SUPPLEMENTARY MATERIAL

TITLE:

A cross-sectional concept elicitation study to understand the impact of herpes zoster on patients' health-related quality of life

Authors details:

Desirée Van Oorschot MS¹, Ashleigh McGirr PhD MPH², Philibert Goulet MFin³,
Patricia Koochaki PhD⁴, Ramya Pratiwadi MS⁵, Selam Shah MPH⁶, Desmond Curran
PhD¹

¹GSK, Wavre, Belgium

²GSK, Mississauga, Canada

³Former affiliation: GSK, Wavre, Belgium. Current affiliation: Incyte, Morges,

Switzerland

⁴Mapi Group, Health Research and Commercialization ICON plc, Cincinnati, Ohio, USA

⁵ICON plc, San Francisco, California, USA

⁶ICON plc, Boston, Massachusetts, USA

Corresponding author

Desirée Van Oorschot

GSK, Wavre, Belgium

Email: desiree.x.van-oorschot@gsk.com

Tel: +32 10 85 5111

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Participant ID:	
Date & Time:	
Interviewer Initials:	

[Prior to starting the audio recording]

- On behalf of our sponsor, GlaxoSmithKline, and ICON study team, thank you for taking the time to speak with me today.
- You have been asked to participate in this interview because you have been diagnosed with shingles. We are conducting these interviews in order to learn more about your experience with this condition and any impacts that it may have had on your life and ability to function.
- We would like for this to be a fluid conversation driven by your personal experience with shingles, but I do have some questions prepared that may help guide our conversation. The interview should last about an hour, and you will receive \$150 for your participation in the form of a general gift card (i.e. not specific to any store or vendor) that will be mailed to you following the interview. You will receive an additional \$25 for providing confirmation of diagnosis from your physician.
- All of the information you provide will be used for the purpose of this research study only. You do not have to answer any questions you don't feel comfortable answering, and you may stop the interview at any time. We are interested in your thoughts and opinions so there are no right or wrong answers.
- I would also like to let you know that I am a research professional, not a medical doctor, so I am not able to answer any questions related to your condition or treatment. Do you have any questions about the interview procedures before we get started?
- With your permission, I will be audio-recording this interview to make sure we capture all of your comments and feedback. Later, we'll transcribe the interview, so that we can closely review your responses later. We will not use your name on the transcripts or on any documents or reports. Instead, we will use an ID number to identify you in order to protect your confidentiality.
- Do you have any questions before we begin?
- Do I have your permission to audio-record the interview?

[If NO]

As part of the study, we are required to audio-record the interviews so that we can carefully review the responses at a later time. If you do not agree to be audio-recorded, you will not be able to participate in this study. We will protect your confidentiality by not associating your name with any of your comments. Do you agree to be audio-recorded? [If participant declines to be audio-recorded, thank the participant for their time and terminate interview.]

[If YES]

Thank you. Now I will turn on the audio-recorders. I'll be using two recorders just in case of any technical problems. First, I will say the name of the study, followed by the date and then your participant ID number. I will not say your name on the recording to protect your confidentiality. Then I will ask you to again confirm that I have your permission to record the interview.

[Interviewer - Turn on recorder]

INTRODUCTION

- This is study 0018-0873. Today's date is [date], and I am interviewing participant ID [ID number].
- Can you please confirm that you agree to have this interview audio recorded?
- [Pause for response; continue only if "YES"]
- Can you please confirm that you have reviewed the informed consent form and consent to participating in this interview?
- [Pause for response; continue only if "YES"]
- Thank you very much, we can now begin the interview.

1. BACKGROUND

QUESTIONS	NOTES
Let's start with a quick creative exercise to begin	Words/phrases:
our conversation.	
1. Can you tell me some words or phrases	1
that come to mind that best describe what	
it is like to experience shingles?	2
[Jot down each word or phrase mentioned].	3
2. So you mentioned, "[#1 word/phrase]", in a few words can you tell me why this	4
describes your shingles experience?	5

2. SYMPTOMS

QUESTIONS	NOTES
Now that we've gotten a sense of your shingles experience,	Symptoms/complications experienced leading to diagnosis:
let's start from the beginning by briefly talking about your	•
diagnosis.	•
3. What led you to seek medical attention ("go see the	•
doctor")?	•
a. Can you describe what you were experiencing?	•
(i.e. what symptoms did you have at the time?)	
4. What kind of treatment were you prescribed?	Improvements/changes in symptoms after treatment:
a. What improvement/changes did you experience	•
in your symptoms?	•
b. How quickly did these improvements/changes	•
occur?	•
	•

 5. Can you tell me about the symptoms you're experiencing now? [Listen specifically for pain and how participant experiences or describes this pain]. a. How often do you experience [symptom]? b. How long does [symptom] last? c. Do you always experience [symptom] the same way? d. [For PHN patients only]: How have these symptoms changed over time? [Probe for acute phase of shingles, and experience of change since then]. 	
6. What symptom(s) bother you the most? Can you tell me why these are the most bothersome?	Most Bothersome Symptoms: • • • • • • •
7. To end this section, I would you like to ask: During your experience with shingles, what has been your worst pain level on a score of 0 to 10, where 10 represents the worst pain severity and 0 represents no	

pain.		
Dalli.		

3. IMPACTS

QUESTIONS	NOTES
Now I'd like to talk to you about your shingles and how the	Spontaneously reported impacts:
symptoms have affected your life.	•
8. Can you please walk me through a typical day since	•
having shingles and describe how shingles has affected	•
your usual activities, i.e. things you would normally do	•
on a day-to-day or weekly basis?	•
a. Are there things you are unable to do because of	•
your shingles?	
b. [For PHN patients only]: How has this changed	
over time? [Probe for acute phase of shingles, and	
experience of change since then in terms of things	
they were unable to do during their experience with	
PHN]	
[Allow participant to spontaneously report impacts, jotting down key	
words/areas to probe on later if more detail is needed.]	

9. What would you say are the main ways in which shingles		Spontaneously reported areas of impact (check off if applicable):
	has affected or impacted your life?	☐ Physical functioning
	a. [For PHN patients only]: How has this changed	☐ Activities of daily living
	over time?	□ Sleep
		□ Social functioning and relationships
	[Check off the box if participant spontaneously confirms	☐ Emotional functioning
	experiencing this impact. Will probe areas not mentioned in next	□ Work/career
	question].	☐ Pain/disease management

10. You've talked about a few areas of your life that have been impacted by shingles, such as *[list aspects mentioned above]*.

[For each area from spontaneous list above:]

- a. Can you tell me more about each of these areas?
- b. [For PHN patients only]: How has this changed over time?

[Where patients have not spontaneously mentioned certain areas, please use the questions below to probe for impacts]:

I have a few more questions about areas of impact that you have not yet mentioned. Since you were diagnosed:

- c. [Physical Functioning]: How well have you been able to function physically in your day-to-day life?
 - Do you have any difficulty walking short distances, using stairs, sitting/laying down, standing up?
 - ii. Do you have any difficulty with more rigorous physical activities, such as running or walking long distances, or playing sports?

- d. [Activities of Daily Living]: How well have you been able to function in your activities of daily living?
 - i. Is there any change in your ability to perform basic self-care, such as showering or getting dressed?
 - ii. Is there any change in your ability to do household chores or errands, such as cleaning or shopping for groceries?
- e. [Sleep]: Have there been any changes in your sleep pattern?
 - i. Have you had difficulties falling or staying asleep?
 - ii. Have you felt tired during the day because of lack of sleep due to shingles?

- f. [Social functioning/relationships]: Have there been any changes in your social life?
 - i. How have your relationships with friends and family been?
 - ii. Have you been able to keep up with your hobbies?
- g. [Emotional functioning]: And how have you been doing emotionally? Have there been any changes?
 - i. Have you experienced feelings of frustration, sadness, rage, worry, depression, isolation, etc.?
- h. [Work/career]: Has having shingles had any impact on your work or career?
 - i. Have you experienced a change in your ability to go to work, be productive or concentrate?
 - ii. Have there been changes in your ability to plan for your career and opportunities in the long term?
 - iii. Has there been a financial impact associated with having shingles?

i. [Pain/disease management]: Have you experienced an increase in time or finances spent on pain medication or pain management as a result of having shingles?	
 j. [Vaccination]: Would you consider a vaccination to prevent Shingles from happening in the future? i. If yes: i. Probe for more information about why ii. If no: i. Probe for more information about why not. 	
Ranking Exercise: Now that we've discussed the various areas and aspects of your life that have been impacted by shingles, I'd like to do a quick ranking exercise.	Ranking of Impacts: 1 2
11. Can you rank the top 3 to 5 areas that have been most impacted because of shingles? Afterwards, I'd like for you to walk me through why you chose to rank them in this order.	3.

12. Your answer may or may not be the same as the #1 choice of the ranking exercise, so I'd like to ask: what is the most difficult part about having shingles?	
13. Are there any other aspects of shingles that affects/has affected you that we haven't discussed yet?	

4. WRAP-UP

QUESTIONS	NOTES
14. We have completed all of the interview questions. Is	
there anything else you would like to share with me	
about your experience with shingles?	

Final comments:

Thank you for taking the time to participate in this study. I will now turn the audio recorder off. [Interviewer to turn audio recorder off]

Before we finish, I have a few final descriptive questions to ask you about your age, gender etc., that will be combined with answers from all our other participants so we can describe the overall group who took part in this study. [Interviewer to use the sociodemographic form to record participants' answers]

Fig. S1. MEDLINE and PsycINFO search PRISMA diagram

HZ, herpes zoster

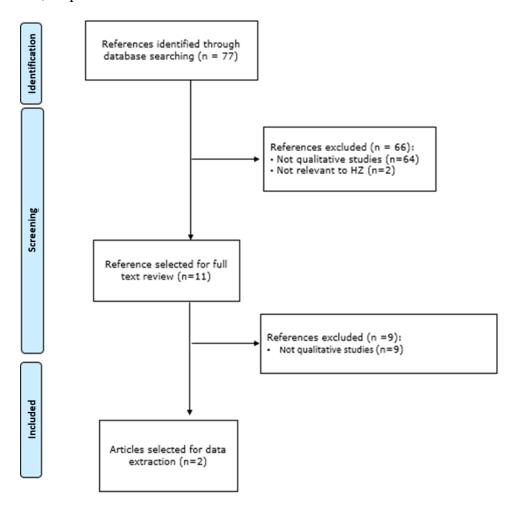


Fig. S2. MEDLINE/Embase search PRISMA diagram

HZ, herpes zoster; PRO, patient-reported outcome

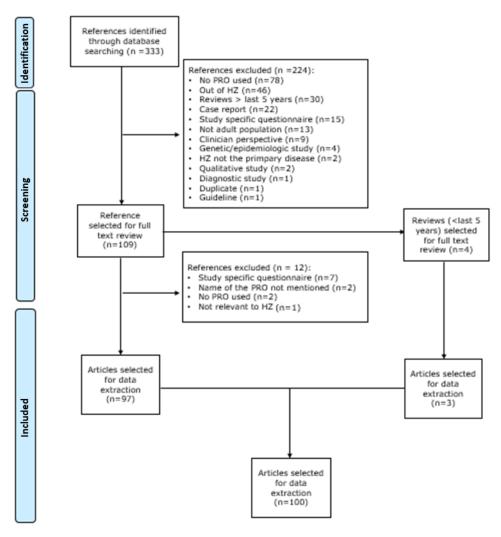


Fig. S3. Draft conceptual model

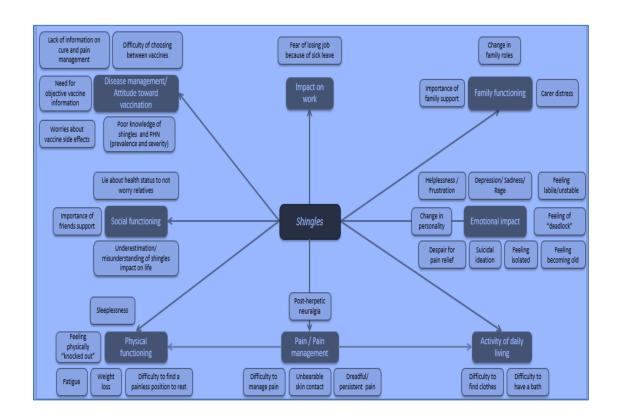


Fig. S4. Patient descriptions of rash

F, female; HZ, herpes zoster; M, male; PHN, postherpetic neuralgia. Group A1, HZ 7–30 days post diagnosis; Group A2, HZ 31–60 days post diagnosis; Group B, PHN *words and/or phrases only reported by 1 patient not included

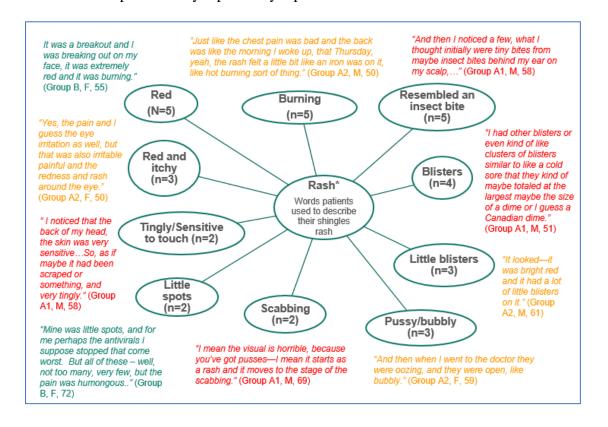


Table S1. Patient characteristics

	Group A1: HZ 7-30 (n=8)	Group A2: HZ 31-60 (n=10)	Group B: PHN 90-365 (n=14)	Total (N=32)
Sex				
Male	1 (13%)	6 (60%)	2 (17%)	9 (28%)
Female	7 (88%)	4 (40%)	12 (86%)	23 (72%)
Race				
White, Caucasian	8 (100%)	10 (100%)	12 (86%)	30 (94%)
Other	-	-	1 (7%)	1 (3%)
Hispanic or Latin American	-	-	1 (7%)	1 (3%)
Marital Status				
Single	2 (25%)	1 (10%)	3 (21%)	6 (19%)
Common-law relationship	-	-	1 (7%)	1 (3%)
Married	4 (50%)	8 (80%)	4 (29%)	16 (50%)
Divorced/separated	2 (25%)	1 (10%)	4 (29%)	7 (22%)
Widowed	-	-	2 (14%)	2 (6%)
Age				
50-60 years	3 (38%)	5 (50%)	9 (64%)	17 (53%)
61-70 years	5 (63%)	4 (40%)	-	9 (28%)
71-80 years	-	1 (10%)	4 (29%)	5 (16%)
80-90 years	-	-	1 (7%)	1 (3%)

Note: HZ, herpes zoster; PHN, postherpetic neuralgia

Table S2. Health-related quality of life (HRQoL) impacts of HZ/PHN reported, by group

Impact	Spontaneously Reported Reported post- reported overall acute phase			Illustrative quotation(s) (group, gender, age in years)
Emotional func	tioning			
Group A1 (n=8)	7 (88%)	8 (100%)	-	"Oh, with the acute phase gone it's better now but I'm still living in fear if
Group A2 (n=10)	8 (80%)	10 (100%)	-	it's going to come back. I think that's the worst part, that fear and not paranoia—well it is I guess a type of paranoia thinking it might come
Group B (n=14)	12 (86%)	13 (93%)	1 (7%)	back so that robs you of your innocence, so to speak. I know it sounds weird to say innocence but it makes you—it still sometimes, even when I move it, it's there but it's not as bad as it was but it still haunts me because it can come back. That's the thing there's no really—I don't know, because I've never really experienced this before so I guess it's the fear of the return, how I'll cope with it or will it go away or will it be worse or better." (Group B, F, 56)
				"I was afraid to let people see it, so I would make sure—like I said, we have a trailer and I avoided going in the pool. I avoided exposing it because I was afraid of people's reactions. It really changed, I wouldn't go to the pool and I made sure that I was always covered up so people wouldn't get freaked out. So it prevented me only in regards to other people's reaction. Yeah, that was my worry, if it changed it was because I was afraid how other people would react if they saw it, so I just stopped doing things that I needed to expose my back. I know it sounds odd, why are you exposing your back, but at the trailer park in the summertime everybody is walking around in bathing suits or stuff, right. So in that area it changed, it changed the way I presented myself to the public, that's what changed." (Group B, F, 55)

Impact	Spontaneously reported	Reported overall	Reported post- acute phase	Illustrative quotation(s) (group, gender, age in years)
				"Yes, I was frustrated and sad. You know, it was a why me, you know, what did I do and how did I get this? I mean, it brought me right to the vaccination every time. You know, there are more the sadness that I didn't get that vaccination because I would have avoided that pain. You know where I'm going? That is it. Yeah, you feel all those feelings. I felt all those feelings." (Group B, F, 73)
ADL a				
Group A1 (n=8)	7 (88%)	8 (100%)	-	"Well, just combing my hair, brushing my hair on that one side, like it
Group A2 (n=10)	6 (60%)	9 (90%)		hurts to touch the brush on my head, it hurts for like when you're brushing and your hair kind of pulls a little bit? That hurts, too. Like this
Group B (n=14)	11 (79%)	14 (100%)	3 (21%)	hurts to brush my hair." (Group A1, F, 61)
				"Well, I remember cleaning the house and I was completely exhausted. I'm somebody who goes to the gym regularly and works out, exercise, couldn't do any of that. Yeah, I couldn't do a lot around the house, sometimes I think my husband—I mean I would try to cook dinner, but I think sometimes he would try to help me by stepping in and doing it certain nights." (Group A2, F, 59)
				"Getting dressed was—the first week getting dressed was a torture, putting a shirt on was a torture. So, what I did was I wore big shirts, you know what I mean?" (Group A2, M, 61)
				"I had to get a friend to come over and my kids were helpful with that because vacuuming or picking up items were very difficult. That was hard

Impact	1 0 1		Reported post- acute phase	Illustrative quotation(s) (group, gender, age in years)
				to do because if you can imagine when you stretch out unfortunately your back does hurt." (Group B, F, 56)
Sleep				
Group A1 (n=8)	7 (88%)	7 (88%)	-	"Well, I was able to fall asleep up until two days ago, when I'm lying
Group A2 (n=10)	5 (50%)	8 (80%)	-	awake there with this itching and everything going on, and having to get up and put aloe on and put that other stuff that I said. Finally I guess at
Group B (n=14)	8 (57%)	14 (100%)	2 (14%)	around 1:30 I fell asleep, probably I tried to just ignore it as best I could." (Group A1, F, 69)
				"I go down to sleep, and four hours. After four hours, I wake up. I wake up, and it's very difficult to go back to sleep. And then, what I need to do is get out of the bed, because it's better to get out of the bed, read, come to the living room, read, use the computer, do something, and then after 2-3 hours after that activity at night, I go back to bed, and I can sleep again during the morning another three hours. Which is terrible for a person that could be working." (Group B, F, 72)
Physical functioning				
Group A1 (n=8)	7 (88%)	7 (88%)	-	"With the taking stairs, again, it was awkward, because I was trying not
Group A2 (n=10)	3 (30%)	6 (60%)	-	to have my clothes touch my skin. [laughs] So, I'd kind of like hunch over to let the clothes hang off me kind of thing." (Group A2, M, 51)
Group B (n=14)	7 (50%)	12 (86%)	4 (29%)	"I like to go for walks and I might be able to manage a half an hour or something like that, but certainly nothing compared to how I like to walk briskly, hikes and things like that, I just couldn't. So I really felt like it

Impact	Spontaneously Reported Reported post- reported overall acute phase			Illustrative quotation(s) (group, gender, age in years)
				took away just my enjoyment of just little day to day activities, I just couldn't participate in them. (Group A2, F, 59)
				"Oh, no, forget about exercising. I mean I could walk a little bit around but to actually do any exercise at a gym like I like to go spinning and stuff like that, I could not do that. The spinning really was very—it was anything to do with using your back muscles you just felt like a soldier the way you had to stand to avoid any pain. That I didn't want to do to invoke that. Anything to keep that pain away was the goal." (Group B, F, 56)
				"Now, it's like I'm moving more slowly, I have way less energy, I don't have—like I haven't gone—I've gone to the gym maybe twice of having shingles, maybe three times, I just don't have the energy. I'll do yoga at home or whatever, but it's like I don't have that level of energy yet—not yet." (Group B, F, 50)
Hobbies				
Group A1 (n=8)	3 (38%)	5 (63%)	-	"No, I'm not going back to the gym. That was a good hobby for me. I
Group A2 (n=10)	2 (20%)	5 (50%)	-	was doing it five times a week. They said every day, I used to check myself, I would say go every day and I would average five times a week."
Group B (n=14)	5 (36%)	11 (79%)	2 (14%)	$(Group\ B,\ M,\ 53)$
Social functioning ^b				
Group A1 (n=8)	3 (38%)	5 (63%)	-	

Impact	Spontaneously reported			Illustrative quotation(s) (group, gender, age in years)
Group A2 (n=10)	7 (70%)	8 (80%)	-	"Probably in the short-term with my husband because I was training crazy hours, so I didn't see him even during the training. And then I got
Group B (n=14)	5 (36%)	7 (50%)	-	the shingles and I was sleeping in a spare room for about three weeks just because I just didn't want the risk of getting accidentally knocked by him. So I did isolate myself and like I said, I just said no, don't touch me, told him don't touch me. So I guess, yeah, in the short-term it did. With friends, yeah, I mean I was still in contact with them texting and things like that, but in terms of seeing them curtailed my social life obviously." (Group A2, F, 59)
				"Well, like I just said, it isolated me. I told a couple of my close friends on the phone, and I didn't go around anybody—I cancelled any social events because of it." (Group B, F, 59)
Work/career				
Group A1 (n=8)	1 (13%)	1 (13%)	-	"Yes, I had to take two days off, I just couldn't function. I wasn't there, I
Group A2 (n=10)	3 (30%)	4 (40%)	-	knew that I couldn't and for me to be at work is to me it's meaning presentations to be able to deliver results sometimes very quickly. And I
Group B (n=14)	5 (36%)	7 (50%)	-	knew I couldn't, so I did make a decision that I'm not going to go work, but essentially that meant for me kind of step away from some of the responsibilities and maybe not being involved in some of the projects that were coming up, some were smaller, some were a little bit bigger, but it did disappoint me, it did bother me to have to step back like that." (Group A2, F, 50)
				"Oh, definitely there was things I wasn't able to do. I had to take time off work so that I wasn't at work because I couldn't really work. Anytime I

Impact	Spontaneously reported	Reported overall	Reported post- acute phase	Illustrative quotation(s) (group, gender, age in years)			
				tried to move or repositionI wanted to work because it would help me forget but at the same time it took my breath away to have that pain and not really knowing how to manage it. It took my breath away to work so I didn't work because it was too tough to manage the day to day activities of my job." (Group B, F, 56)			
Cognitive functioning ^c							
Group A1 (n=8)	-	-	-	"I just couldn't concentrate, I bought some wool and thought, okay, I'll			
Group A2 (n=10)	3 (30%)	6 (60%)	-	knit something, but I just found my concentration wasn't there. I couldn't seem to focus too long on anything." (Group A2, F, 59)			
Group B (n=14)	3 (21%)	3 (21%)	-				
Financial			-				
Group A1 (n=8)	-	3 (38%)	-	"Well, yes, but because knock on wood we are able to pay for it – that's			
Group A2 (n=10)	1 (10%)	3 (30%)	-	another thing I thought about. All these poor people out there that can't. I think oh, my God, what would that be like? Yeah, it's very			
Group B (n=14)	-	3 (21%)	1 (7%)	expensive. I think we're into this thing now for about \$2,000." (Group A1, F, 69)			
Appetite/diet ^d							
Group A1 (n=8)	2 (25%)	2 (25%)	-	"It did, yeah, it did affect my diet. Like I started to eat way more junk			
Group A2 (n=10)	1 (10%)	2 (20%)	-	food because I just – like I said you just want to take it easy with everything, so it's oh, yeah, that would taste good, so[laughs] A lot			
Group B (n=14)	1 (7%)	1 (7%)	-	less self-disciplined. About food, about everything." (Group A2, M, 63)			
Impairment due to rash site ^e	;						

Impact	Spontaneously reported	Reported overall	Reported post- acute phase	Illustrative quotation(s) (group, gender, age in years)
Group A1 (n=8)	-	-	-	"I had some visual problems and it was, the rash came out and was right
Group A2 (n=10)	-	-	-	down in through my eye, my right eye, and then across to my ear." (Group B, F, 78)
Group B (n=14)	1 (7%)	1 (7%)		

Note: F, female; M, male

^a ADL (activities of daily living) includes self-care, activities inside and outside the home, driving, etc., ^b includes social isolation; ^c includes concentration, memory, etc., ^d includes weight gain and loss; ^e includes hearing loss from ear rash, visual problems from rash at eye

Table S3. Domains of quality of life most affected by HZ/PHN

1st most impacted domain		2nd most impacted domain ^c		3rd most impacted do			4th most impacted domain ^c		5th most impacted domain ^c	
Pain	9 (28%)	Physical functioning ^b	8 (25%)	Social functioning a	5 (16%)	Social functioning a	3 (9%)	Frustration with modern medicine	1 (7%)	
Social functioning ^a	6 (19%)	Social functioning ^a	4 (13%)	Fatigue	2 (6%)	Emotional impacts	2 (6%)	-		
Fatigue	5 (16%)	Pain	4 (13%)	Pain	2 (6%)	Sleep	1 (3%)	-		
Physical functioning ^b	2 (6%)	Emotional functioning	4 (13%)	Physical functioning b	3 (9%)	Pain	1 (3%)	-		
Emotional functioning	3 (9%)	Contagiousnes s	2 (6%)	Sleep	3 (9%)	Itchiness	1 (3%)	-		
Grooming	1 (3%)	Unpredictabilit y	2 (6%)	General wellbeing	1 (3%)	Loss of faith in doctors	1 (3%)	-		
Sleep	1 (3%)	Sleep	1 (3%)	Itchiness	1 (3%)	Having to pace themselves	1 (3%)	-		
Contagiousnes s	(3%)	Clothing restrictions	1 (3%)	Emotional functioning	1 (3%)	General well-being	1 (3%)	-		

1st most impacted domain		2nd most impacted domain ^c	3rd most impacted domain ^c	4th most impacted domain ^c	5th most impacted domain ^c
Financial impacts	1 (3%)	More 1 (3% proactive) Work/career 1 (3%)	Financial 1 (3%) impacts	-
HRQoL impacts	1 (3%)	Hygiene 1 (3%) Financial 1 (3%) impact	-	-
Work/career	1 (3%)	Wormy feeling 1 (3%	Numbness 1 (3%) and tingling	-	-
Rash/lesions	1 (3%)	Itchiness 1 (3%) -	-	-

Note: HRQoL, health-related quality of life; HZ, herpes zoster; PHN, postherpetic neuralgia'

 $[^]a$ includes social isolation, social interactions, and family and/or relationship impacts, etc; b includes hobbies, mobility, and recovery time; c not all patients provided responses