		
Worsening of pain Before I had biological medication, I could not get up from the floor Difficulty with cutting because of the pain Had a hard time getting up because of pain in fingers and wrist Wake up with severe pain at night Hurts a lot - dietary does not help My arthritis is very much influenced by the fluctuating Danish weather	-	1		1 2 2 1	2 2 2 1 1	4.7 4.7 4.5 4.3 3.0 2.5	5 5 4 3 3		
Worsening of pain Before I had biological medication, I could not get up from the floor Difficulty with cutting because of the pain Had a hard time getting up because of pain in fingers and wrist Wake up with severe pain at night Hurts a lot - dietary does not help My arthritis is very much influenced by the fluctuating Danish weather It's a vicious cycle I have fallen into	-	1		1 2 2 1	2 2 2 1 1 2	4.7 4.7 4.5 4.3 3.0 2.5 4.7	5 5 4 3 3 5		
Worsening of pain Before I had biological medication, I could not get up from the floor Difficulty with cutting because of the pain Had a hard time getting up because of pain in fingers and wrist Wake up with severe pain at night Hurts a lot - dietary does not help My arthritis is very much influenced by the fluctuating Danish weather It's a vicious cycle I have fallen into It is stressful because they (the system) do not do anything to help me	-	1		1 2 1 1 2 2 2	2 2 1 1 2 2 2 2 2 1	4.7 4.7 4.5 4.3 3.0 2.5 4.7 4.5 4.3	5 5 4 3 3 5 5 4	2 7	
Worsening of pain Before I had biological medication, I could not get up from the floor Difficulty with cutting because of the pain Had a hard time getting up because of pain in fingers and wrist Wake up with severe pain at night Hurts a lot - dietary does not help My arthritis is very much influenced by the fluctuating Danish weather It's a vicious cycle I have fallen into It is stressful because they (the system) do not do anything to help me My husband is also affected by me receiving chemotherapy (MTX)	-	1		1 2 2 1 1 2	2 2 2 1 1 2 2 2 2	4.7 4.7 4.5 4.3 3.0 2.5 4.7 4.5	5 5 4 3 3 5 5 5	3.7	4
Worsening of pain Before I had biological medication, I could not get up from the floor Difficulty with cutting because of the pain Had a hard time getting up because of pain in fingers and wrist Wake up with severe pain at night Hurts a lot - dietary does not help My arthritis is very much influenced by the fluctuating Danish weather It's a vicious cycle I have fallen into It is stressful because they (the system) do not do anything to help me My husband is also affected by me receiving chemotherapy (MTX) My husband is anxious on my behalf because I am receiving	-	1		1 2 1 1 2 2 2	2 2 1 1 2 2 2 2 2 1	4.7 4.7 4.5 4.3 3.0 2.5 4.7 4.5 4.3	5 5 4 3 3 5 5 4	3.7	4
Worsening of pain Before I had biological medication, I could not get up from the floor Difficulty with cutting because of the pain Had a hard time getting up because of pain in fingers and wrist Wake up with severe pain at night Hurts a lot - dietary does not help My arthritis is very much influenced by the fluctuating Danish weather It's a vicious cycle I have fallen into It is stressful because they (the system) do not do anything to help me My husband is also affected by me receiving chemotherapy (MTX) My husband is anxious on my behalf because I am receiving chemotherapy (MTX)	-	1		1 2 1 1 2 2 2 2	2 2 1 1 2 2 1 2 2 1 1 1	4.7 4.7 4.5 4.3 3.0 2.5 4.7 4.5 4.3 4.3	5 5 4 3 3 5 5 4 4 4	3.7	4
Worsening of pain Before I had biological medication, I could not get up from the floor Difficulty with cutting because of the pain Had a hard time getting up because of pain in fingers and wrist Wake up with severe pain at night Hurts a lot - dietary does not help My arthritis is very much influenced by the fluctuating Danish weather It's a vicious cycle I have fallen into It is stressful because they (the system) do not do anything to help me My husband is also affected by me receiving chemotherapy (MTX) My husband is anxious on my behalf because I am receiving chemotherapy (MTX) I hide my hands	-	1		1 2 1 1 2 2 2 2 2	2 2 1 1 2 2 1 2 2 1 1 1 1	4.7 4.7 4.5 4.3 3.0 2.5 4.7 4.5 4.3 4.3 4.3	5 5 4 3 3 5 5 4 4 4 4	3.7	4
Worsening of pain Before I had biological medication, I could not get up from the floor Difficulty with cutting because of the pain Had a hard time getting up because of pain in fingers and wrist Wake up with severe pain at night Hurts a lot - dietary does not help My arthritis is very much influenced by the fluctuating Danish weather It's a vicious cycle I have fallen into It is stressful because they (the system) do not do anything to help me My husband is also affected by me receiving chemotherapy (MTX) My husband is anxious on my behalf because I am receiving chemotherapy (MTX) I hide my hands When I am in pain, I do not use my body as I would like, - affects me a lot	-	1	1	1 2 1 1 2 2 2 2 3	2 2 1 1 2 2 1 2 2 1 1 1 1 1	4.7 4.7 4.5 4.3 3.0 2.5 4.7 4.5 4.3 4.3 4.3 4.3	5 5 4 3 3 5 5 4 4 4 4 4	3.7	4
Worsening of pain Before I had biological medication, I could not get up from the floor Difficulty with cutting because of the pain Had a hard time getting up because of pain in fingers and wrist Wake up with severe pain at night Hurts a lot - dietary does not help My arthritis is very much influenced by the fluctuating Danish weather It's a vicious cycle I have fallen into It is stressful because they (the system) do not do anything to help me My husband is also affected by me receiving chemotherapy (MTX) My husband is anxious on my behalf because I am receiving chemotherapy (MTX) I hide my hands When I am in pain, I do not use my body as I would like, - affects me a lot I turn the anger inward so as not to upset anybody	-	1	1	1 2 1 1 2 2 2 2 2 3 2 2 2 2	2 2 1 1 2 2 1 2 1 1 1 1 1 1	4.7 4.7 4.5 4.3 3.0 2.5 4.7 4.5 4.3 4.3 4.3 4.3 4.3	5 5 4 3 3 5 5 4 4 4 4 4 4 4	3.7	4
Worsening of pain Before I had biological medication, I could not get up from the floor Difficulty with cutting because of the pain Had a hard time getting up because of pain in fingers and wrist Wake up with severe pain at night Hurts a lot - dietary does not help My arthritis is very much influenced by the fluctuating Danish weather It's a vicious cycle I have fallen into It is stressful because they (the system) do not do anything to help me My husband is also affected by me receiving chemotherapy (MTX) My husband is anxious on my behalf because I am receiving chemotherapy (MTX) I hide my hands When I am in pain, I do not use my body as I would like, - affects me a lot I turn the anger inward so as not to upset anybody Mental impact - the illness dampens my mood	-		1	1 2 1 1 2 2 2 2 3 2 1	2 2 1 1 2 2 1 2 1 1 1 1 1 1	4.7 4.5 4.3 3.0 2.5 4.7 4.5 4.3 4.3 4.3 4.3 4.3 4.0 3.8	5 5 4 3 3 5 5 4 4 4 4 4 4 4 4	3.7	4
Worsening of pain Before I had biological medication, I could not get up from the floor Difficulty with cutting because of the pain Had a hard time getting up because of pain in fingers and wrist Wake up with severe pain at night Hurts a lot - dietary does not help My arthritis is very much influenced by the fluctuating Danish weather It's a vicious cycle I have fallen into It is stressful because they (the system) do not do anything to help me My husband is also affected by me receiving chemotherapy (MTX) My husband is anxious on my behalf because I am receiving chemotherapy (MTX) I hide my hands When I am in pain, I do not use my body as I would like, - affects me a lot I turn the anger inward so as not to upset anybody Mental impact - the illness dampens my mood The pain associated with psoriatic arthritis is great	-		1 1 2 1	1 2 1 1 2 2 2 2 2 3 2 2 3 2 1 3	2 2 2 1 1 1 2 2 2 1 1 1 1 1 1 1 1	4.7 4.7 4.5 4.3 3.0 2.5 4.7 4.5 4.3 4.3 4.3 4.3 4.3 4.0 3.8 3.8	5 5 4 3 5 5 5 4 4 4 4 4 4 4 4 4 4	3.7	4
Worsening of painBefore I had biological medication, I could not get up from the floorDifficulty with cutting because of the painHad a hard time getting up because of pain in fingers and wristWake up with severe pain at nightHurts a lot - dietary does not helpMy arthritis is very much influenced by the fluctuating Danish weatherIt's a vicious cycle I have fallen intoIt is stressful because they (the system) do not do anything to help meMy husband is also affected by me receiving chemotherapy (MTX)My husband is anxious on my behalf because I am receivingchemotherapy (MTX)I hide my handsWhen I am in pain, I do not use my body as I would like, - affects me a lotI turn the anger inward so as not to upset anybodyMental impact - the illness dampens my moodThe pain associated with psoriatic arthritis is greatFeel guilty about not doing what I know I can to feel better	-		1 1 2 1 2	1 2 1 1 2 2 2 2 3 2 1 3 1 3 1	2 2 2 1 1 1 2 2 2 1 1 1 1 1 1 1 1	4.7 4.7 4.5 4.3 3.0 2.5 4.7 4.5 4.3 4.3 4.3 4.3 4.3 4.0 3.8 3.8 3.8	5 5 4 3 5 5 5 4 4 4 4 4 4 4 4 4 4 4	3.7	4
Worsening of pain Before I had biological medication, I could not get up from the floor Difficulty with cutting because of the pain Had a hard time getting up because of pain in fingers and wrist Wake up with severe pain at night Hurts a lot - dietary does not help My arthritis is very much influenced by the fluctuating Danish weather It's a vicious cycle I have fallen into It is stressful because they (the system) do not do anything to help me My husband is also affected by me receiving chemotherapy (MTX) My husband is anxious on my behalf because I am receiving chemotherapy (MTX) I hide my hands When I am in pain, I do not use my body as I would like, - affects me a lot I turn the anger inward so as not to upset anybody Mental impact - the illness dampens my mood The pain associated with psoriatic arthritis is great Feel guilty about not doing what I know I can to feel better Suffering from psoriatic arthritis is a full-time job			1 1 2 1 2 1	1 2 1 1 2 2 2 2 3 2 2 1 3 1 2 1 2	2 2 2 1 1 1 2 2 2 1 1 1 1 1 1 1 1	4.7 4.7 4.5 4.3 3.0 2.5 4.7 4.5 4.3 4.3 4.3 4.3 4.3 4.3 4.3 8.8 3.8 3.8 3.3	5 5 4 3 3 5 5 4 4 4 4 4 4 4 4 4 4 4 4 4	3.7	4

My body is becoming more and more twisted (due to illness/inactivity)	1			2	1	3.5	4		
I have to sleep for a few hours when I get home from work	2	1			1	2.3	2		
I am very much affected by fatigue				1	2	4.7	5		
Increased fatigue				2	2	4.5	5		
I am very tired - use up all my energy at work	1	1	1		1	2.8	3		
My pain restricts my participation in Yoga etc. (physical activity)			2	1	1	3.8	4		
Lose things	1			2	1	3.5	4		
Constantly losing things, - very frustrating	1			2	1	3.5	4		
Difficulty performing work because of arthritis	1			1	1	3.3	3		
Many limitations as regards being with my children - need help from	-								
others	2		1		1	2.5	2		
Limitations as regards my grandchildren	3					1.0	1		
Have difficulty climbing stairs - no strength in my joints (hard)	-		1	1	1	4.0	4		
Medication (effects and adve	erse	eff	ects)					
Concerns about the medication					4	5.0	5		
Does the medication work?			1		3	4.5	5		
Decreases the effect (of the medication) over time				2	2	4.5	5		
What impact does the medication have on me				3	1	4.3	4		
There are many adverse effects from all the medications I take because of				•	4	4.2			
my illness(es)				3	1	4.3	4		
You never hear any good stories about MTX - why should I take it?			1	1	1	4.0	4		
I worry a lot about whether the biological medication I receive can cause				4	1	4.0	F		
cancer		1		1	2	4.0	5		
If the medication does not work - will I be on a roundabout for the rest of	1			2	1	25	4		
my life	1			2	1	3.5	4		
Concerned about whether I can have children because of the medication	2				2	3.0	3		
The medication causes hair loss (Arava)				1	2	4.7	5		
The frequency of the arthritis attacks has increased markedly after I				1	1	4 5	F		
received MTX				1	1	4.5	5		
I am mentally affected by medication				2	2	4.5	5		
Hair loss (adverse effect)				2	2	4.5	5		
It's annoying that I have to howl all the time (adverse effect)				2	1	4.3	4		
I get angry over nothing - snarling all the time				2	1	4.3	4		
I don't want to read the leaflet about the adverse effects, as I'll just feel			1	1	2	4.2	F		
bad			1	1	2	4.3	5		
Get sore ankles and swollen toes (arthritis) from MTX			1	1	2	4.3	5		
Become more tired when I take the medication (MTX)			1	1	1	4.0	4	3.8	4
After I started the MTX, I become very sad			1	2	1	4.0	4		
I think I get a fever from the MTX (adverse effect) - my bedclothes are			1	1	1	10	4		
dripping wet after I take it			1	1	1	4.0	4		
After I started taking MTX I feel that I suffer flu-like symptoms			1	2	1	4.0	4		
Adverse effects from the medication (MTX)			1	1	2	4.3	5		
I become aggressive for the first few days I take MTX (adverse effect)		1		2	1	3.8	4		
Adverse effects from the medication (MTX)	1			1	2	3.8	5		
I am emotionally affected by the medication			2	2		3.5	4		
The medication (MTX) and something else was stopped, as my liver	2				4	2.0	4		
countsincreased a lot	3				1	2.0	1		
If it gets worse I will stop taking MTX			1	2	1	4.0	4		
I have tried to stop taking the medication (but it did not go as well as I had				4		10			
hoped				4		4.0	4		
Has my condition improved while I took the medication could I			2	•		2.5			
possibly do without it?	L		2	2		3.5	4		
I tried to stop taking MTX, but I became very poorly	2			1	1	2.8	3		
I have thought about whether I could do without the medication				3	1	4.3	4		
I've finally received biological medication	2			1	1	2.8	3		
I have high expectations for my biological medication	1			1	2	3.8	5		
The medication works very differently on different people. Many also				~			,		
have great success stories	1		1	2		3.0	4		
Can I get the medication I want		1		2	1	4.0	5		
	-	-				-			

I have tosted many of the biological proparations, but they had so effect									
I have tested many of the biological preparations - but they had no effect or I could not tolerate them	2		1	1		2.3	2		
Frustrated about having to take MTX for a long time, without it having				-	-				
worked				2	2	4.5	5		
My own approach (I do some	thin	g m	yse	lf)					
I am not overly affected by the illness, such that I can tolerate it if it does	1								
not get worse				1	2	4.7	5		
I have difficulty performing everyday objects at home - but I will find a				_					
solution		1		3		3.5	4		
One finds a way			2	1	1	3.8	4		
Everything is possible, a way is found			2	1	1	3.8	4		
I find a solution to the problems - so that they do not take over			1	3		3.8	4		
I refuse to spend my time worrying about myself - otherwise I couldn't do		1	1	2		3.3	4		
anything			_		-			-	
Exercise improves my mood		1		1	2	4.0	5	-	
I think a lot about my illness before I go to the doctor	1	1	1	1	2	4.0	5	3.6	4
When I was diagnosed, I tried many alternative methods What can I do myself?	1		1	1	2	3.5 3.8	4		
I am amazed that there has been no focus on diet	1	1	2	1	2	3.3	4		
Heat helps my illness	1	-		1	2	3.8	5		
When I have been in the sun for 14 days, I can do things I otherwise		-		-					
cannot	1				3	4.0	5		
Dietary changes can help a person's general condition		1	2	1		3.0	3		
Did not have the patience to wait for the alternative methods to work	1		2	1		2.8	3		
Very dry heat helps my arthritis a lot	1			2	1	3.5	4		
I am not physically active - but I am active with many other things, which				2	1	4.3	4		
keeps me going									
The patient against the bureaucracy (Doctors' authority – they ha			-	-		tientizat	ion (not	t a perso	n, but
just someone in the system)/Powe	eries		rus	-		1.0	F		
Feel that the doctor must "dot the i's" - very bureaucratic It seems odd (I feel stupid) that I must first go through several different		1		1	2	4.0	5		
drugs before I get the biological medication	1			2	1	3.5	4		
I do not like the fact that I have to try different medication before I get									
the biological one	1		1	1	1	3.3	4		
Very difficult to get biological medication	2				2	3.0	3		
	1	1	2						
They wear white coats, - so they must know what they are saying	-					2.3	3		
You can feel like an experimental animal	1	1	1	1		2.3 2.5	3 3		
	1					2.5	3		
You can feel like an experimental animal Some doctors have a personal interest in issuing the medication they say you have to take	1	1	1	1		2.5 2.5	3 3	3.2	3
You can feel like an experimental animal Some doctors have a personal interest in issuing the medication they say you have to take I have received lots of treatments that did not work	1			1 2		2.5 2.5 3.0	3 3 4	3.2	3
You can feel like an experimental animal Some doctors have a personal interest in issuing the medication they say you have to take I have received lots of treatments that did not work I've been lucky, doctors have believed in me	1			1 2 1	3	2.5 2.5 3.0 4.8	3 3 4 5	3.2	3
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A lot of the arthritis pain is difficult to explain 2 1 4.3 4	A lot of the arthritic pain is difficult to explain				2	1	4.3	4		
*Rating - 1: 'Not important at all', 2: 'A little important', 3: 'Somewhat important', 4: 'Very important' and 5: 'Of great importance'.	A lot of the artificts pair is difficult to explain		1		-			· ·		

All statements divided in concepts from the PSORIASIS workshops

	Fre	quer	ncy o	f rat	ing*	State	ement	Con	cept
Statements	1	2	3	4	5	Mean	Median	Mean	Median
Social and psychological proble	ms.	the	sha	me					
				1	4	4.0			
It scares me to show my illness to strangers			1	1		4.8	5		
The shame of skin flaking			1		4	4.6	5		
Self-esteem disappears	2		2		3	4.2	5		
I was terrified to talk to girls (as a teenager)	2		1		2	3.0	3		
It goes beyond my vanity			2	4	-	4.2	5		
Do not want to display it in public			2	1	2	4.0	4		
Ashamed of the impression the illness makes (must shake the sheets after		1			4	4.4	5		
sleeping in the homes of others)			3		2	2.0	2		
It affected me socially			3	1	4	3.8	3		
My nails look like they've been hit with a hammer				1	4	4.8	5		
Do not show it to others (if, for example, I sleep in a hotel room with	1				4	4.2	5	4.0	4
others)	1			2	2	2.0	4		
Hated physical education in school			2	2	2	3.8 3.4	4		
Socially hampered me greatly	1					-	-		
Build barriers to protect myself			1	2	2	3.0	3		
Life before biological treatment $- \rightarrow$ I would not wear t-shirts or shorts	1	2	2	2	2	3.0	3		
Felt like a leper	1	2			2	3.0	2		
Was very modest	1		4			2.6	3		
I have to prepare myself mentally for a few days beforehand if I have to		2		1	2	3.6	4		
show myself/my illness in public			2	2		2.0			
Do not wear t-shirts	1		2	2	-	3.0	3		
You shut yourself in	2		1		1	2.5	2		
Genes, pain, sympto	oms								
It itches all the time	1	1		1	3	4.8	5		
Bleeding wounds - hurts			1	-	3	4.5	5		
The wounds are very painful			1		3	4.5	5		
Painful when wounds cracks			2		3	4.2	4		
Cannot help scratching			2		2	4.0	4		
The nails come loose (very fragile)			2	1	4	4.8	5		
Affects the nails - nails take on another shape				1	4	4.8	5		
Can be hard to sleep due to pain				T	5	5.0	5		
The cracks are very painful			3		1	3.4	3		
Wake up because you feel it all the time			5	2	3	4.6	5		
It's a kind of hell for us			2	1	2	4.0	4		
"don't scratch it" - it's really hard!		2	2	3	2	3.2	4		
I have become thin-skinned		2	2	5	1	3.8	4	3.7	4
The skin cracks if I bend down, - very painful		1	1		1	3.5	4		
Often have difficulty walking and running (bottom of feet crack)		1	T	1	5		5		
Cutting nails f**king hurts	2			1	2	5.0 3.2	4		
	2					-			
Constantly in pain				3	2	4.4	4		
Constant inflammation in the elbows. I chose not to protect myself (due		1	2	1		3.0	3		
to my work) The clothes can be troublesome - feels painful			3	2		2.4	2		
			-			3.4	3		
Itching can become pain			4	1	1	3.2	3		
Burning and stinging underfoot, mostly at night - wake in the night	2		2	2	1	3.8	4		
Outbreaks make eyes sensitive to light	2	1	2	1	2	2.6	3		
I think it has been a serious disability	1	1	L		2	3.3	4		
At the doctor/the doctor kno	ows	my	bod	У					
The doctors must listen to what I say				3	2	4.4	4		
	1	1		3	2	4.4	4	3.7	4
It is a matter of being taken seriously as a person		1		-				0.7	

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There is no understanding that I know my body better - "try to investigate 1 1 2 2 4.2 4 What I think the problem is' 3 2 3.8 4 Stems anonying constantly having to tell the same story again and again 3 2 3.8 4 Hard to relate to "numbers" the doctor uses. 3 1 1 3 1 4.3 4 Pointiced about the fact that no one knew what was wrong with me 3 1 4.3 4 Pointiced about the fact that no one knew what was wrong with me 3 1 1 1 1 3.5 4 Pointiced about the fact that no one knew what was wrong with me 3 1 1.3 3.5 4 North are sing to no idea what was wrong with me and recommended itry all so in the sing to no idea what was wrong with me and recommended itry all so in the sing to no idea what was wrong with me and recommended itry all so in the sing to no idea what was wrong with me and recommended itry all so in the sing to no idea what was wrong with me and recommended itry all in	It is infinitely annoying that doctors focus on numbers and not on what			3		2	3.8	4		
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Friends think it is helping, but it is not - it's f**king annoying when they			1		1	2	4.0	5		
			~	1						
	There's training is built is not it is in king annoying when they									

It looks ugly	1	1			2	3.3	4		
I think it is uncomfortable for others (girlfriend/wife) to hold my hand	2		2	1		2.4	3		
Confronted with my illness everyday	3				1	2.0	1		
Must always explain why you do not have a shot with your coffee		4	1			2.2	2		
Many offer me good advice - know-it-alls	2		3			2.2	3		
No understanding of the limitations caused by the illness (cannot drink a		4	1			2.2	2		
little schnapps) "It's not an illness that can kill you," but that does not alter the illness's									
impact on life	1	1	1	1		2.5	3		
Own attitude/personal pe	erce	ptio	n						
The sooner you accept the illness the better			1	2	1	4.0	4		
The illness controlled my life more before I learned to accept it			2	1	2	4.0	4		
In my teenage years, I always had an answer ready if someone asked	2		2			2.2	2	1	
about the illness	2		3			2.2	3		
Will have to accept the illness	1			1	2	3.8	5		
Depends on the stage of your life when you are diagnosed (how old you		1		2	1	3.8	4		
are) as regards accepting the illness		1		2	-	5.0	4		
You must be careful that it does not take over your life	1		2	1		2.8	3		
I was dressed up in the summer - would not show myself due to the illness	1		2		1	3.0	3		
Will my children also suffer this illness?	1		1		2	3.5	4		
Decided early on that I would not bring children into the world - do not	1		-		2	5.5			
want them to experience the same thing			4		1	3.3	3		
When you reach the stage of daring to expose yourself, then you have			2	1	2	4.0	4		
won a battle			2	2		2 5	4		
I believe you have to be honest and speak about it I have decided that it is not my problem what others think	1		2	2	1	3.5 3.5	4	3.2	3
I don't want to hear about my "oatmeal"	1	1		1	1	3.0	3		
I don't want to hear that it is contagious or it's disgusting	1	1		1	1	3.0	3		
I told my friends that I do not want to constantly hear about the illness	2	1		1	1	2.8	3		
I won't cover myself up - if they want, they can just ask me	3			1	1	2.0	1		
It would be fine if my psoriasis remains stable - I can live with itching	5	2			3	3.8	5		
You learn to live with it		2	1		2	3.4	3		
Only learned to accept the illness at the age of 40		-	2	1	2	4.0	4		
Men are not as meticulous as women as regards appearance			3	1	2	3.3	3	-	
You cannot be cured of the illness		2	Ŭ	1	2	3.6	4		
"To be looked at and touched is very nice"	1	-	1	2		3.0	4		
I have to vacuum constantly (white flakes over everything)	2		2	-		2.0	2		
"Kids thought I had burned myself in a fire"	3		-		1	2.0	1		
I have never experienced itching	3		1			1.5	1		
Nivea cream can combat the worst dryness	1	4				1.8	2		
The impact of the illness/the	illn	ess	itse	lf					
There were jobs that I did not get because of my illness (was turned down			1						
by the Military - could not wear a helmet because I had psoriasis)			1		3	4.5	5		
People really focused on my hands (due to the illness) as regards my job		1		1	2	4.0	5		
(working with people)					-				
Jobs don't grow on trees (especially with illness)		2	1	2		3.0	3		
Absenteeism for treatment can be a problem	-	2	1	2		3.0	3		
My illness has prevented me from taking some jobs	1	1	1		1	2.8	3		
Psoriasis is triggered by stress	-	2	2	1	2	4.0	4		
I cannot tolerate alcohol - the illness flares up	2	2	2	1	2	2.8	3		
Stress can trigger the symptoms	2		1		2	3.0	3		
I think that psoriasis can be controlled through diet	1	2	3	<u> </u>	n	2.5	3		
It is a lifelong treatment - it limits the joy when it works Due to large patches on my buttocks, it was hard to sit on the bus etc.		2		2	3	3.8 4.5	5 5		
Can I move to Aarhus and get my medication there?	1	-	1	2	2	4.5 3.3	4		
You must always take the medication	1	1	1	-	1	2.8	3		
Tou must always take the medication	-	1 -	1 -	I	-	2.0	5	1	

When planning holidays, it must be taken into account when the medication must be taken etc.	1	1	1	1		2.5	3	
It is too difficult to bring the medication on vacation - we plan our vacation on that basis	1	1	1	1		2.5	3	
I would like to get a tattoo - but do not dare - imagine it caused the illness to come back	1		3			2.5	3	
I think about my illness, since it requires logistics (must be retrieved, brought along, etc.)	1	1	1	1		2.5	3	
I cannot just leave on my boat for long periods, because I must have the treatment	2		3			2.2	3	
*Rating - 1: 'Not important at all', 2: 'A little important', 3: 'Somewhat important', 4: 'Very important' and 5: 'Of great importance'.								