A systematic review of questionnaires on itch by the Special Interest Group “Questionnaires” of the International Forum for the Study of Itch (IFSI)

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A systematic review of questionnaires on itch by the Special Interest Group "Questionnaires" of the International Forum for the Study of Itch (IFSI)

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Introduction: Itch can be perceived differently across patients and it can affect daily life in various ways. It is essential to assess those aspects that are relevant for the individual patient's needs to improve treatment of patients suffering from acute or chronic itch. The International Forum for the Study on Itch (IFSI) Special Interest Group on "Questionnaires" aims to propose tools to assess different dimensions of itch and improve patient care. As a first step, this study aimed at a systematically reviewing existing patients' self-report questionnaires on itch.

Materials and methods: The databases PubMed, PsycINFO, and CINAHL were systematically searched for any scientific publication describing patients' self-report questionnaires that assess itch-related information ($\geq$2 items). Information about the publication was extracted by 2 experts as well as which of the 14 predefined dimensions of itch (by the IFSI Special Interest Group) were assessed within the questionnaire, for instance, duration of itch, itch aggravating or relieving factors, and effects on quality of life.

Results: From a total of 5282 records, 58 articles were derived describing 62 questionnaires. Over half of the questionnaires were developed for dermatological conditions, and the vast majority targeted at adults. Most questionnaires address itch-related disability and itch intensity. Affective qualities of itch, coping with itch, response to current itch treatment, and the opinion on the origin of itch are infrequently asked for.

Discussion: The number and content of the items within a dimension vary greatly. Measurement properties of the questionnaires were not systematically addressed, as these were often not reported in the original publication. Future research should focus on selecting adequate and reliable (sub)scales to develop a modular questionnaire system in order to uniformly assess the individual patient's demands and improve care.

Keywords: Itch, Itch dimensions, Pruritus, Questionnaire, PROM, Itch intensity

Introduction

The Special Interest Group (SIG) on itch questionnaires of the International Forum on the Study of Itch (IFSI) published a consensus paper[1] giving recommendations on what dimensions of itch could be assessed in an itch questionnaire in order to assess itch and, consequently, guide therapy. This is essential because chronic itch (defined by IFSI as lasting at least 6 wk[2]) is a prevalent symptom[3–6] of various conditions, such as dermatoses (eg, atopic dermatitis, psoriasis, chronic urticaria), systemic (eg, liver or renal failure), and neurological diseases (eg, postherpetic neuralgia) or its origin can be multifactorial (for an extensive classification of chronic itch see Ständer et al[2]). Itch can affect patients' quality of life, which, in turn, can also intensify itch[7,8], making it an interdisciplinary clinical problem and challenge. In order to adequately help each individual patient, it is essential to explore various dimensions of the patient's itch. The following 14 itch dimensions were put forward by the SIG: localization, frequency, duration, intensity, sensory qualities, scratch responses, opinion on origin, affective qualities, itch aggravating or relieving factors, disability/impairment, response to current and previous itch treatments, coping, cognitions, quality of life[1]. The SIG involved in this subject has the ultimate aim to provide, within an interdisciplinary team, a template for the use of questionnaires for different diagnoses that can be applied in a modular manner. To this end, validated questionnaires are needed.

Various scales, questionnaires, and surveys have been developed to measure itch-related characteristics and itch' impact on quality of life. Frequently, only one aspect of the itch sensation has been assessed, that is mainly the intensity of itch measured with a Numeric Rating Scale (NRS) or Visual Analogue Scale (VAS)[9–11]. In addition, various questionnaires were developed to primarily

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assess multiple dimensions of itch. Most of these questionnaires were developed for dermatological diseases, for example, the Eppendorf Itch Questionnaire (EIQ)[12] and the 5-D-Itch-Scale[13]. Multiple questionnaires within the nondermatological field had a different primary aim, but often also include itch questions. Some questionnaires were designed to measure acute itch (<6 wk[2]), others to assess chronic itch. It has been a challenge to document all itch questionnaires along with their content. Previous reviews focused on patient-reported outcome measures (PROM) especially for their use in clinical trials[14,15]. These included not only questionnaires but also monodimensional scales like the NRS[9,16]. Ständer et al[15,17], provided an overview and additional recommendations for useful PROMs in the treatment of itch. However, to date, an overview of all existing itch questionnaires, while examining their content has not yet been made.

This study aimed at creating a systematic overview of which self-report itch questionnaires (defined by the presence at least 2 items) exist, in any study design or (patient) population, and which itch dimensions these questionnaires address. This overview is the first step to a modular system of itch questionnaires.

Materials and methods

Literature search

A systematic literature search was conducted up to 15 June 2018 (no time limitation for the beginning of the search). To this end, we searched the databases PubMed, PsycINFO, and CINAHL. We also included articles describing questionnaires, which were mentioned by personal communication or found by hand search. References of included articles were screened by 1 expert (F.D.) for eligibility; if questionable a second expert (A.I.M.v.L.) was involved.

The databases were searched for original studies that used itch questionnaires or questionnaires that included multiple questions on itch in (a) population(s) of patients suffering from chronic itch. In the search, itch-related terms were combined with questionnaire-related terms. Medical Subject Headings [MeSH] terms, or equivalent for the respective database were used whenever possible, that is, Pruritus, Surveys and Questionnaires, and Patient Reported Outcome Measures. These MeSH terms were combined with the following terms that were searched for in title or abstract: pruritus* or itch*, questionnaire* or survey* or scale* or patient reported outcome. Detailed search algorithms for the above-mentioned databases are shown in Supplementary Table 1, Supplemental Digital Content 1 (http://links.lww.com/ITX/A2).

Eligibility criteria

All titles were screened; abstracts and full texts were also screened when necessary. We included studies if they met the following inclusion criteria:

- the article describes the use of a questionnaire (or equivalent, like a scale or survey) inquiring the patients' itch characteristics;
- the article describes a questionnaire, not only a single scale (see Reich et al[9,18] for reviews on single items assessing itch), that is, it contains at least 2 questions about itch;
- the questionnaire was filled in by the patients and potentially partly by the clinician;
- the article was full text published in a scientific journal (ie, dissertations or conference abstracts were excluded);
- the full text article as well as the questionnaire items could be retrieved; and
- the paper was published in English, German, Japanese, Dutch, or French.

Data extraction

A prepiloted form was used by one expert (F.D.) to extract the following information about each included questionnaire: Information about the initial publication of the questionnaire (authors, year), the study population(s) along with the sample size and mean age of the sample, and the reported or presumed original language(s) the questionnaire was developed for. In addition, the length of each questionnaire was judged as short (≤ 25 items), medium (26–50 items) or long (≥ 51 items). Unclarities were resolved by involvement of a second expert (A.I.M.v.L.). Another prepiloted form was used to assess which of the 14 dimensions of itch as defined in the IFSI SIG itch questionnaires consensus paper were inquired about in each questionnaire[1]. Half of these dimensions can be classified within the category "Characteristics of itch," that is: *localization of itch* (Where on your body do you feel itch?); *frequency of itch* [How often does the itch occur (eg, once per day, twice per week, during certain times of the day, etc.)]; *duration of itch*—the reference frame of this question can vary between days and years [For how long have you already had the itch or for how long has the itch been present? Both for how long in your life (eg, months or years) and how long it lasts if present (eg, minutes, hours, days) are taken into account]; *intensity of itch* measured by VAS or NRS, or Likert scales (and is your itch getting better/worse is also taken into account here); *sensory qualities of itch* (Which descriptors are applicable to the itch sensation, eg pure itch, stinging, burning, mixed sensation. What does the itch feel like?); *scratch response* (What is your behavioral response when you have itch? Eg, scratching, rubbing, squeezing, pinching the skin). The other 7 dimensions can be classified within the category "itch in daily life": *opinion on origin* of the itch (What is the patient's personal view on the origin of itch symptoms?); *affective dimensions* (Which descriptors are applicable to the itch sensation, eg, whether the itch is bothersome or unbearable); *itch aggravating or relieving factors* (What makes the itch better or worse, eg hot water, cold weather?); *disability/impairment* (How does the itch affects the patient's everyday life physically, including work, social activities, and sleep?); *response to current and previous itch treatments* (How effective have drugs and other treatments been to reduce itch?); *coping with itch* (itch specific coping styles, eg looking for distraction by doing something else); *itch cognitions* [Cognitions about itch, such as catastrophizing (eg, I cannot withstand the itch anymore) and problem focused coping (eg, the itch will only take one minute)] and *quality of life* (*How does the itch affect the patient's emotional wellbeing*). The form assessing the dimensions of itch was filled out by one expert (F.D.) and checked by a second expert (A.I.M.v.L.); discrepancies were solved by discussion.

Data synthesis

A synthesis of the extracted data will serve as the overview of the current itch questionnaires. For each questionnaire, we present the study population described in the included paper as well as the mean age of this population. In addition, we report the underlying origin of these itch populations in accordance with the etiological IFSI classification of itch[2]. This classification is developed for chronic itch and includes 6 different categories containing dermatological, systemic, neurological, psychosomatic, mixed diseases, and diseases of other undetermined origin

(IFSI category I–VI); questionnaires that were administered in patient populations not classified according to the clinical classification of itch by IFSI (eg, students or the general population), were classified separately. We also analyzed the reported (or presumed) original language and the length of the questionnaire. We defined one item as one possible answer and assumed therefore 4 groups: very short (2–4 items), short (5–25 items), medium (26–50 item), and long (≥ 51 items).

Results

Study selection

In total we identified 5754 records in the three databases, after removing duplicates, 5282 records remained (for flow diagram see **Fig. 1** and for overview of the included questionnaires see **Table 2**). Ten additional papers describing questionnaires were found by hand search or by personal communication. Of these 5282 records, 795 abstracts and 251 full texts were screened. In total, we excluded 64 records, because the concerning questionnaire did not assess itch at all (eg, the DLQI[19]) or because the questionnaire did not assess characteristics of itch at all (eg, the patient-relevant benefit in the treatment of pruritus[20]), 119 articles because of various reasons (eg, only a single item on itch was assessed, eg the VAS or NRS[9,11] or the questionnaire was already included). Also, 10 questionnaires could not be included because information relevant for this review was lacking for the respective questionnaire because it could not be derived from the publication and/or the questionnaire itself could not be obtained[21–30]. We identified 58 relevant articles with in total 62 itch questionnaires that fulfilled the inclusion criteria.

Study characteristics

In **Table 1**, an overview of all included studies is provided. Most itch questionnaires (n = 37, 60%) were primarily developed for dermatological diseases (IFSI category I), followed by systemic diseases (IFSI category II) with n = 19 (31%). Only 2 questionnaires each were developed to assess neuropathic itch (IFSI category III) or to assess overlapping/coexisting diseases (IFSI category V Mixed), 2 questionnaires were administered in populations not classified by IFSI, specifically, the general population[86] and students[85] (**Fig. 2**). Around 81% of the included papers were published in the year 2000 or later. Seventy-one percent of the studies had a sample size over 100 people. The mean age of the individuals included ranged from 8.9 years for a pediatric questionnaire[51] up to 67 years for a wound-itching questionnaire[52]. Two of the 62 questionnaires were especially developed for children[51,81].

The questionnaires were original published in one or more reported (or presumed) languages. Thirty-one questionnaires were published in the English language, followed by 8 questionnaires which were published in the German language. One study was conducted in Nigeria, here no language was reported or could be

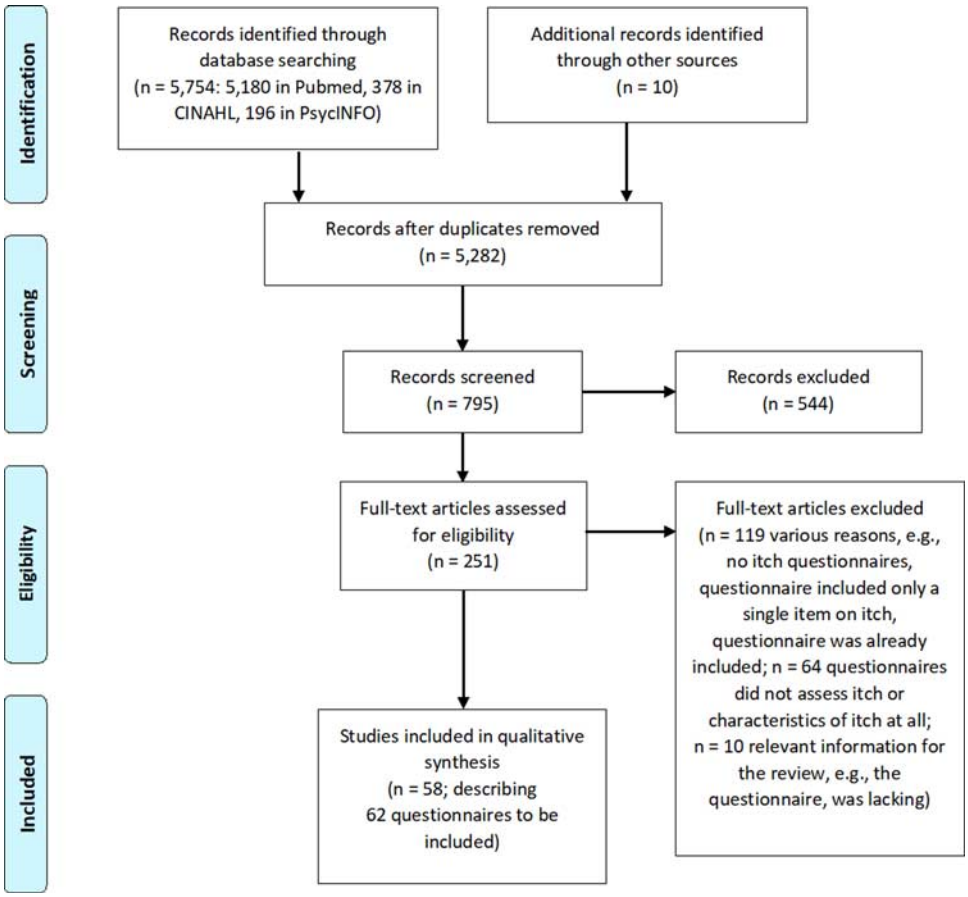

Figure 1. Flow diagram of literature search.

Table 1

Overview of studies included that describe itch questionnaires (organized per IFSI etiological classification category in alphabetical order).

Questionnaire	Published By	Year	Study Population	Sample Size (n) (M:F)	Mean Age (SD or Range) (y)	Reported (or Presumed) Original Language	Length of Questionnaire
Dermatological diseases (IFSI category I)							
12-Item Pruritus Severity Scale	Reich et al[31]	2017	Chronic PD	148 (67:81)	50.0 (15.7)	Polish	Short
4-D score	Amtmann et al[32]	2017	BP	173 (111:62)	34 (17)	English	Short
5-D-itch-scale	Elman et al[13]	2010	Pruritus secondary to: primary DD, BP; HIV; HBP; CKD	234 (80:154)	48 (13.8)	English	Short
Adult Burn Outcome Questionnaire Short Form (by hand searching)	Chen et al[33]	2018	BP	120 (81:39)	NR	English	Short
AGP-Questionnaire	Weisshaar et al[34]	2011	DD	100 (44:56)	52.3 (13.3)	German	Long
American Burn Association Young Adult Burn Outcome Questionnaire	Ryan et al[35]	2013	BP; non-BP	Total: 265 (134:131) BP: 153 (112:41); non-non-BP: 112 (22:90)	Total: NR BP: 24.7 (3.6); non-BP: 25.2 (3.4)	English	Long
Atopic dermatitis screening and evaluation questionnaire (ADSEQ)	Chen et al[36]	2016	AD; DD	Total = 108 (NR) AD (cases): 27 (NR) DD-not AD (controls): 81 (NR)	NR	English	Medium
Brest Questionnaire	Brenaut et al[37]	2013	DD	150 (NR)	NR	French	Medium
Burns Itch Questionnaire	Van Loey et al[38]	2016	BP	Total for T1: 384 (NR) For T2: BP with itch: 195 (135:60)	NR for T1 For T2: with itch: 41.7 (15.1)	Dutch	Short
Characteristics of Itch Questionnaire (adapted to the Eppendorf itch questionnaire) - Short-form Itch Questionnaire	Darsow et al[39]	2001	AD	108 (43:65)	33.4 (11.4)	German	Long
Chronic Skin Disease Questionnaire–Marburger Hautfragebogen	Stangier et al[40]	2003	AD	Study 4: 165 (59:106)	25.2 (7.1)	German	Long
Epidermolysis Bullosa and Pruritus Questionnaire	Danial et al[41]	2015	EB	146 (73:73)	22.3 (0–67)	English	Long
Eppendorfer Juckreizfragebogen; Eppendorf pruritus questionnaire; Eppendorf itch questionnaire	Darsow et al[12]	1997	PD	30 (NR)	NR	German	Long
Impact of Chronic Skin Disease on Daily Life (ISDL)	Evers et al[42]	2007	PSO; AD	301 in total: PSO:173 (69: 104); AD: 128 (40:88)	PSO: 47.6 (14.6); AD: 35.0 (15.3)	Dutch	Long
Itch Severity Scale (ISS)	Majeski et al[43]	2007	PSO	93 (45:48)	NR	English	Short
Itching Cognitions Questionnaire (ICQ)	Ehlers et al[44]	1993	AD	Sample 1: 138 (52:86); sample 2: 60 (24:36)	Sample 1: 25.2 (6.9); sample 2: 28.3 (9.9)	German	Medium
ItchyQoL	Desai et al[45]	2008	PD	Validation: 89 (35:54); evaluation: 104 (47:57)	Validation: 58.1 (16.7); evaluation: 55.9 (16.4)	English	Short
Kawashima's pruritus score	Kawashima et al[46]	2003	AD	Total: 400 (214:186)	Total: 26.6 (6.8)	Japanese	Very short
Leuven Itch Scale	Haest et al[47]	2011	BP; AD; CU	Total: 150; BP: 46 (21:25); AD: 63 (36:27); CU: 41 (29:12)	BP: 41.0 (16.4); AD: 33.4 (11.6); CU: 47.4 (13.6)	Dutch	Medium
Modified 5-D	Vossen et al[48]	2017	HS	211 (76:135)	38 (29–49)	Dutch	Short
Modified Itch Severity Scale	Acar et al[49]	2010	Recurrent external auditory canal itching	Total: 40 (4:36) Group 1: 20 (1:19); group 2: 20 (3:17)	Group 1: 44.6 (12.2); group 2: 43.3 (12.8)	Turkish	Short
Otology Questionnaire Amsterdam	Bruinewoud et al[50]	2017	EC	Field testing: 351 (174:177)	49 (16–93)	Dutch	Medium
Parents Symptom Questionnaire (school-based asthma and allergy screening questionnaire)	Redline et al[51]	2003	Parents to upper and lower elementary school children	2057 (NR)	NR	English	Short

Table 1

(*Continued*)

Questionnaire	Published By	Year	Study Population	Sample Size (n) (M:F)	Mean Age (SD or Range) (y)	Reported (or Presumed) Original Language	Length of Questionnaire
Paul-Pieper-Itching	Paul[52]	2013	WP	WP with itch: 56 (30:26); WP without itch: 142 (82:60)	Total: 67 (21–98)	English	Long
Pruritus questionnaire	Weisshaar et al[53]	2006	DD	Germany: 132 (59:73) Uganda: 84 (37:47)	Germany: 54.5 (14–84) Uganda: 28 (15–75)	German	Long
Pruritusrelated Life Quality Index (PLQI) questionnaire	Erturk et al[54]	2012	DD	110 (44:66)	49 (15)	Turkish	Short
Psoriasis Symptom Diary	Lebwohl et al[55]	2014	PSO	Sample for cognitive interviews about the questionnaire: 16 (11:5)	39 (22–59)	English	Short
Questionnaire for Pruritus Assessment	Parent-Vachon et al[56]	2008	BP	Step 6: 32 (7:25)	43.3 (15.6)	French	Long
Questionnaire survey of pruritus and rash	Hogan et al[57]	1986	PGEW	1954 (1954:0)	35.5 (NR)	English	Medium
Questionnaire survey of pruritus and rash	Hogan et al[58]	1986	PGEW	796 (NR)	36.3 (NR)	English	Short
Rhinitis Symptom Utility Index	Revicki et al[47]	1998	RH	100 (40:60)	36.9 (10.9)	English	Short
Shiratori's pruritus score (by hand searching)	Shiratori et al[59]	1983	PD	124 (79:45)	NR	Japanese	Very short
Skindex-61 (by hand searching)	Chren et al[60]	1996	DD	201 (80:121)	51 (17)	English	Long
Skindex-29 (by hand searching)	Chren et al[61]	1997	DD	Sample for responsiveness analysis: 508 (NR)	56 (18)	English	Medium
Skindex-16 (by hand searching)	Chren et al[62]	2001	DD	541 (352:189)	58 (18)	English	Short
Student Symptom Questionnaire (school-based asthma and allergy screening questionnaire)	Redline et al[51]	2003	Upper and lower elementary schools	Validation sample: 107 (50:57)	Validation sample: 8.9 (1.9)	English	Short
W-AZS (Wskaźnik dla Atopowego Zapalenia Skóry; Index for Atopic Dermatitis) (by hand searching)	Silny et al[63]	2005	AD	NR	NR	Polish	Very short
Systemic diseases (IFSI category II)							
14-item Uraemic Pruritus Scale in Dialysis Patients questionnaire (UP-Dial)	Nochaiwong et al[64]	2017	UP: ESRD on HD or PD	168 (100:68)	60.9 (12.0)	Thai	Short
5-D-itch-scale	Elman et al[13]	2010	Pruritus secondary to: primary DD, BP; HIV; HBP; CKD	234 (80:154)	48 (13.8)	English	Short
Brief Itching Inventory for UP	Mathur et al[65]	2010	ESRD on HD	103 (53:50)	56 (14.2)	English	Short
Dialysis itching questionnaire	Shirazian et al[66]	2013	HD	50 (29:21)	66.2 (NR)	English	Short
Flushing Symptoms Questionnaire	Norquist et al[67]	2007	Pts. appropriate for niacin	175 (108:67)	48.8 (11.9)	English	Short
Itch MOS (of sleep) for UP	Mathur et al[65]	2010	ESRD on HD	103 (53:50)	56 (14.2)	English	Short
Itch questionnaire	Rishe et al[68]	2008	PBC	Total: 239 (8:231) PBC with itch: 165 (NR) PBC without itch: 74 (NR)	Total: NR (20–71)	English	Short
Itching in hemodialysis patients	Subach and Marx[69]	2002	HD	HD with itch: 49 (20:29); HD without itch: 21 (9:12)	Itch: 50 (15); no itch: 54 (14)	English	Short
Liver disease symptom index 2.0 (LDSI-2.0) (by hand searching)	Van der Plas et al[70]	2004	CLD	1175 (497:678)	48 (12)	Dutch	Short
MSAS-Memorial Symptom Assessment Scale (by hand searching)	Portenoy et al[71]	1994	BC; CC; OC; PC	218 (71:147)	55.5 (23-86)	English	Medium
Primary biliary cirrhosis-40 (PBC-40)	Jacoby et al[72]	2005	PBC	Validation of the questionnaire: 240 (12:223; 5 NA)	Validation of the questionnaire: 60 (10)	English	Medium
Primary biliary cirrhosis-27 (PBC-27) (by hand searching)	Montali et al[73]	2010	PBC	Total: 290 (31:259) Italian: 125 (9:116); Japanese: 165 (22:143)	Total: 62 (10) Italian: 62 (10); Japanese: 61 (10)	Italian, Japanese	Medium

Table 1

(*Continued*)

Questionnaire	Published By	Year	Study Population	Sample Size (n) (M:F)	Mean Age (SD or Range) (y)	Reported (or Presumed) Original Language	Length of Questionnaire
Pruritus questionnaire	Gilchrest et al[74]	1982	HD	Boston: 130 (66:64) Miami: 107 (60:47)	Boston: 54 (16) Miami: 50 (16)	English	Short
Pruritus questionnaire	Aubia et al[75]	1980	HD	53 (NR)	NR	Spanish	Very short
Pruritus questionnaire	Balaskas et al[76]	1998	CAPD; HD	CAPD: 43 (26:17); HD: 54 (29:25)	CAPD: 64 (21-83); HD: 61 (24-81)	Greek	Short
Pruritus questionnaire	Wittbrodt et al[77]	2013	HES-pts.	190 (105:85)	66 (59–74)	Danish	Short
Questionnaire Kimme	Kimme et al[78]	2001	HES-pts.	50 (18:32)	52 (11)	Swedish	Very short
Skindex 10 for UP	Mathur et al[65]	2010	ESRD on HD	103 (53:50)	56 (14.2)	English	Short
Survey on uremic pruritus	Wikstrom[79]	2007	ESRD on HD	6137 (NR)	NR	English, (French, German, Italian, Japanese, Spanish)	Very short
Survey questions Kamimura	Kamimura et al[80]	2017	CLD	Total: 41 (15:26); CLD with itch: 18 (4:14); CLD without itch: 23 (11:12)	Total: NR (median = 68) (41–82); CLD with itch: NR (median 69) (45–82); CLD without itch: NR (median 67) (41–80)	Japanese	Short
Neurological diseases (IFSI category III)							
PedsQL Neurofibromatosis Type 1 Module	Nutakki et al[81]	2018	NF1	343 (169:174)	12.4 (5.9)	English	Long
Questionnaire about pruritus in neurofibromatosis 1	Brenaut et al[82]	2016	NF1	40 (16:24)	46.5 (20–75)	French	Medium
Mixed diseases (IFSI category V)							
Dermatomyositis questionnaire	Shirani et al[83]	2004	DeMy	70 (16:54)	56.7 (10.5)	English	Very short
Questionnaire for Notalgia paresthetica	Pagliarello et al[84]	2017	BPR	65 (25:40)	NR (median:48)	Italian	Medium
Populations not classified according to IFSI's etiological classification							
Aquagenic pruritus questionnaire	Salami et al[85]	2009	Stud.	840 (420:420)	25 (3.8)	NR (administered in Nigeria)	Medium
Prevalence of chronic itch	Matterne et al[86]	2009	General population and history of chronic pruritus	Total: 199 (68:131) Patient group: 84 (35:49)	Total: 63.7 (16.4) Patient group: 64.2 (16.4)	German	Medium

Length of questionnaire: very short: 2–4 items, short 5–25 items, medium = 26–50 items, long = ≥ 51 items (1 item is defined as 1 possible answer).
AD indicates atopic dermatitis; BC, breast cancer; BP, burn patients; BPR, back pruritus; CAPD, continuous ambulatory peritoneal dialysis; CC, colon cancer; CLD, chronic liver disease; CU, chronic urticaria; DD, dermatological diseases; DeMy, dermatomyositis; EB, epidermolysis bullosa; EC, ear complaints; ESRD, end-stage renal disease; HD, hemodialysis; HES, hydroxyethyl starch; HS, hidradenitis suppurativa; IFSI, International Forum for the Study of Itch; NA, not applicable; NR, not reported; NF1, neurofibromatosis 1; OC, ovarian cancer; PBC, primary biliary cirrhosis; PC, prostate cancer; PD, pruritic dermatoses; PDia, peritoneal dialysis; PGEW, primary grain elevator workers; PSO, psoriasis; Pts., patients; QoL, quality of life; RH, rhinitis; Stud., students; UP, uremic pruritus; WP, wound patients.

assumed because this country has multiple official languages. Seven questionnaires were very short (2–4 items), 29 were short (5–25 items), 14 questionnaires had a medium size (26–50 items) and 12 questionnaires were long (≥ 51 items).

Results of individual studies and its synthesis

Table 2 displays the 14 dimensions of itch as defined in the IFSI SIG itch questionnaires. Around 92% of the questionnaires consisted of self-report questions filled out by the patient [and additionally by caregivers in the case of children (Redline, 2003 #5469)]. In 8%, a clinician's judgment was additionally asked for. This concerned questions about the origin of pruritus, skin findings like lesions, previous therapies and investigations as well as secondary diagnoses. Only 4 questionnaires assessed all dimensions within the category *characteristics of itch* (**Table 2** and **Fig. 3**) and none of the questionnaires assessed all dimensions within the category *itch in daily life* (**Table 2** and **Fig. 4**).

For the category *characteristics of itch*, the most frequently measured dimensions were intensity of itch (65%) followed by frequency of itch (53%) and localization of itch (52%). Scratch response and sensory qualities were assessed in only 37% and 26% of the questionnaires, respectively. The dimension of itch within the category *itch in daily life* that was most frequently assessed, was disability (79% of the questionnaires), followed by quality of life (56%) and itch aggravating or relieving factors (34%). Of the 49 questionnaires that assessed disability, 74% asked for itch-related disability, whereas 22% assessed disability in relation to the patients' (skin) condition. Itch cognitions and coping with itch were seldom part of the questionnaires, both in only 15%. The opinion on the origin of itch was included in only 6% of the questionnaires (**Table 1**).

Corresponding to the distribution of the questionnaires and the IFSI-classification, the most assessed dimensions are distributed in questionnaires administered in conditions classified in the IFSI-I category (dermatological diseases like psoriasis or atopic

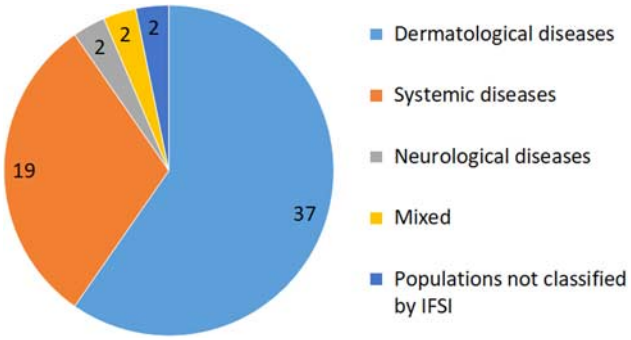

Figure 2. Frequencies of itch questionnaires per etiological classification according to the IFSI. Dermatological diseases according to IFSI category I; systemic diseases according to IFSI category II; neurological diseases according to IFSI category III; mixed according to IFSI category V. IFSI indicates International Forum for the Study of Itch.

dermatitis) followed by the IFSI–II category (systemic diseases like end-stage renal disease or chronic liver disease) (**Figs. 3**, **4**).

Discussion

This review provides a systematic overview of questionnaires that assess itch. This is an initial step in developing a modular questionnaire system that can broadly be used to personalize treatments for patients suffering from itch. The majority (60%) of the 62 included itch questionnaires were developed for dermatological conditions, followed by 31% developed for systemic itch. Only 9% of the questionnaires were developed for other itch conditions and the general population (surveys). None of the included questionnaires addresses all itch dimensions considered important by the SIG[1], but most covered both itch-related characteristics and quality of life. The dimensions localization, frequency, intensity of itch, and disability were covered by questionnaires within 5 IFSI-categories. The other dimensions were included in numerous combinations with high heterogeneity across questionnaires, which seems generally independent of the assessed itch condition. Exceptions are the dimension *opinion on origin*, which was only included when assessing populations not classified by IFSI and dermatological diseases[12,57,85,86], *itch cognitions*, which was only included in dermatological itch questionnaires, and *response to itch treatment*, which was mainly included in questionnaires for systemic diseases. Notably, the clinician's judgment was rarely included and mostly for clinical skin assessments[12,37,56,84].

Within the category *characteristics of itch* (**Table 2**), it is evident that each questionnaire investigated a specific combination of dimensions. Only some dermatological questionnaires assessed all dimensions within this category[12,34,39,56]. When assessing how each dimension was addressed within the questionnaires, we found a lot of approaches. Specifically, *localization of itch* was frequently assessed by displaying drawings of the body on which patients had to indicate the location of their itch[47,64,65], or patients had to circle which of the listed body parts were itchy[13,69]. For specific conditions, it was often inquired whether the itch was localized within the body parts affected by the condition, for example, neurofibromas or rhinitis[58,82]. *Frequency of itch* was asked for using frames ranging from one day to multiple weeks. Particularly for postburn itch, it is essential to map the frequency of itch per day and week[87], as this seems more sensitive to change than intensity given its episodic nature[88]. *Duration of itch* was included in less than half of the questionnaires, of which some only refer to perceived itch during the day[43,67]. Whereas the latter information can be relevant for some types of itch, for example, postburn itch occurs most often in the afternoon and evening[88], knowledge on the itch duration over a longer period is useful to determine whether the itch is acute or chronic[2]. For most questionnaires, it was even unclear if the questionnaire was developed for population(s) suffering from acute or chronic itch or both. Besides, different questionnaires follow different definitions of chronic itch, for example, itch present for a minimum of 6 weeks and with episodes occurring (defined by itch present for 5 min several times a day) at least twice a week[43] or present for at least 3 months[54]. Especially for systemic diseases, including liver or kidney disease, for which the comorbidity of chronic itch is lower than in skin conditions such as atopic dermatitis[5,6,65,89], information about the duration of itch could be beneficial.

Itch intensity was assessed in only 65% of the questionnaires. This is surprising given its high correlation with the patient's well-being[88,90]. If included, intensity was frequently assessed using a VAS or NRS[34,69], while some questionnaires used Likert scales[31,64]. Despite the major role scratching plays in itch and its chronification, for example, the itch-scratch cycle[91], *scratch responses* were assessed in about one third of the questionnaires. Those questions often refer to the effects of scratching, such as inflicted lesions[39,64], associated feelings[39,65,82], its frequency[82], or whether scratching occurs intentionally or automatically[53]. *Sensory qualities of itch* were assessed extensively in some questionnaires[12,39], whereas other questionnaires only included some sensory (neuropathic-like) descriptors like stabbing or burning[41,43]. Questions on *affective qualities of itch*, for example, annoying, irritating, unbearable, were almost exclusively found in dermatological questionnaires. Assessing both sensory and affective descriptors may be useful to distinguish different types of itch[92], for example, postburn itch has been characterized by neuropathic descriptors such as stinging, pinching, and burning[93]. Comparable distinctions have been described for pain[94].

The findings for the category *itch in daily life* (**Table 2**) show that often the effects of itch on daily life were parallelly inquired at a physical (*disability*) and emotional (*QoL*) level. The number of items addressing these dimensions varied, however, largely; that is, from 1 item[83], to a unidimensional focus on sleep[65], to a broad focus of itch on physical and emotional aspects[43,65]. *Opinion on the origin of itch* was predominantly assessed in surveys[57,85,86], for which the underlying cause of itch varies *Itch aggravating or relieving factors*, whether or not actively pursued by the patient, were primarily assessed in relation to dermatological conditions. Examples of such factors are sleep, rest, stress, heat[82], different seasons[68,74], mixing in company to forget the itch, and applying ointment[39]. Sometimes this was asked in an open question[38]. The dimensions *coping with itch*, and *cognitions about itch* were barely included in questionnaires, whilst these are good targets for multidisciplinary interventions[95]. The *response to itch treatments* has incidentally been included, and, proportionally, mainly in relation to systemic itch diseases[68,69,76,80]. Yet, information about (in) effectivity of current treatment can be useful to signal if a patient's treatment regimen should be adjusted.

A strength of this study is that it for the first time systematically searched, in multiple databases, for existing itch questionnaires and that it also provides an overview of which itch dimensions recommended by IFSI[1] are addressed in these questionnaires. At

Table 2

Overview of the dimensions of itch acknowledged by the SIG itch Questionnaires[1] that were assessed in the itch questionnaires included in this review (organized per IFSI etiological classification category in alphabetical order).

				Self-report by Patient													
				Characteristics of Itch							Itch in Daily Life						
	Questionnaire Name	References	Clinician's Judgment	Localization	Frequency	Duration	Intensity	Sensory Qualities	Scratch Response	Affective Qualities	Opinion on Origin	Aggravating or Relieving Factors	Disability (Sleep)	Response to Itch Treatment	Coping	Cognitions	QoL
Dermatological diseases (IFSI category I)																	
1.	12-Item Pruritus Severity Scale	Reich et al[31]	No	+	+		+		+	+			+ (+)				+
2.	4-D score	Amtmann et al[32]	No			+	+						+ (+)				+
3.	5-D-Itch-Scale	Elman et al[13]	No	+		+	+						+ (+)				+
4.	Adult Burn Outcome Questionnaire Short Form	Chen et al[33]	No		+								±	+			±
5.	AGP-Questionnaire	Weisshaar et al[34]	No	+	+	+	+	+	+	+		+	+ (+)		+	+	+
6.	American Burn Association Young Adult Burn Outcome Questionnaire	Ryan et al[35]	No			+	+						± (±)				±
7.	Atopic dermatitis screening and evaluation questionnaire	Chen et al[36]	No	±		±	+						+ (+)				
8.	Brest questionnaire	Brenaut et al[37]	Yes	+	+	+	+	+	+			+					
9.	Burns Itch Questionnaire	Van Loey et al[38]	No	+	+		+			+		+	+ (+)	+			+
10.	Characteristics of Itch Questionnaire (adapted to the Eppendorf itch questionnaire) – Short-form Itch Questionnaire	Darsow et al[39]	Yes	+	+	+	+	+	+	+		+	+ (+)				+
11.	Chronic Skin Disease Questionnaire-Marburger Hautfrage-bogen	Stangier et al[40]	No						+				± (±)		±	±	+
12.	Epidermolysis Bullosa and Pruritus Questionnaire	Danial et al[41]	No	+	+		±	+	+			+	+ (+)			+	+
13.	Eppendorf itch questionnaire	Darsow et al[12]	Yes	+	+	+	+	+	+	+	+	+	+ (+)		+	+	+
14.	Impact of Chronic Skin Disease on Daily Life (ISDL)	Evers et al[42]	No	±	+	+	+		+			±	± (±)				±

15.	Itch Severity Scale (ISS)	Majeski et al[43]	No	+		+		+	+	+		+			+ (+)				
16.	Itching Cognitions Questionnaire (ICQ)	Ehlers et al[44]	No															+	
17.	ItchyQoL	Desai et al[45]	No							±		±			± (±)			+	±
18.	Kawashima's pruritus score	Kawashima et al[46]	No						+			+			+ (+)				
19.	Leuven Itch Scale	Haest et al[47]	No	+		+		+	+	+				+	+ (+)	+			+
20.	Modified 5-D-Itch-Scale	Vossen et al[48]	No	+				+	+						+ (+)				
21.	Modified Itch Severity Scale	Acar et al[49]	No			+			+	+		+			+ (+)				
22.	Otology Questionnaire Amsterdam*	Bruinewoud et al[50]	No			+			+						±				±
23.	Parents Symptom Questionnaire (school-based asthma and allergy screening questionnaire)	Redline et al[51]	No	+		+†								±†	±†				±
24.	Paul-Pieper-Itching	Paul[52]	No	+		+		+	+			+					+		
25.	Pruritus questionnaire	Weisshaar et al[53]	No	+		+		+		+	+	+			+		+		+
26.	Pruritusrelated Life Quality Index (PLQI) questionnaire	Erturk et al[54]	No												+				+
27.	Psoriasis Symptom Diary	Lebwohl et al[55]	No						+	±					±				+
28.	Questionnaire for Pruritus Assessment	Parent-Vachon et al[56]	Yes	+		+		+	+	+	+	+		+	+ (+)	+	+		+
29.	Questionnaire survey of pruritus and rash 1978/1979	Hogan et al[57]	No	±		+		±					+						
30.	Questionnaire survey of pruritus and rash 1986	Hogan et al[57]	No					+			+			+					
31.	Rhinitis Symptom Utility Index†	Revicki et al[58]	No	+				+	+										+
32.	Shiratori's pruritus score	Shiratori et al[59]	No					+	+		+	+			+ (+)				
33.	Skindex-61	Chren et al[60]	No			+									± (±)			±	±
34.	Skindex-29	Chren et al[61]	No		+									±	± (±)			±	±
35.	Skindex-16	Chren et al[62]	No			+									±			±	±

Table 2

(*Continued*)

				Self-report by Patient													
				Characteristics of Itch							Itch in Daily Life						
	Questionnaire Name	References	Clinician's Judgment	Localization	Frequency	Duration	Intensity	Sensory Qualities	Scratch Response	Affective Qualities	Opinion on Origin	Aggravating or Relieving Factors	Disability (Sleep)	Response to Itch Treatment	Coping	Cognitions	QoL
36.	W-AZS (Wskaźnik dla Atopowego Zapalenia Skóry; Index for Atopic Dermatitis)	Silny et al[63]	No	+		+	+		+				+ (+)				
37.	Student Symptom Questionnaire (school-based asthma and allergy screening questionnaire)	Redline et al[51]	No	+†	+†							+†	±†				+†
Systemic diseases (IFSI category II)																	
38.	14-Uraemic Pruritus in Dialysis Patients scale	Nochaiwong et al[64]	No	+		+	+	+	+				+ (+)				+
	5-D-Itch-Scale	Elman et al[13]	No	+		+	+						+ (+)				+
39.	Brief Itching Inventory for UP	Mathur et al[65]	No	+									+ (+)				+
40.	Dialysis itching questionnaire	Shirazian et al[66]	No	+			+						+ (+)				
41.	Flushing Symptoms Questionnaire‡	Norquist et al[67]	No		±	±	+			±			± (±)				
42.	Itch MOS (of sleep) for UP	Mathur et al[65]	No										+ (+)				
43.	Itch questionnaire	Rishe et al[68]	No			+		+	+			+	+ (+)	+			
44.	Itching in hemodialysis patients	Subach and Marx[69]	No	+	+		+						+ (+)	+			
45.	Liver disease symptom index 2.0 (LDSI-2.0)	Van der Plas et al[70]	No		+		+						+ (+)				
46.	MSAS-Memorial Symptom Assessment Scale	Portenoy et al[71]	No		+		+										+
47.	Primary biliary cirrhosis-40 (PBC-40)	Jacoby et al[72]	No						+				+ (+)				+
48.	Primary biliary cirrhosis-27 (PBC-27)	Montali et al[73]	No						+				+ (+)				+
49.	Pruritus questionnaire	Gilchrest et al[74]	No	+	+	+	+					+					
50.	Pruritus questionnaire	Aubia et al[75]	No	+	+		+										

51.	Pruritus questionnaire	Balaskas et al[76]	No	+	+	+	+		+			+	+ (+)	+				
52.	Pruritus questionnaire	Wittbrodt et al[77]	No				+								+			
53.	Questionnaire Kimme	Kimme et al[78]	No	+		+	+											
54.	Skindex 10 for UP	Mathur et al[65]	No										+					+
55.	Survey on uremic pruritus	Wikstrom[79]	No										+ (+)					+
56.	Survey questions	Kamimura et al[80]	No		+		+		+					+				
Neurological diseases (IFSI category III)																		
57.	PedsQL Neurofibromatosis Type 1 Module	Nutakki et al[81]	No					±					+ (+)					+
58.	Questionnaire about pruritus in neurofibromatosis 1§	Brenaut et al[82]	No	+§	+	+	+	+	+			+	+	+				
Mixed diseases (IFSI category V)																		
59.	Dermatomyositis questionnaire	Shirani et al[83]	No				+						+ (+)					
60.	Questionnaire for Notalgia paresthetica	Pagliarello et al[84]	Yes	+	+		+											
Populations not classified according to IFSI's etiological classification																		
61.	Aquagenic pruritus questionnaire	Salami et al[85]	No			+				+		+	+		+			+
62	Prevalence of chronic itch	Matterne et al[86]	No	+	+	+	+			+			+ (+)	+				+

+ The questionnaire assesses this dimension of itch.

± The questionnaire assesses this dimension, however not in direct relation to itch, but in relation to the patients' (skin) condition.

*Only in relation to the ear.

†Only in relation to the eyes, nose or throat.

‡Only in relation to flushing symptoms, that include itch.

§Only in relation to neurofibromas.

IFSI indicates International Forum for the Study of Itch.

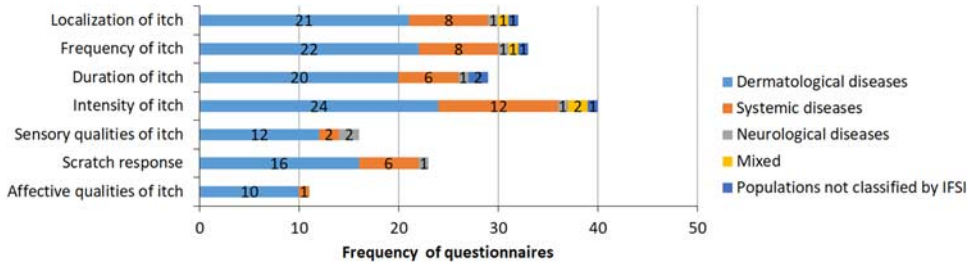

Figure 3. Number of itch questionnaires including the dimensions within the category "characteristics of itch," displayed per IFSI etiological classification category. Dermatological diseases according to IFSI category I; systemic diseases according to IFSI category II; neurological diseases according to IFSI category III; mixed according to IFSI category V. IFSI indicates International Forum for the Study of Itch.

the same time, this outline provides an overview of what is still missing. Such an approach has to our knowledge not yet been taken in previous reviews, in which, for instance, monodimensional scales or clinical assessments and PROMs were reviewed for their use in clinical trials[14,15,17]. Another strong point is that the included questionnaires cover various medical areas, which we systematically organized in accordance with the IFSI-categories classifying the underlying diseases.

Several limitations need to be addressed. At first, we aimed at including papers describing any itch questionnaire for the first time, but often no measures of reliability and/or validity were reported. If we were to provide a full overview of these measures, we should have taken into account all publications of each questionnaire, for example, in different populations or languages. When developing a modular questionnaire system, validated and reliable subscales, derived from studies with low risk of bias should be included to guarantee quality. Second, for the same reasons, the current investigation did not focus on whether the questionnaires were sensitive to change, which is an essential measure when assessing these dimensions of itch over time. Third, this inventory only focused on written self-report measures to assess the different itch dimensions. It is likely that in clinical practice, next to these measures, also other PROMs as described in previous reviews[14,15,17] as well as clinician's judgments on these dimensions are included. Especially for dermatological diseases, a wide range of clinician's scores exist that directly or indirectly relate to itch dimensions, like the SCORAD (SCORing Atopic Dermatitis)[96], EASI (Eczema Area and Severity Index)[97], and PASI (Psoriasis Area and Severity Index)[98]. Fourth, we used the IFSI-classification for chronic itch, irrespective of whether the questionnaire was developed for acute or chronic itch (if known), as we are not aware of such classification system for *acute* itch. Fifth, a possible bias in this overview is that we excluded papers based on language restrictions and absence of the full text article and questionnaire.

To conclude, there is a large number of itch questionnaires, each with its own focus. The number and content of the items within a dimension vary greatly and important aspects of itch, like the intensity, or how responsive the itch is to treatment, are, remarkably, often not assessed. Moreover, acute and chronic itch are often not discriminated for in the questionnaires and measurement properties, such as validity, reliability, and capability to detect change over time, were often not reported by the included articles. In view of feasibility, it is unlikely that there will be a questionnaire that includes all itch dimensions and fulfills all needs. This is why the SIG supports the idea of having a modular system with some basic questions complemented by additional modules, for example, for treatment, QoL, etcetera. When developing such modules, the above described variability should have to be overcome. As this variability seems largely independent of the underlying medical conditions, basic (sub)scales could probably be used for each dimension, complemented by condition-specific questions as desired. This way, both general itch-related information and the demands for specific patient populations can be investigated in a standardized and comparable manner. Future research should focus on gaining agreement on how to select the (sub)scales for each dimension, in order to develop modules containing valid and reliable questions that are sensitive to change. At the same time, usefulness and feasibility in all kinds of settings, for example, clinic, research, cultural

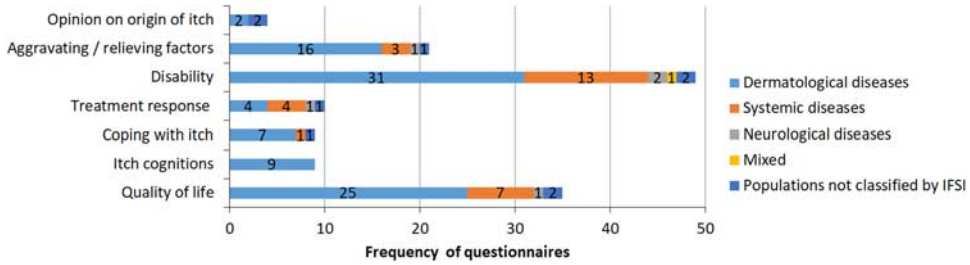

Figure 4. Number of itch questionnaires including the dimensions within the category "itch in daily life," displayed per IFSI etiological classification category. Dermatological diseases according to IFSI category I; systemic diseases according to IFSI category II; neurological diseases according to IFSI category III; mixed according to IFSI category V. IFSI indicates International Forum for the Study of Itch.

suitability[99], should be taken into account. This hopefully leads to improved care for patients suffering from itch.

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Authors' contribution

F.D. and A.I.M.v.L. contributed equally.

Conflict of interest statement

The authors declare that they have no financial conflict of interest with regard to the content of this report.

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