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**Table SI. Other: specified monthly out-of-pocket costs for health aspects.**

Other aspects:	n=19	Expenses
Nutritional supplements	5	100€, 80€, 50€, 20€, 15€
Make-up (partially permanent)	4	42€, 40€, 11€, 3€
Products for wigs (adhesive tapes)	4	84€, 23€, 20€, 20€
Homeopathy	4	300€, 200€, 80€, 20€
Caps	1	50€
Hairdresser	1	70€

**Table SII. Specified monthly out-of-pocket costs for health aspects.**

Other aspects:	n=31	Extra expenses (relative to expenses of areas of daily life)
Wig	8	100%, 100%, 100%, 50%, 30%, 10%, 10%, 10%
Nutritional supplements	8	200%, 90%, 60%, 50%, 25%, 20%, 10%, 5%
Medication	5	50%, 25%, 20%, 10%, 5%
Towels	3	10%, 5%, 5%
Make-up	2	70%, 5%
Headwear	2	100%, 1%
Activities	1	15%
Alternative practitioner	1	15%
Hairdresser	1	10%
Hair tinting	1	0.1%

**Table SIII. Mean and median monthly out of pocket expenses in € by type of treatment.**

Monthly out-of-pocket costs in €		Treatment by dermatologist	Treatment by GP	Treatment by naturopath	No treatment	Overall
		n=59	n=15	n=17	n=255	n=346
Hair care products and emollient	Mean (SD)	25.4 (39.1)	20.4 (20.2)	20.6 (17.8)	8.9 (14.8)	13.0 (22.2)
	Median (IQR)	15.0 (16.0)	20.0 (37.0)	20.0 (20.0)	0.0 (10.0)	5.0 (20.0)
Hair replacement products	Mean (SD)	42.8 (57.9)	25.0 (36.6)	37.9 (47.3)	38.3 (62.2)	38.4 (59.8)
	Median (IQR)	20.0 (60.0)	0.0 (50.0)	40.0 (50.0)	0.0 (50.0)	10.0 (50.0)
Medication	Mean (SD)	26.6 (32.2)	39.9 (48.9)	53.2 (80.4)	8.8 (22.2)	15.3 (32.9)
	Median (IQR)	20.0 (27.5)	25.0 (43.0)	30.0 (45.0)	0.0 (10.0)	2.0 (20.0)
Doctor/hospital care (consultations)	Mean (SD)	38.3 (71.2)	62.3 (134.0)	70.0 (75.2)	7.4 (30.8)	18.1 (53.9)
	Median (IQR)	0.0 (50.0)	0.0 (62.5)	50.0 (100.0)	0.0 (0.0)	2.0 (5.0)
Travel expenses	Mean (SD)	21.3 (45.5)	8.0 (25.7)	34.7 (85.1)	5.8 (25.3)	9.9 (35.3)
	Median (IQR)	0.0 (17.5)	0.0 (0.0)	0.0 (20.0)	0.0 (0.0)	0.0 (0.0)
In-patient treatment	Mean (SD)	1.4 (7.5)	22.0 (72.5)	0.0 (0.0)	0.8 (7.4)	1.8 (16.8)
	Median (IQR)	0.0 (0.0)	0.0 (0.0)	0.0 (0.0)	0.0 (0.0)	0.0 (0.0)
Other	Mean (SD)	15.4 (58.4)	6.0 (18.4)	10.0 (28.3)	5.2 (35.2)	7.2 (39.4)
	Median (IQR)	0.0 (0.0)	0.0 (0.0)	0.0 (0.0)	0.0 (0.0)	0.0 (0.0)
<b>Total</b>	Mean (SD)	<b>171.0</b> (145.0)	<b>184.0</b> (197.0)	<b>226.0</b> (166.0)	<b>75.2</b> (103.0)	<b>104.0</b> (129.0)
	Median (IQR)	<b>120.0</b> (218.0)	<b>115.0</b> (201.0)	<b>170.0</b> (180.0)	<b>32.0</b> (100.0)	<b>51.0</b> (144.0)

**Table SIV. Selected responses to open-ended questions regarding the current treatment.**

Question	Response categories	Examples
Why are you not seeing a doctor? (asked when receiving alternative treatment)	No doctor could help me/No long-term success	"I am currently trying my hand at alternative healing. I drink barley grass every day. Doctors have given up on me and that is why I have turned away from them" (20-F)
		"It is all for nothing" (19-F) "None of it worked" (26-F)
	Doctors: psychological condition	"Doctors said the condition was only psychological" (25-F)
	Cortisone therapy	"No more, because the cortisone application, which has not helped, only harmed" (58-F)
		"Because there is treatment only with cortisone, and with that I don't want to harm my body even more" (58-F)
	Alternative, holistic medicine helped	"Dermatologists have not suggested any treatment solutions that I think would have done anything. Conventional medicine has no solutions that would not put too much stress on my body. It does not see the real problem of the autoimmune process. There is the naturopathy with the holistic paragraph better positioned. I have after 3 years AA universalis now for 1 year again almost complete hair growth after holistic treatment with chelation therapy and bioresonance targeted against chronic inflammation, allergies, etc" (40-F)
Why are you not under treatment? (asked when not	No successful therapy available, gave up (152)	"Out of hopelessness as far as treatment is concerned" (33-F)
		"Tried everything and gave up" (65-F)
		"No desire, too little chance of success" (28-M)

receiving current treatment) (n)		<p>“I have learned to live with it. All treatments that might help are too uncertain for me and I don't want to get my hopes up unnecessarily” (26-F)</p>
		<p>“There is no cure for Alopecia Areata and very little you can actually do about it. Personally, I find that it just grinds your nerves even more when you are constantly running to some doctors and doing everything possible just to keep from losing your hair. I ask myself again and again the question, why one runs again and again to the doctor, if their hands are tied anyway” (25-F)</p>
		<p>“In the first years I visited many doctors and followed every possible treatment tip, always unsuccessfully, which in turn had put a lot of psychological strain on me. “ (54-F)</p>
		<p>“I was in treatment for a very long time, but unfortunately without success. Accordingly, at some point I just gave up.” (35-M)</p>
	Good life without therapy, acceptance of disease (47)	<p>“Because I feel better, just to accept. And not try and anyway nothing helps, every time again the hope which is shattered is much harder to take than the acceptance” (46-F)</p>
		<p>“At the age of 15, I was done with treatment with conventional medicine, followed by 3 years of homeopathic therapies. Nothing led to the desired result. In the meantime I am happier without any therapy attempts” (30-F)</p>
		<p>“Tried everything, frustration too high when something doesn't work and meanwhile resigned“ (22-F)</p>
		<p>“Accept the disease, since cure is uncertain anyway. Save me long 'suffering time“ (52-F)</p>

		<p>“School medicine exhausted, tried Ayurveda, but now found peace, because not curable” (34-F)</p> <p>“No need, it's fine the way it is” (47-M)</p>
	Side effects are too severe (16)	<p>“Shortly after the birth of my child it had started and I wanted to continue” breastfeeding my child. I don't think much of high-dose cortisone either” (30-F)</p> <p>“I have tried a lot of things, up to the intravenous pulse therapy of cortisone. After that I decided that my health is more important to me than my hair” (39-F)</p> <p>“There is no causative treatment, the side effects of symptomatic treatments are too severe” (26-F)</p>
	Hair growth/Condition is good now (12)	<p>“The hair grows back well at the moment” (28-F)</p> <p>“Initially I went to different doctors, cortisone therapy didn't kick in. In the end, areas have grown back on their own or have grown larger more slowly with supplements” (25-F)</p>
	Do not want to feel like a guinea pig anymore. (10)	<p>“I did not want to be a guinea pig - they wanted to try new treatments only on half the head - I did not feel like it. And in the meantime I got used to it and I don't believe that after so many years hair would grow on my head again...” (50-F)</p> <p>“I have tried everything and no longer want to be a test subject” (51-F)</p>
	Insensitive doctors (4)	<p>“Rude, insensitive doctors, who once drove over my head with the comment: "there is still a lot of hair, what are you doing here", without explanations creams written down by several doctors” (21-F)</p> <p>“Because nothing has helped, too long waiting times in the hospital, no understanding from the doctors, even more stress” (61-F)</p>

	Not covered by Health insurance/Financial burden (4)	“Too expensive and does nothing anyway” (34-F)
		“I have been to many doctors, alternative practitioners and none of them could even come close to helping me, but only earn money with me” (37-F)
	Self-treatment (2)	“I was in treatment for a short time, but saw no success. I myself work in a healing profession and work with different methods” (55-F)
	It is said to be psychologically caused (2)	“The doctors have no more advice for me. No one can help me. They only tell me that there is nothing new for this disease. Some say it is an autoimmune disease and some say it is psychological” (54-F)
	Other reasons (6)	“For me, only cortisone-containing or stronger products work. Also, the hair grows back after a longer period of time (about 2 years). For this reason, I let my remaining hair grow and by tying the hair together, you do not see the bald spots with me” (49-F)
		“I don't see this hair loss as a disease but as a mutation. As a Darwinist, I know that I have already reached the next stage in evolution“ (36-F)

Example: (XX-F/M); XX: Age in years, F: female, M: male

(X) in middle section: number of individuals stating same response category