

Online Resource 2 Methods used by caregivers to determine whether a patient with Alagille syndrome is itching

Method ($N = 20$) ^a	Exemplary quotes
Evidence of skin damage	(F-01-P-01-01) Like you don't see her, you, she's, like constantly scratching that to me is severe
$n = 6$ (30.0 %)	already... Yeah, constantly, like that be like the other day we see her like she's like have blood, like
<i>Age categories</i>	know, like you know. And then there are time when she was younger, like we'd see blood on the
0–2 years: $n = 4$ (20.0 %)	sheets because she's scratching and that is all over the sheets and then those are like, to me, is very
3–5 years: $n = 0$	severe.
6–8 years: $n = 1$ (5.0 %)	(F-02-P-01-13) ...because her skin is dark where you can see the – M: Ash. A: the ash marks –
9–11 years: $n = 0$	...they're really dry... I mean, you'll see cuts and you'll ask how it happened, "Uh, I don't know."
≥ 12 years: $n = 1$ (5.0 %)	You see, uh, even sometimes the bruising, because she would rub so hard she would bruise, um, not
	so much the bruising... M: Ask you, you to scratch. A: Yeah, ask us to scratch, um, you know, now
	that she's older she's always going into the Band-Aid drawer, right – ... "Oh, I just need a Band-Aid,
	just need a Band-Aid"... So yeah, that's, those are the tell-tale signs. Q: <i>Okay, and the Band-Aid,</i>
	<i>what does that do?</i> M: For the blood, where she got a cut, she puts a Band-Aid on top of it.

Method (N = 20) ^a	Exemplary quotes
Child reported n = 7 (35.0 %)	(F-08-P-01-04) Uh, She doesn't wear certain types of shoes because she says her ankle hurts... And that is when she tells me... It just depends on what she is wearing. So she pre... She'll tell you she prefers not to wear skirts because she tells me they itch her...If she wakes up in the morning and constantly repeats herself almost to like get our attention whether it be itch me, itch me, itch me or um, I'm itchy, Daddy I'm sleepy, whatever. And if it's just repetitive, that's when you know you are in for a bad day. Because she can't stop. Q: <i>And do you rely a lot on her telling you?</i> A: Now at this stage yes, because she is old enough to tell us.
<i>Age categories</i> 0–2 years: n = 0 3–5 years: n = 4 (20.0 %)	
6–8 years: n = 1 (5.0 %)	
9–11 years: n = 1 (5.0 %)	
≥12 years: n = 1 (5.0 %)	(F-40-P-01-09) ...it starts off with, Mommy, scratch my back and, you know, no, no, no, not there. To the left, to the left. Come on, hurry up, please. I'm itchy...
Sleep problems n = 5 (25.0 %)	(F-30-P-01-10 MONTHS) Q: <i>And just to ask you, um, again – how do you know that – that your child's, um, itching or scratching is worse at night?</i> A: Um, just because it really interrupted his sleeping. And now that he's on the Atarax and – on top of the rifampin, he's sleeping soundly at night – soundly and waking up way more refreshed and more energized than he has, mm, the many
<i>Age categories</i> 0–2 years: n = 3 (15.0 %)	

Method ($N = 20$) ^a	Exemplary quotes
3–5 years: $n = 2$ (10.0 %)	months, so. <i>Q: And when you say it – it interr— uh, interrupted his sleeping, what do you mean by that?</i>
6–8 years: $n = 0$	<i>A: Woke him up, um, every 2 hours, sometimes every 3 hours. And then, if he wasn't – if his</i>
9–11 years: $n = 0$	<i>medicine wasn't increased right away, uh, it also interfered with his naps. He would wake from his</i>
≥ 12 : $n = 0$	<i>nap and wouldn't be able to go back down for a nap by himself, because it's bright out, so he thinks</i> <i>it's time to be awake. But if he was woken up, he couldn't settle by himself. He needed like a parent</i> <i>to do it for him.</i>
	(F-50-P-02-04) When she has trouble sleeping – when, um, uh – she causes herself to – to have scratches, um, when she picks at the scratches that's already there... When she whines, complains in general – not in the best of moods.
Other reporter	(F-01-P-01-01) I would ask my, whoever the caregiver for that day. You know, like my husband,
$n = 3$ (15.0 %)	then I'd just ask him, hey, you know, did you see her scratch or like you know, how bad it is and
<i>Age categories</i>	where did she scratch? Did she have, did she have bleed uh, you know? I'll ask him like, I think as
0–2 years: $n = 1$ (5.0 %)	the caregiver.

Method ($N = 20$) ^a	Exemplary quotes
3–5 years: $n = 2$ (10.0 %)	(F-08-P-01-04) I mean the nanny tells me my child had the itches, I mean everyone gets it by the
6–8 years: $n = 0$	itches
9–11 years: $n = 0$	(F-50-P-02-04) So, there's a good part of the day that I don't see her... but I still get to hear from the
≥ 12 years: $n = 0$	teachers and from her, herself, so it's – so, I think – so, it – it doesn't always on – based on what you saw.

^aFour families each included two caregivers; concepts that were reported by both caregivers of a patient were counted once to avoid inflation of the result