



Clinical science

How is the patient perspective captured in ANCA-associated vasculitis research? An integrative review

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Abstract

Objective: The aim was to describe how the patient perspective is captured in clinical research on ANCA-associated vasculitis (AAV).

Methods: This integrative review included 2149 publications found in four different databases and manual searches. After screening, 156 articles remained. All articles were sorted and categorized, and 77 original articles were analysed further.

Results: The patient perspective was captured with patient-reported outcome measures (PROMs), single-item questionnaires, project-specific questionnaires and interviews. The most common aspects measured were health-related quality of life, anxiety and depression, and fatigue, and the least common were lifestyle habits, relationships and self-management.

Conclusion: The patient perspective was captured predominantly with generic PROMs and occasionally with a qualitative approach. AAV is a lifelong disease, and the results from this review show that not all aspects of importance to patients are covered with the PROMs used in research. Future studies should include the areas that are the most important for patients.

Lay Summary

What does this mean for patients?

People living with ANCA-associated vasculitis (AAV) can be affected by the disease in different ways and can experience several symptoms that affect everyday life. We have studied how the patient perspective has been captured in research investigating AAV. We investigated what part of a patient's experience had been included in the research and how that was captured. After looking at 156 different articles about AAV from 1997 until 2023, we found that the patient perspective was mostly captured through questionnaires evaluating either quality of life or anxiety and depression. Less common were questionnaires that assessed lifestyle habits or relationships. Interview studies were not often used. We noticed that parts of living with AAV, such as airway problems, problems related to medication and side effects, and concerns about the future, were seldom included in the research. This study adds to our understanding of how the patient experience of AAV is investigated in research. Our results give researchers insight into which measurements are commonly used in research, in addition to areas that have not been included in research and should be investigated further. There is lack of studies that use interviews to ask patients about their experiences of living with AAV.

Keywords: patient-reported outcome measures, patient perspective, ANCA-associated vasculitis, integrative review.

Key messages

- Inclusion of the patient perspective in research has increased since 1997.
- This review includes a substantial amount of literature describing the patient perspective.
- There is a lack of ANCA-associated vasculitis-specific instruments for capturing the patient perspective.

Introduction

ANCA-associated vasculitis (AAV) is a type of vasculitis that affects mainly the small vessels. It encompasses three main subtypes: granulomatosis with polyangiitis (GPA); microscopic polyangiitis (MPA); and eosinophilic granulomatosis with polyangiitis (EGPA) [1], and has an estimated prevalence of ~46–184 cases per million globally and European annual incidence rates of 0.5–14.4 cases per million [2].

AAV is most common in older adults, with an equal distribution between men and women. The consequences of AAV for the patient include a substantial disease burden that can negatively impact social relationships, employment, education and family life. Health-related quality of life (HRQoL) has been shown to be decreased, and patients can experience pain, fatigue and muscle weakness as part of the disease or as side effects of treatments [3].

It is generally accepted that patients' own assessments of disease burden and impact on function should be included in disease evaluation and research [3, 4]. The OMERACT (Outcome Measures in Rheumatology) organization [5, 6] advocates incorporating measures important to patients and clinicians in order to improve endpoints in clinical trials, in addition to highlighting the importance of including validated patient-reported outcome measures (PROMs) in clinical trials of AAV. A patient-reported outcome (PRO) is defined as any patient-reported status of a health condition that is either self-reported or provided via an interview [7]. PROMs, then, are tools (often self-reported questionnaires) to measure a patient's health status [8]. Current outcomes in research do not always capture the areas that are most affected according to patients [9].

To our knowledge, there is no previously published overview of how the patient perspective is captured or of how existing instruments for including the patient perspective have been used in AAV research. The aim of this review was to describe how the patient perspective has been captured in clinical research on AAV.

Methods

To capture diverse publications describing the patient's own perspective (e.g. through PROs and patient experiences and preferences), the method for an integrative review described by Whittemore and Knafl [10] was followed. This type of review aims to summarize the literature in order to provide an understanding of the topic or health-care problem, and allows inclusion of both quantitative and qualitative materials. A research protocol has been published previously [11].

Literature search

Comprehensive identical searches was performed on 7 May 2021, 14 October 2021 and August 31 2023, in the databases PubMed, CINAHL, Web of Science and PsycInfo. In the searches, no limits were set regarding year or language, because the aim was to obtain a wide overview of the existing literature and its origins.

The key terms used were as follows: patient-reported outcome measures, health-related quality of life, assessments, patient outcome, patient outcome assessment, patient preference, experience, perspective, perception, patient view, ANCA-associated vasculitis and small vessel vasculitis. Further details are given in the search matrix in

Supplementary Table S1, available at *Rheumatology Advances in Practice* online.

These searches yielded 2145 publications, and 4 more were added after manual searches. In the first screening, 646 duplicates were immediately removed, leaving 1503 publications for data evaluation (Fig. 1).

Data evaluation

The literature was screened, evaluated and extracted with Covidence software, a web-based platform that provides a structured framework for reviews [12]. Four of the authors (A.G., K.D., S.P. and E.W.) collaborated in the data evaluation and extraction process. The process is summarized in the flow chart given in Fig. 1.

Inclusion and exclusion criteria for the publications were discussed and decided among the authors. The inclusion criteria were as follows: studies examining the patient perspective among adults with AAV, where the patient perspective was defined as a patient's own expressed view captured through a questionnaire or interview, and not by a proxy (e.g. a health-care professional or next of kin). Studies with a small proportion of adolescents were also included.

Exclusion criterion were as follows. Publications were excluded if they only used the BVAS as an outcome, because this is a physician-evaluated measure. Although BVAS does include the evaluation of, for example, arthralgia, it is assessed by the physician rather than directly self-assessed by a patient. To ensure that all relevant literature was included during the data evaluation, language was not an exclusion criterion until full-text screening. Only studies written in English were included in the analysis.

All 1503 titles/abstracts, in addition to the 282 full-text studies, were screened individually by two authors (AG, SP, EW or KD), to exclude literature that did not meet the inclusion criteria. Unclear cases were discussed among the four authors, and any conflicts were solved by a minimum of two authors. Full-text screening was performed on 282 publications. Finally, 156 publications were included in this review (Fig. 1).

Data extraction

Information from the included articles was extracted in Covidence using a form designed for this study, and comprised author, year, title, type of publication, type of study, how the patient perspective was captured, type of questionnaire or interview guide, and other. Details of the data extraction are given in the article matrix in Supplementary Table S2, available at *Rheumatology Advances in Practice* online. All authors collaborated in the data extraction, and to achieve consensus, two authors extracted information from each article.

Given that the aim was to obtain an overview of all published materials regarding the patient perspective in AAV, quality evaluation was considered not relevant for this study and was thus not performed.

Data analysis and presentation

All publications were sorted and analysed as follows: original articles, conference abstracts, reviews or miscellaneous (Supplementary Table S2, available at *Rheumatology Advances in Practice* online). In addition, the 77 original articles were thoroughly analysed. The analysis resulted in four categories.

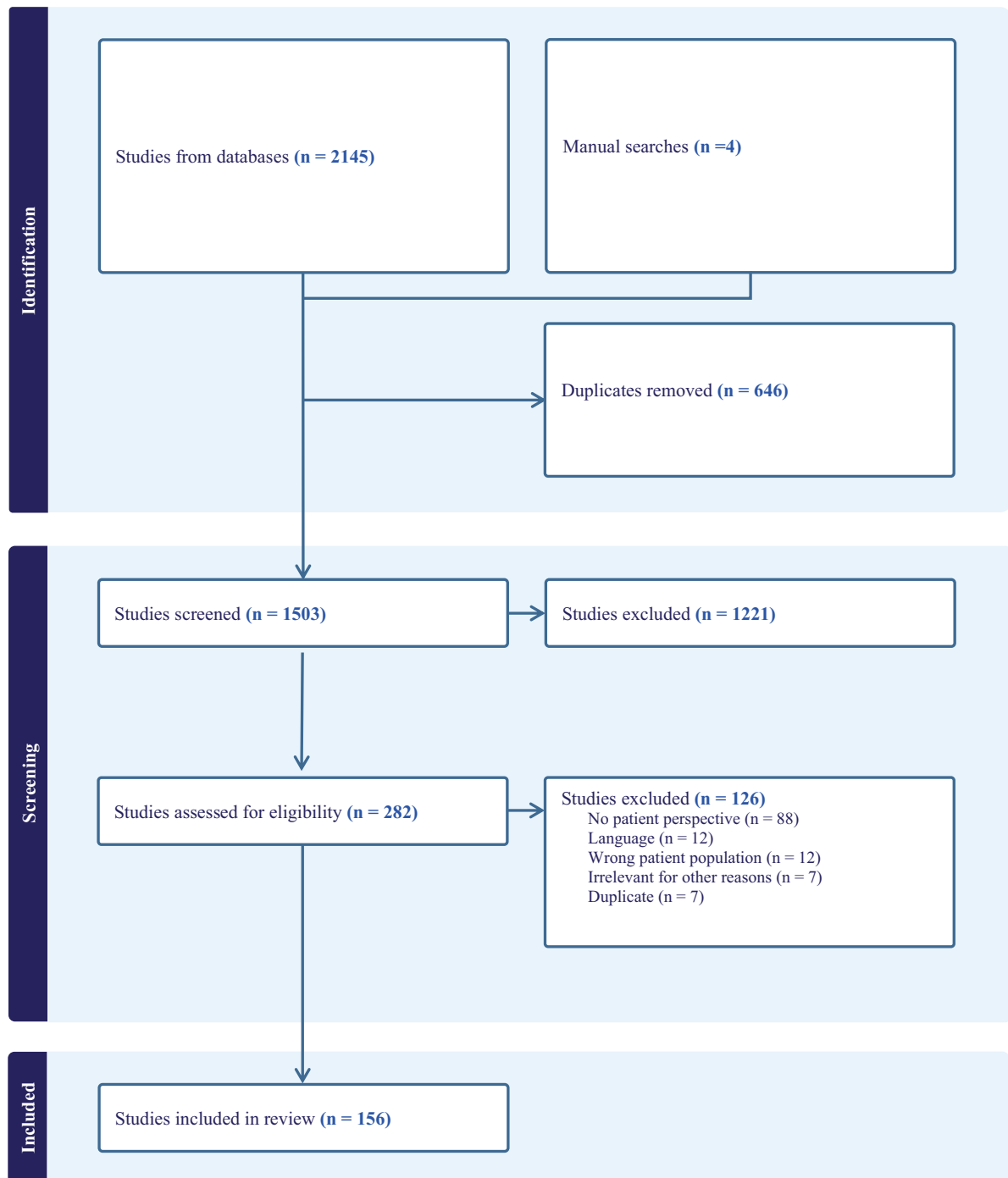


Figure 1. Flow chart

Original articles

The methods used for capturing the patient perspective were extracted and categorized into four types: multi-item PROMs, single-item PROMs [e.g. visual analogue scales (VAS) or yes/no questions], interviews and project-specific questionnaires/questions (i.e. developed and used in one study). The patient perspectives were analysed and sorted further according to which aspects of the patient perspective were captured. The aspects were grouped into categories that described the focus of the perspective that was captured. We identified 18 aspects and four categories.

Conference abstracts

The conference abstracts were grouped on the basis of the method used for capturing the patient perspective and the different patient perspectives that were described. We also conducted a search to check whether the conference abstracts had also been published as original studies.

Reviews

The reviews were grouped according to type of review, and the different approaches for capturing the patient perspective were described.

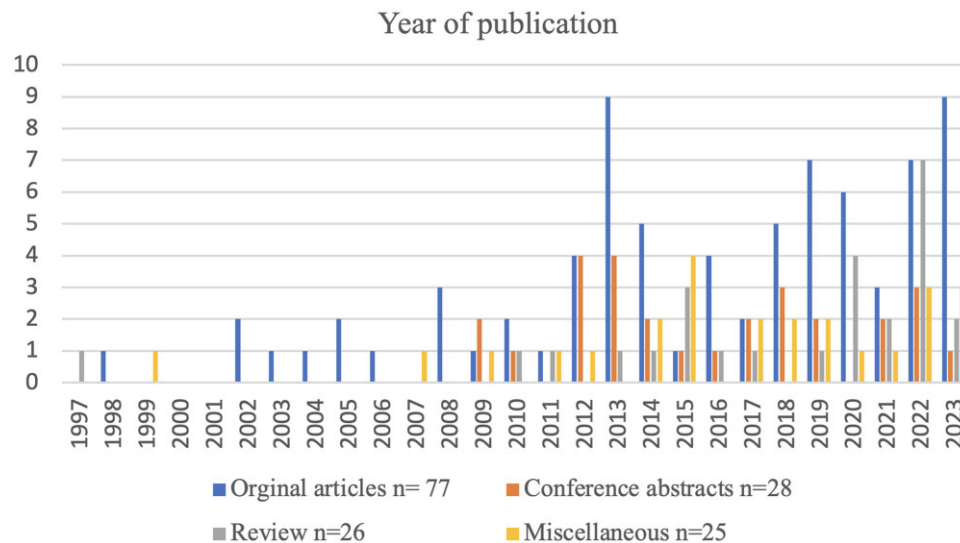


Figure 2. Year of publication of the articles included in this review

Table 1. Characteristics of original articles examining the patient perspective in ANCA-associated vasculitis ($n = 77$)

	<i>n</i>	Percentage
Study design		
Cross-sectional	35	45.5
Case-control	9	11.7
Cohort study	12	15.6
RCT	5	6.5
Qualitative	6	6.5
Other ^a	10	13.0
Geographical origin		
Europe	41	53.3
North America	17	22.1
Asia	6	7.8
Australia	1	1.3
Africa	1	1.3
Transnational collaboration	11	14.3

^a Mixed methods, pilot study, post-hoc analysis, psychometric evaluation, observational study, online patient survey.
RCT: randomized controlled trial.

Miscellaneous publications

The miscellaneous articles were grouped according to type of publication, and the various ways in which the patient perspective was captured were described.

Results

Characteristics of included studies

In total, we identified 156 articles that were included in this integrative review. Of these, 77 were original studies (49.4%), 28 were conference abstracts (18%), 26 were reviews (16.7%), and 25 were classified as miscellaneous (16%). All of them were published between 1997 and 2023 (Fig. 2).

Original studies

The 77 original studies [13–89] were analysed further. They were published between 1998 and 2023 (Fig. 2), and the majority (45.5%) used a cross-sectional study design. The publications originated from all over the world, with the majority (53.3%) from Europe (Table 1).

Patient characteristics in the original studies

A total of 9980 patients were included in the original studies. Of these, 55.3% were female and 44.7% male (data available from 71 studies); the age range was 14–90 years (data available from 24 studies), and mean age varied between 43 and 66.6 years (data available from 47 studies). Studies including all three patient groups (GPA, MPA and EGPA) were the

most common ($n=34$), followed by studies including GPA patients only ($n=13$).

Methods for capturing the patient perspective

The original studies captured several different aspects of the patient perspective using a variety of methods: multi-item PROMs, single-item PROMs, interviews and project-specific questionnaires (Table 2). Four major categories, including 18 different aspects of the patient perspective, were created from the information in these articles: educational needs and medical adherence, physical impact and consequences of AAV, physiological consequences and management of AAV, and social and work-related consequences of AAV (Table 2).

The most common method for capturing the patient perspective was multi-item PROMs ($n=55$), followed by different single-item questionnaires ($n=19$) and project-specific questionnaires ($n=17$). Interviews ($n=6$) were the least common method. Some PROMs/questionnaires covered more than one aspect and were included in more than one category. Multi-item PROMs were mostly generic, although a few were disease specific, both for vasculitis and for other diseases. Single-item PROMs included different VASs and direct questions with answers such as yes/no. Most of the project-specific questionnaires were constructed and included in only one study; the sole exception was a questionnaire by Hoffman *et al.* [42], which was included twice [40, 42]. Six studies used qualitative methodology to capture the patient perspective, and one used mixed methods. Of these, five used semi-structured individual interviews [17, 39, 59, 84, 88], one used focus groups and individual interviews [16], and one used a written questionnaire that included an open-ended question [87] (Table 2). Details of the PROMs and questionnaires are given in Supplementary Table S3, available at *Rheumatology Advances in Practice* online.

Aspects of the patient perspective

Four categories of patient perspective were identified: educational needs and medication adherence, physical impact and consequences of AAV, psychological consequences and management of AAV, and social and work-related consequences of AAV.

Educational needs and medication adherence

Educational needs and medication adherence covered aspects of the patient's need for information, their knowledge of treatment side effects, and evaluation of medicine adherence. In this group, multi-item PROMs were the most common method, followed by project-specific questionnaires. Interviews were least common (Table 2).

Physical impact and consequences of AAV

Physical impact and consequences of AAV included patient perspectives related to symptoms and consequences of AAV. The identified aspects were airway and nasal symptoms, disease activity and symptoms, fatigue, pain, and treatments and side effects.

Fatigue was the most common aspect to assess, and treatments and side effects were the least common ($n=9$). Multi-item PROMs were the most commonly used method, with the multi-dimensional fatigue inventory-20 being the most commonly used instrument ($n=7$) (Table 2).

Psychological consequences and management of AAV

Psychological consequences and management of AAV covered different areas of how AAV affects patients psychologically and their ability to manage the disease. This category included psychological wellbeing, cognition, coping, HRQoL and self-management.

The most common aspect to assess was HRQoL, and the least common were cognition and self-management ($n=4$). Multi-item PROMs were the most common method, and the short form-36 (SF-36) was the most commonly used instrument ($n=34$) (Table 2).

Social and work-related consequences of AAV

Social and work-related consequences of AAV covered aspects of patients' everyday life that were affected by AAV, and included activities of daily living, lifestyle habits, relationships and intimacy, sleep, and work/work disability.

Activities of daily living were the most commonly assessed aspect and were mostly captured by multi-item PROMs; HAQ was the most common of these ($n=4$). Relationships and intimacy, and lifestyle habits were least commonly investigated. Multi-item PROMs, single-item PROMs and project-specific questionnaires were used (Table 2).

Other publications

Other publications that captured and described different aspects of the patient perspective included conference abstracts, different types of reviews and miscellaneous articles.

Conference abstracts

The 28 conference abstracts [90–117] most commonly captured the patient perspective through PROMs, which covered HRQoL [92–96, 100, 101, 104, 107, 108, 112–115], fatigue [95, 96, 98, 105, 112], psychological wellbeing [95, 96, 98, 112, 114], disease activity and symptoms [90, 91, 98, 114, 116, 117], sleep problems [95, 96], work disability [93, 104], activities of daily living [100], coping [95], pain [95], and relationships and intimacy [117]. Less common were project-specific questionnaires that covered knowledge of treatments and their impact [102, 103]. Interview studies covered patients' experiences of living with AAV [110] and their experience of treatments [106]. Clinical records were used to collect patients' experiences of symptoms and adverse events [97, 111]. Four conference abstracts [99, 104, 106, 117] were later published as articles [38, 59, 61, 86]. Three of the abstracts [95, 96, 109] used the same cohort as in two of the articles [32, 57], and two other abstracts [95, 109] were similar to each other but presented at different times. Two abstracts [90, 91] analysed material from the same cohort of patients. Finally, two abstracts [102, 103] were similar but presented at different conferences; to our knowledge, these results have not been published further.

Reviews

The 26 reviews [118–143] included the patient perspective by discussing the importance of PROMs and the ways that AAV can affect different aspects of a patient's life.

Narrative review was the most common study design [118–120, 122, 125–128, 130–133, 135, 137, 138, 143]. Five of the publications were systematic reviews [123, 124, 129, 136, 139, 140, 142], one was a scoping review [127], one was a meta-analysis [134], and one was an expert

Table 2. Methods used to capture the patient perspective. For details, see abbreviations, [Supplementary Table S3](#) and reference list.

Category	Aspects of patient perspective	Multi-item PROMs	Single-item PROMs	Interviews	Project-specific questionnaires
Educational needs and medication adherence	Information/disease knowledge	ENAT [13, 14] SLENQ [13] VINQ ^a [15]		[16, 17]	[13, 18]
	Medical adherence	MMAS-4 [13] VSMS ^{a,b} [19]			[19]
Physical impact and consequences of AAV	Airway and nasal symptoms	ACT [20, 21] NOSE [22] SNOT-22 [20–25] SNOT-25 [22, 25]	[26]		[27]
	Disease activity and symptoms	AAV-PRO ^a [55, 78, 86] B-IPQ [13, 28, 29] DSQ [30] IPQ-R [29, 31] RAPID-3 [32] WPI SSS [30, 33]	[29, 34–38]	[39]	[34, 39–48]
	Fatigue	BRAF-MDQ [49] CFS [32, 50–53] FSS [33] MFI-20 [29–31, 34, 49, 54, 55] SI [56]	[38]		
	Pain	CWP [50, 52, 53, 57] LFESSQ-4 [56] SI [56] WPI [30, 33]	[32, 35, 37, 38, 53, 57, 58]		
Psychological consequences and management of AAV	Consequences of treatments and side effects			[59]	[40, 42, 44, 45, 60–63]
	Psychological wellbeing	BDI [28, 47, 53] B-PHQ [33, 56] CESD-R [64] GAD-7 [33] HADS [30, 32, 34, 35, 49–52, 54, 57] POMS [64] GHQ [32]			
	Cognition	ACE-R [65] CFQ [30]			
	Coping	BC [50, 57] FKV-LIS [28] MCSD [46]			
	Health-related quality of life	AQLQ [21] EQ-5D [65–67] RAND-36 [68, 69] ROLQ [21] SF-8 [53] SF-36 [20, 22, 23, 25, 28–30, 34–36, 44, 47, 49, 52, 54, 55, 57, 61, 64, 66, 70–83] SGRQ [73]	[38]	[84]	
	Self-management	VSMS ^a [19, 46]			
	Activities of daily living	HAQ [33–35, 37, 58, 75, 82] MDHAQ ^c [85] NEADL [65]			[76]
Social and work-related consequences of AAV	Lifestyle habits	AHEI-2010 [13] BPAQ [69]			[34]
	Relationships and intimacy	IIEF-5 [86] QMI ^b [68]		[87, 88]	[19]
	Sleep	ESS [33, 56] JSES [32, 50, 57] PSQI [30, 34, 49, 54]	[23, 38]		

(continued)

Table 2. (continued)

Category	Aspects of patient perspective	Multi-item PROMs	Single-item PROMs	Interviews	Project-specific questionnaires
	Work/work disability	WPAI-SHP [89]	[50]		[40, 42, 44, 61, 76, 89]

For details, see abbreviations, [Supplementary Table S3](#) and reference list.

^a Vasculitis specific.

^b One item from the questionnaire included.

^c Parts of questionnaire included.

ACE-R: Addenbrooke's cognitive examination; ACT: level of asthma control; AHEI-2010: alternate healthy eating index-2010; AAV-PRO: ANCA-associated vasculitis patient-reported outcomes questionnaire; AQLQ: asthma quality of life questionnaire; BC: brief cope; BDI: Beck's depression inventory; B-IPQ: brief illness questionnaire; BPAQ: Baecke physical activity questionnaire; B-PHQ: brief patient health questionnaire; BRAF-MDQ: Bristol RA fatigue questionnaire; CESD-R: Centre for Epidemiologic Studies depression scale; CFS: Chalder fatigue scale; CFQ: cognitive failure questionnaire; CWP: ACR definition of chronic widespread pain; DSQ: DePaul symptom questionnaire; ENAT: educational needs assessment tool; ESS: Epworth sleepiness scale; EQ-5D-3L, EQ-5D-5L: European quality of life-5D; FKV-LIS: Freiburg questionnaire of illness coping; FSS: fatigue severity scale; GAD-7: general anxiety disorder 7-item scale; GHQ-12: general health questionnaire-12; HADS: hospital anxiety and depression scale; IIEF-5: international index of erectile function questionnaire; IPQ-R: illness perception questionnaire-revised; JSES: Jenkins sleep estimation scale; LFESSQ-4: London FM epidemiologic study screening questionnaire; MCSDS: Marlowe-Crowne social desirability scale; MDHAQ: multidimensional health assessment questionnaire; MFI-20: multi-dimensional fatigue inventory-20, MMAS-4: Morisky medication adherence scale; NEADL: Nottingham extended activities of daily living; NOSE: nasal obstruction symptom evaluation; PSQI: the Pittsburgh sleep quality index; POMS: profile of mood states; QMI: quality marriage index; RAND-36: RAND 36-item health survey; RAPID-3: routine assessment of patient index data-3; ROLQ: rhino conjunctivitis quality of life questionnaire; SF-8: short form 8; SF-36: medical outcomes study short form-36, SGRQ: St George's respiratory questionnaire; SI: symptom intensity scale to assess for FMS; SLENQ: SLE needs questionnaire; SNOT 22: sino nasal obstruction test 22; SNOT 25: sino nasal obstruction test 25; VINQ: vasculitis informational needs questionnaire; WPAI-SHP: work productivity and activity impairment-specific health problem; WPI: widespread pain index; WPI SSS: widespread pain index symptom severity score; VSMS: vasculitis self-management scale.

consensus [121]. The earliest was published in 1997 and the latest in 2023. They covered which PROMs have been developed, used or are recommended in clinical trials [119, 122, 125, 126, 129, 132, 133, 136–138, 141], how PROMs play a part in evaluation of treatments and risk of disease [120, 121, 128, 131, 135–138, 141, 143], the experience or factors of HRQoL, and different aspects of how patients are affected by AAV [118, 123, 124, 127, 130, 134, 139, 140, 142].

Miscellaneous

The group of miscellaneous articles [144–168] included a diversity of publications incorporating the patient perspective, such as reports [148, 150, 151, 153–155, 168], editorials/letters [147, 158, 161, 162, 164, 165, 167], guidelines [144, 146, 149], case reports [156, 157], study protocols [145, 159, 163, 166], an economic evaluation [152], and text and opinion publications [160].

The reports described the development of PROMs and the importance of including PROMs in clinical trials of AAV [148, 150, 153–155], patient participation to identify items of importance to patients [168], and the limitations of the International Classification of Function, Disability and Health in the representation of concepts related to AAV [151]. The editorials and letters covered the burden of living with AAV [161], discrepancies between patients' and physicians' perspective of AAV, the benefits and use of certain treatments [164, 165], the importance of incorporating PROMs in assessments [147, 167], current challenges in clinical trials [158], and findings in patient-reported data between two cohorts of GPA patients [162]. The guidelines described the importance of incorporating the patient perspective and a multidisciplinary perspective in clinical trials, in addition to HRQoL and vasculitis-specific PROMs in research [122, 123, 127, 135].

One of the case reports described the patient perspective through a narrative of a patient's disease journey [157] and the other used a retrospective review of medical charts [157]. Four study protocols were included, one proposing the use of the ANCA-associated vasculitis patient-reported outcome (AAV-PRO) instrument in a new patient registry [159], and

three in which the patient perspective was captured with several PROMs [145, 163, 166]; the second of these was later published as an article [49]. An economic evaluation included SF-36 as an outcome [152], and a text and opinion publication described the current available outcome measures and highlighted that PROMs can capture unique disease components [160].

Discussion

This study contributes a broad overview of how the patient perspective has been addressed in research to date, and the inclusion of the patient perspective over time. Four methods of capturing the patient perspective were seen in the original articles, along with 18 different aspects of the patient perspective that could be grouped into four categories. The most commonly investigated aspects of the patient perspective were HRQoL and fatigue. The results from the original articles show how the patient perspective has been captured in clinical research among patients with AAV, and the inclusion of PROMs in research over time. As early as 1998, Hoffman *et al.* [42] included an evaluation of the patient-perceived impact of AAV and its effect on quality of life and functional status, and addressed the need for standardized instruments to evaluate quality of life. Since then, the patient perspective has been incorporated increasingly into research in several different publication types, as seen in the present results. However, our results indicate that the most commonly used PROMs in research among AAV patients are generic and mainly cover HRQoL, anxiety and depression, and fatigue.

Living with a chronic illness, such as AAV, impacts several aspects of life, including the physical, psychological and social. It also shares many manifestations and needs with other chronic inflammatory diseases, such as RA, SSc and SLE [9, 169–172]. Previous research acknowledges a discrepancy between patients and physicians in what aspects are considered the most important when living with a chronic disease [34, 155, 173, 174], in addition to highlighting a lack of sufficient methods to include the patient perspective [9, 84]. Only a few

studies in our review included a rating of what patients considered to be the most important aspects of living with AAV [9, 84]. This is important, because including the patient's view of living with a chronic illness allows researchers and caregivers to identify aspects with a major impact on the patient's health status, which in turn can lead to better health outcomes, shared decision-making [173, 175, 176], patient safety [177], patient participation and communication [175].

To understand a chronic illness, such as vasculitis, from the patient's perspective, qualitative studies can capture nuances and aspects that matter the most for patients and that are not predefined by the available PROMs. The qualitative studies in our review covered only 5 of our 18 identified aspects, namely information/disease knowledge, disease activity and symptoms, consequences of treatments and side effects, HRQoL and relationships, which indicates a lack of knowledge in some areas. Future qualitative research thus has an opportunity to broaden knowledge of the patient's lived experience of living with a chronic disease.

The recently developed disease-specific questionnaire AAV-PRO [67], which is also included in our results increasingly in the most recent years, identifies six dimensions of importance for patients with AAV: organ-specific symptoms, systemic symptoms, treatment side effects, social and emotional impact, concerns about the future, and physical function. The aspects of patient perspective revealed by our review are, to some extent coherent, with the dimensions in AAV-PRO. Systemic symptoms, which include pain and fatigue, were often described in our results, and some parts of social and emotional impact, including anxiety and depression, were also frequently covered. The other dimensions were included by only a small number of studies. Organ-specific symptoms were covered in the few articles investigating airway and nasal symptoms. Given that symptoms from the ear, nose and respiratory tract are considered burdensome by patients [39], this area would benefit from more research that includes the perspectives that matter to patients with AAV. Treatments and side effects were rarely described in the results, but the need for evaluation of the impact of CS treatment has been identified, and a PROM is currently under development [137]. Concerns about the future were seldom addressed, and physical function was evaluated in only a few studies. Based on our findings and aspects identified as important in AAV, more studies aiming to evaluate what matters for patients with AAV could improve patient safety and satisfaction.

AAV patients' needs are multidimensional, including physical, psychological, social and economic aspects, and these needs impact and affect a person throughout life [9]. Including the patient perspective on living with this disease can improve the quality of care, shared decision-making and patient participation [173, 175–177]. Our results show that not all patients' needs and perspectives can be captured with the available PROMs. To provide good-quality care and evidence-based practice, we must ask the patients about what matters most for them. A person-centred approach to care for patients with AAV, which is built on a partnership between the patient and the caregiver, gives patients the opportunity to express their own insights into living with a lifelong disease. Person-centred care can enhance the quality of care, the possibility to provide an environment for shared decision-making and the use of evidence-based medicine, which can

lead to better health outcomes, higher treatment adherence and increased patient satisfaction [178–180].

The conference abstracts, reviews and miscellaneous articles included patient perspectives in several areas, captured with different methods. The most common method for capturing the patient perspective was generic PROMs, which is consistent with the results from the original articles. One article contributed an aspect not seen in the rest of the results, i.e. a narrative from a patient [157], who expressed and described the experienced burden of living with EGPA and its treatments, while not being limited by the content of the most commonly used PROMs. This story told by a patient contributed knowledge of important aspects, such as the impact of long-term CS treatments, management of living with a chronic disease, and the importance of education.

An integrative review was considered the most suitable method to achieve the aim of this study, because other types of reviews would not allow inclusion of a variety of publications describing the patient perspective. All languages were included in the first part of the literature screening, in order to gain an understanding of the distribution of published literature. Twelve articles were excluded later in the process because they were not written in English.

The strengths of this review are that all authors were involved in the literature screening and extraction process and that the inclusion and exclusion criteria were discussed and decided by consensus. Any conflicts during the process were discussed until consensus, which gives assurance that the correct articles were included and that appropriate data were extracted. The categories and aspects were created by the first author (A.G.) and discussed among the other authors. PROMs where a total score is generated, for example SF-36, were discussed and were allocated the category suited for the general scope of the PROM.

Some limitations should be highlighted. The concept of patient perspective is broad, and no exact definition exists. For example, there is no relevant MeSH term, and therefore the searches could have been incomplete. Articles might have been missed because of indexing issues or incomplete search strings. Four publications were added manually after discussion among the authors.

Conclusion

This study describes various approaches to eliciting the patient perspective in clinical research. The patient perspective was captured in several ways and in several aspects, but predominantly with generic PROMs, and only a few studies adopted a qualitative approach. Previous studies highlight the need to include the patient's own perspective of living with AAV and the lack of disease-specific instruments to do so. Patients living with a chronic disease experience lifelong challenges and needs that are multidimensional, and the results from this review show that not all aspects of importance to patients are covered with the PROMs used in research. Qualitative studies can broaden the knowledge of the patient perspective, and future studies of the patient perspective in AAV should include investigation of the areas that are the most important for patients. Including the patient perspective in research and clinical practice can enhance shared decision-making, patient participation and quality of care.

Supplementary material

Supplementary material is available at *Rheumatology Advances in Practice* online.

Data availability

The data underlying this article are available in the article and in its online [supplementary material](#).

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