

## INVESTIGATIVE REPORT

# Measuring the Prevalence of Chronic Itch in the General Population: Development and Validation of a Questionnaire for Use in Large-scale Studies

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**Itching is the most frequent symptom in dermatology. Little is known about its occurrence and its characteristics in the general population. Instruments specifically designed to measure itch are scarce. The aim of this pilot study was to develop and validate an instrument measuring prevalence and characteristics of chronic itch in the general population. A questionnaire was developed and administered to a sample from the general population ( $n=200$ ) and a sample ( $n=100$ ) of itch-clinic patients. Lifetime prevalence of itch was 22.6% in non-patients and 100% in patients. Principal component, internal consistency and correlational analyses revealed the instrument to be able to reliably and validly measure itch. Strength of itch was higher in patients and was associated with itch-related quality of life and affect in both groups. Preliminary results indicate that itch is prevalent in the general population. We intend to utilize this parsimonious and easy-to-administer questionnaire in a forthcoming population-based study. Key words: epidemiology; itch; prevalence; pruritus; questionnaire.**

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Chronic pruritus or itch (defined as lasting for at least 6 weeks) (1) is a common symptom associated with many dermatological diseases (2, 3), such as eczema or contact dermatitis, and with psychiatric and neurological disorders (4, 5). It also occurs as a result of drug intake (6, 7). Pruritus of unknown origin can often be the initial symptom of a systemic disease (2, 3, 8–10), such as uraemia, liver and haematological diseases, as well as malignancies and lymphomas (1, 11–13). The reported prevalence of itch in systemic patients ranges from 10% to 50% (8, 9, 13). This variation in reported prevalence across different studies may indicate a certain imprecision, possibly derived from methodological problems such as small and diverse samples.

Epidemiological data on pruritus are limited (2, 5, 14). Most studies refer to specific diseases or certain patient groups. In addition, there exists no definite classification of chronic pruritus. Two recently developed classifications focus either on neurophysiological or clinical characteristics of pruritus (1, 12). All this makes comparisons across groups difficult, particularly as not everyone suffering from chronic itch may have an obvious dermatological, systemic or psychiatric disease and consulted or been referred to a physician for treatment. Thus, there may also be people experiencing itch who do not present their symptoms to the medical professional.

In 1976, prurigo and allied conditions showed a prevalence of 8.2% according to the Lambeth study (15). A cross-sectional study in Oslo, Norway (2000 to 2001) (16, 17) including a total of 40,888 adults provided first data on the prevalence of itch. The variable itch was part of a larger questionnaire (18) developed to measure the prevalence of self-reported skin complaints. In this study, the prevalence of itch within the last week was 8.4%. However, itch was not the primary target variable; the reported estimates refer to participants aged 30–76 years only and the sample was drawn from an urban population.

As itch is not restricted to one disease group, the need for an instrument that is able to reliably and validly estimate the prevalence in the general population becomes apparent. Large-scale epidemiological studies are necessary in order to obtain precise estimates of the prevalence of itch in the general population, but these are still lacking.

The aims of this pilot study were: (i) to develop a questionnaire to measure the prevalence of itch for use in epidemiological studies; and (ii) to report on its measurement properties (reliability and validity).

## MATERIALS AND METHODS

The study was approved by the ethics committee of the University of Heidelberg (S-120/2008). All participants provided informed consent after having received a comprehensive written explanation of the study's aims. The study was conducted in full accordance with the World Medical Association's Declaration of Helsinki.

The final postal questionnaire was sent to the two subsamples to be returned in a self-addressed stamped envelope. After 6 weeks a reminder letter was sent. Since data collection was carried out so as to ensure participants' anonymity, reminder letters were sent to all participants advising them that if they had already completed and returned the questionnaire they would not need to send it again.

A total of 300 participants were sent the postal questionnaire: 100 were patients with a history of chronic pruritus from our outpatient pruritus clinic (all were selected); and 200 were a sample of people, randomly selected from the respective telephone directories of the cities of Heidelberg and Ludwigshafen, Germany. For the latter sample, 100 of the total were chosen from the city of Heidelberg, which has a higher socioeconomic status (annual disposable income *per capita*: 19,634 € (19)) and 100 from the city of Ludwigshafen, which has a lower socioeconomic status (annual disposable income *per capita*: 15,167 € (20)). Data collection was carried out in February and March 2008.

#### *Development of the questionnaire*

The development of the questionnaire was based on guidelines for questionnaire construction (21), a thorough literature review (e.g. 1, 15, 18, 22–24), our own expertise gained from the provision of consultations for itch-patients for many years and close liaison with other experts in the field. Preliminary versions of the questionnaire were presented to and discussed with experts, which led to a refinement of the questionnaire. Before it was sent out, five of our patients completed it and appeared to have no difficulty comprehending the questionnaire.

The pilot form of the questionnaire was structured into five sections. The first section contained five items on sociodemographics. The second section was on occurrence of chronic itch (for assessment of point, 12-month and lifetime prevalence, cf. Appendix I). Only those who currently had chronic itch were requested to continue with the remainder of the questionnaire, which contained three sections dealing with the experience of current itch that lasted for at least 6 weeks. The first section contained an item on duration (months, years), two items on frequency of occurrence during the day and night (response format: "never, rarely, every now and then, occasionally, often, always"), an item on regularity of occurrence and three items dealing with the location. The latter four items were measured with the response options "yes", "no" and "do not know", respectively. A visual analogue scale, ranging from zero to ten measured the average subjective strength/extent of experienced chronic itch. The third section inquired about itch-related quality of life (QoL) impairments and effect of itch on affect (four items each). A final question in this section assessed whether health status was affected by other conditions. All these items were measured on a four-point scale (not at all, a little, quite a lot, very much).

In the concluding section one item assessed whether the respondent was aware of the cause of their itch and another item whether treatment by a physician is currently taking or had previously taken place (both yes/no). The last item asked whether treatment had led to an alleviation of the itching.

In addition, an evaluation sheet with eight questions was included. Participants were invited to comment on the clarity and comprehensibility of the questionnaire and whether they could think of missing aspects. All questions provided space for individual comments.

#### *Statistical analyses*

All statistical analyses were performed using SPSS 16. Data is described by absolute and relative frequencies or by means and

standard deviations (SD), respectively. Tests on differences were carried out by  $\chi^2$  or independent *t*-tests. Reliability analyses were conducted for items that were part of meaningful scales (itch-related quality of life and affect) using internal consistency analyses (Cronbach's  $\alpha$ ). The character of the itch scale was subjected to principal component analysis (PCA) using varimax rotation. Validity of the instrument was assessed by correlating reported strength of itch with itch-related quality of life and affect.

## RESULTS

### *Sample characteristics*

The response rate within the patient group was 88% (84 responded, 4 had died). Within the non-patient group the response rate was 59% (115 responded, 3 had died). The characteristics of the sample are displayed in Table I. More women than men responded, but there were no significant differences in gender distribution between the two groups. The two groups were similar with regard to age. The age range was 21–93 years. Significantly fewer respondents in the patient group were still working and their level of education was lower. A significantly higher percentage of the patient group reported being of non-German origin.

### *Prevalence of chronic itch in the sample*

Table I shows the proportion of respondents who reported chronic itch. Almost 79% of the patient group reported currently experiencing chronic itch. This number increased to 95% (12-month prevalence) and to 100% (lifetime prevalence). Among the non-patient sample approximately 14% reported current chronic itch, 17% reported chronic itch within the last 12 months and 23% reported itch sometime during their life. Since only respondents who had reported to currently experience chronic itch were required to continue with the remainder of the questionnaire the following analyses include only 82 respondents ( $n_{\text{patient-group}} = 66$ ;  $n_{\text{non-patients}} = 16$ ).

### *Missing data*

The percentage of missing values in the variables analysed thus far was 0–2% ( $n = 199$ ) and was hence not considered to be problematic (25, p. 63). All the remaining items were to be answered only by those respondents who had indicated that they currently were experiencing chronic itch and the analysis of missing values was based on that sample ( $n_{\text{total}} = 82$ ,  $n_{\text{patients}} = 66$ ;  $n_{\text{non-patients}} = 16$ ). Nine of the 19 quantitative items had no missing values. Among the remaining 10 items the number of missing values ranged from 1.2% to 6.1%. Only one item (itch occurs in different areas of my body) had more than 5% missing values (6.1%). We decided to add a figure to this section of items (itch localization figure), allowing respondents to tick areas of their body where itch often occurs.

Table I. Sample characteristics and occurrence of chronic itch

	Patient group <sup>a</sup> (n=84)	Non-patient group <sup>a</sup> (n=115)	p	Total <sup>a</sup> (n=199)
Gender			ns	
Female	49 (58.3%)	82 (71.3%)		131 (65.8%)
Male	35 (41.7%)	33 (28.7%)		68 (34.2%)
Age, years mean (SD)	64.2 (16.4)	63.4 (16.4)	ns	63.7 (16.4)
Occupational status			<0.05	
Employed/working	21 (25.0%)	47 (40.9%)		68 (34.2%)
Retired	58 (69.0%)	59 (51.3%)		117 (58.8%)
Other <sup>b</sup>	5 (6.0%)	9 (7.8%)		14 (7.0%)
Education			<0.001	
Elementary	46 (54.8%)	30 (26.1%)		76 (38.2%)
Secondary, ordinary	19 (22.6%)	33 (28.7%)		52 (26.1%)
Secondary, advanced	18 (21.4%)	48 (41.7%)		66 (33.2%)
Other	1 (1.2%)	4 (3.5%)		5 (2.5%)
Origin			<0.05	
German	69 (82.1%)	107 (93.0%)		176 (88.4%)
Non-German	15 (17.9%)	8 (7.0%)		23 (11.6%)
Chronic itch				
At present	66 (78.6%)	16 (13.9%)	<0.001	82 (41.2%)
12-months	80 (95.2%)	19 (16.5%)	<0.001	99 (49.7%)
Lifetime	84 (100%)	26 (22.6%)	<0.001	110 (55.3%)

<sup>a</sup>Absolute frequency (relative frequency) unless otherwise stated. <sup>b</sup>Paternity leave, housewives, unemployed. SD: standard deviation; ns: not significant.

### Characteristics of current itch analyses

Table II displays the frequency or means, respectively, of the items of this scale. All respondents had, on average, experienced itch for approximately 7 years, but variation was high. Itch was, on average, restricted to occasional-to-frequent experience, both during the day or night, respectively. Patient group respondents reported significantly more itch during the day compared with the non-patients. The majority of respondents stated that they were receiving medical treatment for itch. Significantly more respondents from the patient group reported receipt of medical treatment. No other significant differences between the two groups were observed. Principal component analysis with varimax rotation revealed a three-factor solution, explaining 63% of the variance. The first factor was summarized as measuring location characteristics, the second as use of treatment and the third as a reflection of time characteristics. Results are displayed in Table III.

### Strength/extent of itch

The average strength of experienced itch was 6.7 on the visual analogue scale, which ranged from 0 (no itch) to 10 (maximum conceivable itch) (SD=2.1). The two groups differed significantly on this scale (mean<sub>patient-group</sub> = 7.0, SD=1.9; mean<sub>non-patients</sub> = 5.3, SD=2.1;  $t=-2.9$ ,  $p<0.01$ ).

### Item analyses of itch-related quality of life and impact of itch on affect

Both scales consisted of four items each. Reliability analyses (Table IV) of the QoL scale showed satisfactory

internal consistency among the four items (Cronbach's  $\alpha=0.8$ ). The analysis also suggested that if the "sleep disturbance" item was deleted, the scale's internal consistency would improve considerably. Also, its corrected correlation with the scale was lower than that of any other item of the scale. However, the correlation between "sleep disturbance" and the item "I experience itch during the night" (from the characteristics of itch scale) was high ( $0.81$ ,  $p<0.001$ ), suggesting that only those who had itch during the night were affected by it. Hence we decided to retain it in the final questionnaire. Reliability analyses of the affect scale showed sufficiently high internal consistency, suggesting that the items were measuring the same construct. We also noted a fairly high correlation between the two scales ( $r=0.72$ ,  $p<0.001$ ).

### Other items

Respondents also reported their state of health to be affected by other conditions (mean=2.7, SD=1.1). No significant difference was observed between the two groups. A total of 47 (57.3%) respondents believed that they knew the cause of their itch. Again, no significant difference was detected between the two groups.

### Relationships among the subscales

In order to calculate correlation coefficients between strength/extent of itch and itch-related quality of life and affect, the respective items were summed up and that score was divided by four. The correlation between strength/extent of itch (on a scale from 0–10) and itch-related quality of life was  $r=0.60$ ,  $p<0.001$  and between strength/extent of itch and affect  $r=0.57$ ,  $p<0.001$ .

Table II. Means and standard deviations (SD) or absolute and relative frequencies of the characteristics of itch items in 82 participants currently experiencing chronic itch

	Patient group (n=66)	Non-patient group (n=16)	p	Total (n=82)
Duration in months, mean (SD)	81.5 (114.6)	93.6 (93.3)	ns	83.9 (110.2)
During the course of the day itch occurs..., mean (SD) <sup>a</sup>	4.7 (0.9)	4.1 (1.0)	<0.05	4.5 (1.0)
I experience itch during the night..., mean (SD) <sup>a</sup>	4.0 (1.6)	4.0 (1.1)	ns	4.0 (1.5)
Itch occurs often in the same location, n (%) <sup>b,c</sup>			ns	
Yes	50 (75.8)	11 (73.3)		61 (75.3)
No	14 (21.2)	2 (13.3)		16 (19.8)
Do not know	2 (3.0)	2 (13.3)		4 (4.9)
Itch occurs often in different areas, n (%) <sup>b,c</sup>			ns	
Yes	42 (67.7)	10 (66.7)		52 (67.5)
No	19 (30.6)	5 (33.3)		24 (31.2)
Do not know	1 (1.6)	0		1 (1.3)
My whole body is itching, n (%) <sup>b,c</sup>			ns	
Yes	22 (35.5)	9 (56.2)		31 (39.7)
No	38 (61.3)	6 (37.5)		44 (56.4)
Do not know	2 (3.2)	1 (6.2)		3 (3.8)
I am being treated for itch, n (%) <sup>c</sup>			<0.01	
Yes	59 (89.4)	9 (56.2)		68 (82.9)
No	7 (10.6)	7 (43.8)		14 (17.1)
The treatment has helped me, n (%) <sup>c</sup>			ns	
Yes	27 (41.5)	2 (13.3)		29 (36.2)
No	37 (56.9)	6 (40.0)		43 (53.3)
I have not been treated	1 (1.5)	7 (46.7)		8 (10.0)

<sup>a</sup>Scaling: 1=never, 2=rarely, 3=every now and then, 4=occasionally, 5=often, 6=always.

<sup>b</sup>Comparisons excluded any “Do not know” answers.

<sup>c</sup>Due to missing values, totals do not always add up to n<sub>patient group</sub> = 66; n<sub>non-patients group</sub> = 16; n<sub>Total</sub> = 82.

Results of the additional evaluation questionnaire

The vast majority of the sample reported having no difficulty in answering the questionnaire. It was found to be well-structured by 98.2% of the sample, and a similar proportion (98.8%) agreed with its length, hence we did not alter the questionnaire’s structure or length. However, approximately 6% of respondents thought that some response options could be enhanced. This applied to the item “the treatment has helped me”, where several respondents suggested an additional category (“helped me somewhat”) should be included; this suggestion was taken up. It was stated by 7.1% of

the sample that there was not enough space for comments in the evaluation questionnaire. In addition, 10% stated that itch interfered with areas not supplied by items within the questionnaire. However, the suggestions for improvement were so individualistic that they could not be incorporated into the questionnaire without making it very long and cumbersome. Finally, 15% of the sample answered yes to the question as to whether something important was missing; in this case respondents referred to the question of localization of frequent itch, and this item was subsequently changed (details in the section on missing values above).

Table III. Factors resulting from principal component analysis of the characteristics of itch items (n = 82)

	Factor 1 Location	Factor 2 Treatment	Factor 3 Time
Duration, months	-0.09	-0.20	-0.50
During the course of the day itch occurs...	-0.07	-0.12	<b>0.80</b>
I experience itch during the night...	-0.27	-0.34	<b>0.60</b>
Itch occurs often in the same location	<b>-0.77</b>	-0.01	-0.11
Itch occurs often in different locations	<b>0.80</b>	0.21	-0.03
My whole body is itching	0.69	-0.13	-0.35
I am being treated for itch	0.09	<b>0.87</b>	-0.24
The treatment has helped me	0.09	<b>0.87</b>	0.17
Eigenvalue	2.3	1.5	1.2
% Variance	22.6	21.9	18.4

Rotation method: varimax with Kaiser normalization.

Bold numbers indicate the two highest loadings on a factor.

Table IV. Item analyses of itch-related quality of life and affect (n = 82)

	Mean (SD)	Corrected item discrimination	Cronbach’s α
Quality of life items			0.8 <sup>a</sup>
Sleep disturbance	2.5 (1.0)	0.3	0.8 <sup>b</sup>
Impact on relationships	2.2 (1.0)	0.7	0.7 <sup>b</sup>
Impact on leisure activities	2.2 (1.0)	0.7	0.6 <sup>b</sup>
Impact on quality of life	2.9 (0.9)	0.7	0.7 <sup>b</sup>
Affect items			0.9 <sup>a</sup>
Drowsiness and lack of drive	2.3 (1.1)	0.8	0.9 <sup>b</sup>
Detrimental impact on mood	2.7 (1.0)	0.7	0.9 <sup>b</sup>
Less joy and fun in life	2.4 (1.1)	0.9	0.9 <sup>b</sup>
Reduced optimism	2.1 (1.0)	0.8	0.9 <sup>b</sup>

Scaling of all items: 1 = not at all, 2 = a little, 3 = quite a lot, 4 = very much.

<sup>a</sup>Cronbach’s α of scale; <sup>b</sup>Cronbach’s α of scale if item were deleted. SD: standard deviation.



## DISCUSSION

The aim of this study was to develop a questionnaire to assess the prevalence and characteristics of itch in the general population, associated factors such as QoL and affect, extent of itch, and sociodemographic data (e.g. gender, age, occupational status, education, ethnicity). A pilot questionnaire was administered both to patients who had previously consulted us for their chronic itch and participants drawn randomly from the general population. Individuals with a known history of itch can assist in the development of a questionnaire since they are experts on its manifold characteristics, which is why we included them in the present study. However, since the questionnaire is intended for future use in the general population it was also administered to a sample from that population. We expected the questionnaire to differentiate between those with and without chronic itch. The two different samples were also given an evaluation questionnaire with open questions, which helped us to enhance the questionnaire and eliminate potential ambiguity.

Statistically significant differences were found between the patient group and the non-patient group in terms of point, period and lifetime prevalence. The questionnaire was able to detect a lifetime prevalence of itch of 100% in the patient and 23% in the non-patient group. The former result is to be expected, whereas the latter is much higher than reported by Dalgard et al. (16). However, the purpose of the study was not to provide prevalence estimates, and the sample size was small. Had confidence intervals around the prevalence estimates been calculated it may have become apparent that the true prevalence is well below the prevalence estimates observed in this study.

We found that the questionnaire measured important differentiating aspects of itch, such as location, time and use of treatment. Individuals from the patient group also reported significantly more subjective itch than non-patients who had also indicated that they were currently experiencing itch.

Analyses of itch-related QoL and impact on affect scales revealed them to have good internal consistency and the items to have good selectivity (discrimination). The obvious difficulty in attempting to measure itch lies in its elusiveness to the scientist's eye. Itch is a subjective experience (17, 26), which is usually assessed by self-report even though newer approaches based on neurophysiological or endocrine systems have been suggested (27, 28). However, as many studies have shown strong correlations with itch-related QoL (29–31) as well as seen an impact on affect (29, 31) and related cognitions (32) these constructs were measured to be used as criteria. A bias-free assessment is difficult with self-report measures. To validate subjective measures they are often correlated with other more objectively

gathered data. Regarding itch, there are no easily administered objective diagnostic measures with which one can correlate subjective data. Validation of a newly developed instrument can, however, also be achieved by correlating it with other scales with which the construct to be assessed is supposed to correlate (convergent validity) or is expected not to correlate (discriminant validity). Itch has been found to be reliably associated with impairment of QoL and to have a negative impact on affect (29–31). We found both constructs to be significantly associated with strength/extent of itch, as measured by the visual analogue scale, suggesting this item to be a valid measure of degree of itch. A better validation procedure would have been to correlate prevalence data with QoL or affect for all respondents. However, this was not possible, since the latter items assumed itch to be present.

During the development of the questionnaire we worked closely with experts in the field to ensure good face validity of the questionnaire. In addition, respondents were asked to provide feedback in an evaluation questionnaire, analysis of which revealed only little need for change. We added an extra answer option to one question and provided a diagram to enable easier indication of the body areas affected by itch.

This study has some limitations. First, validation procedures normally involve an objective or otherwise established criterion against which the new measure is validated. The nature of the phenomenon under study makes measurement of such a criterion difficult. However, future studies could assess associations with neurophysiological correlates, which have emerged of late. Also, the response rate was only 59% in the non-patient group. However, the response rate obtained appears to be within the usual range of such studies. The mean response rate among postal surveys published in medical journals is approximately 60% (33). Despite imperfect response rates, questionnaire surveys can be broadly representative of the target population (34).

Of greater importance, however, is the problem of self-selection. Self-selection is common in empirical research and can seriously bias the results. If individuals with itch are more likely to respond (e.g. they may like the idea of someone showing interest in their condition) it would lead to an overestimation of itch prevalence. For the present study this appears to be no problem; however, in the forthcoming large-scale population-based study precautions must be taken to increase the motivation to respond across all who are selected to take part (35) (e.g. by drafting a carefully phrased cover letter that appears personal, and offers a hassle-free procedure; the chance to take part in a raffle, reminders by letter and telephone, official stationary, initial opening/engaging question, etc.).

In conclusion, our analyses suggest that the questionnaire developed in this study is able to measure the

prevalence, important characteristics and correlates of chronic itch. We intend to utilize this parsimonious and easy-to-administer measure in its revised form in an impending population-based study in order to shed more light on the question of how many individuals in the general population have chronic itch. Unlike previous questionnaires, which assessed itch amongst other conditions and/or in specific samples, this measure predominantly assesses chronic itch and is designed for use in epidemiological studies.

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*The authors declare no conflict of interest.*

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Appendix I. Excerpt from questionnaire on occurrence of chronic itch (translated by UM)

	Yes	No
1. Are you <u>currently</u> suffering from itch that has lasted for more than 6 weeks anywhere on your body?	<input type="checkbox"/>	<input type="checkbox"/>
2. During the <u>last 12 months</u> have you suffered from itch lasting longer than 6 weeks?	<input type="checkbox"/>	<input type="checkbox"/>
3. Have you <u>ever</u> in your life suffered from itch that lasted longer than 6 weeks?	<input type="checkbox"/>	<input type="checkbox"/>