The impact of a structured one–day seminar on disease–specific knowledge, lifestyle habits and disease impairment in ANCA–associated vasculitis. Results of a randomized, controlled study

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Objective: Anti-neutrophil cytoplasmatic antibody (ANCA)-associated vasculitis (AAV) is a complex, chronic autoimmune disease, and its diagnosis triggers considerable anxiety and uncertainty for those affected. There are currently no valid data describing the impact of disease-specific patient education on the disease knowledge, subjective impairment, and changes in lifestyle habits related to AAV.

Method: We designed a one-day educational programme to serve AAV patients with information about their disease and its treatment. Patients were randomized into an intervention group and a waiting list control group. Increase in knowledge was measured with a multiple-choice test. The intervention group completed the questionnaire before, directly after, and 3 months after the seminar, while the waiting list control group was additionally tested 3 months before the seminar to rule out non-specific learning. Furthermore, we investigated the burden of the disease and the impact of our intervention on this burden.

Results: Compared with the control group, the intervention increased the knowledge (mean ± sd score difference 2.2 ± 1.0, 95% confidence interval 0.1–4.3, p = 0.04). From the patients’ point of view, their understanding of the disease had improved and the subjective impairment caused by their rheumatic disease had decreased. There was a tendency to include disease-relevant behaviour, such as nasal care or dietary recommendations, more often in everyday life.

Conclusion: A one-day seminar is suitable to increase the disease-specific knowledge of patients with AAV in a sustainable manner. In addition, our measure positively affected the disease-relevant behaviour.

Anti-neutrophil cytoplasmatic antibody (ANCA)-associated vasculitis (AAV) is a complex autoimmune disease leading to significant impairment of daily activities, and is associated with increased mortality. In recent years, the prognosis of the AAV has improved with respect to life expectancy and quality of life, thanks to better therapeutic options (1). It is postulated that adherence to treatment rises when patients become involved in the therapeutic decision-making process (2–4). Consequently, the establishment of a shared decision between the patients and their specialists has been included as an overarching principle in the European League Against Rheumatism (EULAR) recommendations for the management of AAV (5). However, this requires that the patients obtain specific knowledge of the disease, including typical complications and basic treatment options.

Supplying the necessary medical knowledge in AAV is demanding and time consuming. The stressful psychological situation after receiving the diagnosis of a potentially life-threatening and chronic disease often prevents the patient from understanding the medical facts offered in the first more detailed informative interview (6, 7). Affected individuals have the impression that they lack helpful information, especially in the early stages of the disease (8). However, owing to a lack of time, comprehensive disease-specific education is often not provided, even at a later date (9). In Germany, in-depth information is available electronically from the patient support organization (German League Against Rheumatism).

In Germany, some programmes for structured education for patients with rheumatic diseases offer modular training courses at different time-points and are an essential part of inpatient rehabilitation medicine (10). So far, outpatient structured patient education has mainly been offered for patients with rheumatoid arthritis (RA). An increase in disease-specific knowledge can be achieved with these interventions (11). Currently, there is no in-depth training programme for AAV patients.

It was our aim to investigate whether structured training has an impact on disease burden and is suited to changing lifestyle habits, therefore contributing to the optimal management of the disease.

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To gain insight into the effectiveness and feasibility of an AAV patient education programme, we created a structured one-day seminar with the contribution of the patient support organization (German League Against Rheumatism). The primary endpoint of the study was an increase in the knowledge of the patients participating in the programme. The secondary endpoints were to broaden the field of patient knowledge and to address questions on daily routines, for which AAV patients are urgently in need of information.

**Method**

The ethics committee of the medical faculty of the Martin-Luther University Halle-Wittenberg approved the study (protocol code 2019-021; date of approval 24 May 2019). The study was registered in the German Clinical Trials Register (DRKS) (protocol code DRKS00016603; date of registration 10 October 2019) and was conducted according to the guidelines of the Declaration of Helsinki. Written informed consent was obtained from all participants.

Patients with AAV were invited by our tertiary outpatient clinic, by eight cooperating rheumatological practices in Saxony-Anhalt, and via the homepage of a patient support organization (German League Against Rheumatism) to attend a one-day educational seminar. If the patients were interested in taking part, information material, a consent form for the study, questionnaires, and an invitation to a one-day weekend seminar were provided. Based on the number of inhabitants (about 2 million) in the state of Saxony-Anhalt and the disease prevalence (5/100 000), we calculated a study population of 50 participants. German-speaking AAV patients between the ages of 18 and 90 years were considered eligible for inclusion. Exclusion criteria were high disease activity or severe concomitant disease precluding seminar attendance, and severe mental or cognitive impairment impeding knowledge transfer.

AAV patients were categorized into two groups: the intervention group and the waiting list control group. Participants were assigned randomly by our tertiary outpatient clinic to the groups using external randomization lists upon receipt of enrolment. Study personnel and statisticians were not blinded. Both groups visited an identical, structured, 6 h information session at two different time-points 3 months apart. The session consisted of five modules, dealing with the subjects ‘Immune System and Immune Diseases’, ‘Disease Pattern and Organ Manifestations of AAV’, ‘Medications and Drug Side Effects’, ‘Diagnostics, Therapy and Lifestyle’, and ‘Self-Help, Work and Occupation’. The first four modules lasted 45 min each, and the last module 25 min. After the first two parts, a 40 min lunch break facilitated interaction among the attendants. Spouses of the patients were permitted to join the seminar. The session ended with a concluding discussion and a question-and-answer period of 20 min.

Disease-specific knowledge was measured by a multiple-choice test with 20 questions about disease progression, diagnosis, treatment, and lifestyle of AAV patients. Each question offered a choice of five possible answers, including only one correct answer. During the seminar, the participants were provided with the knowledge necessary to answer the questions correctly. A minimum score of 0 and a maximum of 20 points could be achieved in the test.

The control group was established to quantify or exclude any non-specific learning effects caused by the repeated completion of the identical test. In addition, although the 20 questions were identical with respect to their content, the order of the questions and the sequence of the possible answers varied in each repetition to further reduce non-specific learning effects. There was no communication to the participants about the correct answer choices or the results in the evaluation between each interview.

The intervention group filled in the multiple-choice test 1 month before and immediately after the seminar, as well as 3 months later. The control group completed the test four times: 3 months before and immediately before the seminar, immediately after the seminar, and 3 months later (Figure 1). The knowledge gain was reflected by an increase in points achieved in the test. An increase in the test score after the intervention compared to the score before the intervention was considered a disease-specific knowledge gain.

The primary endpoint was the mean score difference in correct answers between the waiting list control group and the intervention group at baseline and at 3 months after baseline. At this moment in time, the control group would be approaching the point of intervention, while the intervention group had completed it 3 months earlier.

Apart from the multiple-choice test, our survey contained questions addressing the need for disease-specific information for the AAV patients before and 3 months after the intervention. The need for disease-specific information was evaluated using the modified Educational Needs Assessment Tool (ENAT) (12) and the Systemic Lupus Erythematosus Needs Questionnaire (SLENQ) (13). The SLENQ is a 97-item questionnaire considering seven different domains of patients’ needs. In our study, the 13 items dealing with the sector on disease-specific information were used. For each item, patients had to estimate their need on a five-point ordinal scale (1 = no need, 2 = need already satisfied, 3 = low need, 4 = moderate need, and 5 = high need). In addition, we modified the Brief Illness Perception Questionnaire (BIPQ) (14) to obtain information about the cognitive and emotional representation of the AAV disease. The BIPQ uses a nine-item scale to reflect the perception of illness. All items are measured by a 0–10 response scale. To gather information about the disease-relevant behaviour, the level of present knowledge as well as the personal
assessment of the importance of various topics (disease-specific information, treatment, adverse drug effects, nasal care, exercises, dietary recommendations, vaccinations and infection protection, osteoporosis, and professional life), we used questionnaires as described by Mattukat et al (9), also using a 0–10 response scale. To estimate nutritional preferences, patients were asked to disclose how often they consume the food items listed in the Alternative Healthy Eating Index (AHEI 2010) (15). Adherence was evaluated using the Morisky Medication Adherence Scale (MMSA–4) (16).

At the end of the information seminar, study participants were requested to assess the relevance of the content and acceptance of the education format. Differences between the groups were evaluated using the unpaired t-test.

A copy of the questionnaire (in German) is available from the authors on request.

**Results**

In total, 50 patients with AAV were randomized. Of these, 36 patients completed the relevant questionnaires and were included for further analysis (Figure 2). Thus, 19 were allocated to the intervention group and 17 to the wait list control group. The intervention group consisted of 11 female and eight male patients, and the control group of nine female and eight male patients. The mean age of the participants was 63.1 years (intervention group 62.7 years, control group 63.6 years). For further details, see Table 1.

Before the intervention, the mean number of correct answers (score) in the intervention group was 13.1; this increased to 16.2 (score difference 3.1) following the intervention and 15.2 (2.1) 3 months after the intervention. The mean ± sd score difference before and 3 months after the intervention was 2.1 ± 3.4. In the

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**Figure 1.** Study design. Participants were randomized (R) at baseline. Both groups received the intervention (I) consisting of a one-day seminar with knowledge tests directly before and after the lessons. The control group received the intervention after a 3 month waiting period. Additional testing (T) was performed 3 months after the intervention and at baseline for the control group.

**Figure 2.** Study flowchart. Fifty patients with anti-neutrophil cytoplasmic antibody-associated vasculitis (AAV) were randomized. Of these, in the intervention group 19 patients completed all questionnaires, and in the waiting list control group 17 patients completed the first and second questionnaires for further analysis.
control group, the repeated completion of the questions after 3 months without intervention did not increase the score on the multiple-choice test (mean score difference −0.06 ± 2.7). As the primary endpoint of the study, we found that, compared with the control group, the intervention increased the participants’ knowledge (mean score difference 2.2 ± 1.0, 95% confidence interval 0.1–4.3, p = 0.04) (Figure 3). For further details, see Table 2.

Before the intervention, the mean score did not differ between the intervention and waiting list control groups. The intervention improved the test results of the control group equally to those of the intervention group. Thus, the intervention and control groups were merged. In the pooled data before the intervention, the mean score was 13.2 ± 4.5. Immediately after the intervention, the score increased to a mean of 16.6 ± 2.8. Three months later, the value declined. Nevertheless, there remained a moderate increase in knowledge, with a mean of 15.2 ± 2.8 correct answers (Figure 4).

We also recorded which of the following topics were of interest to the participants: physical limitations, daily

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Table 1. Baseline characteristics of participants.

| Characteristics               | Total (n = 36) | Intervention (n = 19) | Control (n = 17) |
|-------------------------------|---------------|----------------------|-----------------|
| Age (years)                   | 63.1 ± 10.7   | 62.7 ± 10.3          | 63.6 ± 11.4     |
| Gender                        |               |                      |                 |
| Men                           | 16 (44.4)     | 8 (42.1)             | 8 (47.1)        |
| Women                         | 20 (55.6)     | 11 (57.9)            | 9 (52.9)        |
| BMI (kg/m²)                   | 28.5 ± 5.4    | 29.9 ± 6.2           | 26.9 ± 4.0      |
| Education                     |               |                      |                 |
| Less than high school         | 7 (19.5)      | 3 (15.8)             | 4 (23.5)        |
| High school                   | 29 (80.5)     | 16 (84.2)            | 13 (76.5)       |
| Employment                    |               |                      |                 |
| Employed/self-employed        | 15 (41.7)     | 6 (31.6)             | 9 (52.9)        |
| Retired                       | 21 (58.3)     | 13 (68.4)            | 8 (47.1)        |
| Smoker                        |               |                      |                 |
| Current smoker                | 1 (2.8)       | 1 (5.3)              | 0               |
| Non-current smoker            | 19 (52.8)     | 9 (47.4)             | 10 (58.8)       |
| Past smoker                   | 16 (44.4)     | 9 (47.4)             | 7 (41.2)        |
| Duration of AAV (years)       | 9.9 ± 7.3     | 7.9 ± 6.6            | 12.8 ± 7.9      |
| AAV manifestation             |               |                      |                 |
| Nose                          | 27 (84.4)     | 16 (84.2)            | 11 (78.5)       |
| Lung                          | 21 (67.7)     | 12 (63.1)            | 9 (60.0)        |
| Eye                           | 16 (59.2)     | 7 (36.9)             | 9 (64.3)        |
| Ear                           | 15 (57.7)     | 8 (42.1)             | 7 (53.9)        |
| Kidney                        | 15 (60.0)     | 10 (52.7)            | 5 (41.7)        |
| Joints                        | 13 (50.0)     | 9 (47.4)             | 4 (30.8)        |
| Skin                          | 10 (43.4)     | 7 (36.9)             | 3 (27.3)        |
| Nervous system                | 7 (38.1)      | 5 (26.3)             | 2 (16.7)        |
| Gastrointestinal system       | 3 (14.3)      | 0                    | 3 (25.0)        |
| Comorbidities                 |               |                      |                 |
| Arterial hypertension         | 17 (50.0)     | 12 (63.2)            | 5 (29.4)        |
| Hypercholesterinaemia         | 11 (37.9)     | 5 (26.3)             | 6 (35.3)        |
| Osteoarthritis                | 9 (29.0)      | 6 (31.6)             | 3 (17.6)        |
| Diabetes mellitus             | 6 (21.4)      | 4 (21.1)             | 2 (12.5)        |
| Osteoporosis                  | 5 (16.1)      | 3 (15.8)             | 2 (11.8)        |
| Heart failure                 | 5 (16.1)      | 5 (26.3)             | 0               |
| Myocardial infarction         | 2 (4.9)       | 1 (5.3)              | 1 (5.9)         |
| Pulmonary disease             | 2 (6.5)       | 2 (10.5)             | 0               |
| Stroke                        | 3 (10.0)      | 2 (10.5)             | 1 (5.9)         |
| Malignancy                    | 3 (9.7)       | 2 (10.5)             | 1 (5.9)         |
| Current therapeutic regimen   |               |                      |                 |
| CYC                           | 0             | 0                    | 0               |
| MTX                           | 9 (40.9)      | 4 (21.1)             | 5 (45.5)        |
| AZA                           | 21 (63.6)     | 14 (73.7)            | 7 (50.0)        |
| MMF                           | 2 (8.7)       | 1 (5.3)              | 1 (10.0)        |
| CsA                           | 0             | 0                    | 0               |
| RTX                           | 9 (37.5)      | 5 (26.3)             | 4 (36.4)        |
| NSAID                         | 1 (5.0)       | 1 (5.3)              | 0               |
| Glucocorticoids               | 29 (82.9)     | 16 (84.2)            | 13 (76.5)       |

Data are shown as mean ± sd or number (%) of patients.
BMI, body mass index; AAV, anti-neutrophil cytoplasmic antibody-associated vasculitis; CYC, cyclophosphamide; MTX, methotrexate; AZA, azathioprine; MMF, mycophenolate mofetil; CsA, ciclosporin A; RTX, rituximab; NSAID, non-steroidal anti-inflammatory drug.
life, psychological stress, social support, physician–patient relations, career and private security, and disease-specific information. The majority of the participants did not need any help with most of these topics (Figure S5a; see supplemental material). Before the seminar, the majority of patients expressed a need for disease-specific information only. In the modified SLENQ, 65.8% of respondents indicated a desire for disease-specific information (with 62.9% wishing for a little and 2.9% a lot more help). After the seminar, this percentage dropped to 30% (Figure S5b; see supplemental material).

In the answers to the question ‘From where have you received information about your disease so far?’, the treating rheumatologist ranked first for almost all respondents. Other sources of information, in descending order of importance, are given in Figure S6 (see supplemental material). Multiple answers were possible. Only one person reported having attended an information seminar on AAV before.

We also surveyed the health status of the participants (Figure S7; see supplemental material). Over a quarter (25.6%) of the participants reported a disease exacerbation in the last 3 months before the seminar. Most of the exacerbations (15.4%) were moderate, and 5.1% each were mild or severe. More than half of the respondents (56.4%) did not observe a relapse. The remaining respondents (17.9%) were unable to assess their health status. Three months after the event, 36.6% of the participants had an exacerbation (mild 20%, moderate 13.3%, severe 3.3%) and 53.3% did not. For the majority of respondents (65.5%), the health assessment remained unchanged. The remaining participants reported an improvement or worsening in their health, in equal shares (17.2% each).

A numeric rating scale (0 = none and 10 = strongest) was used to quantify parameters to assess the burden of the vasculitis (disease activity and fatigue over the past 4 weeks, pain over the last 7 days, symptoms, impairment to health in everyday life, psychological stress, worrying about the disease). There were no differences in disease burden as a result of the intervention.

To determine an influence of our intervention on disease-related behaviour in everyday life,
participants were surveyed regarding aspects of nasal care, exercise, healthy eating, smoking, vaccinations, and osteoporosis. In the first survey, the majority of the respondents stated that they regularly implement nasal care (47.2% always, 22.2% most of the time). Most participants reported exercising for 1–2 h per week (40.6%). In the analysis of data, there were no significant changes in the disease-related behaviour after the seminar, but there was a tendency for the participants to perform nasal care more frequently and to follow dietary recommendations. The majority of respondents claimed to adhere to the recommendations reflected by the AHEI. Table S3 indicates that fruits/vegetables, wholegrain products, vegetable oils, and fish were preferably consumed (see supplemental material). The daily intake of most of these foods increased after the seminar. Food items rich in sugar and salt were already avoided by the majority of participants at the beginning of the study. However, only a minority of respondents followed recommendations to avoid red meat and lower alcohol consumption. Most participants were non-smokers.

Discussion

The study results indicate that a disease-specific one-day educational programme for AAV patients can facilitate a quantifiable and persistent increase in disease-specific knowledge. Our results also signify that it is possible to set up an educational seminar with several parts, even in one day, to achieve a sustainable learning effect. By doing this, we hope to strengthen the health literacy of affected patients and thus enable them to participate as informed partners in medical decision making.

In the literature, positive effects of patient education are described for chronic diseases such as RA, systemic lupus erythematosus (SLE), and diabetes mellitus (17–20). In Germany, an outpatient training programme was conceptualized for RA in cooperation with rheumatology societies and patient support organizations. The participants attended an educational programme comprising three 90 min parts. The increase in knowledge was recorded with the aid of multiple-choice tests (11).

Publications on structured patient education for AAV patients are rare. For German-speaking patients, a multi-day patient education programme (6 day seminar) was designed based on the analysis of educational needs (21, 22), which comprised five 90 min modules in small groups of 10–15 participants. The first two modules focused on knowledge about the disease; the last three modules concerned psychoeducational elements, nutrition consultation, and exercise. The investigators reported a short- and long-term increase in knowledge for 102 vasculitis patients after attending the training programme. They demonstrated a gain in knowledge, which was still measurable after 1–12 months. Furthermore, the health-
related quality of life, patient-assessed health status, and self-efficacy were enhanced (21). This study lacked a control group. However, the results of our intervention, which included a waiting list control group, render a non-specific learning effect from repeated completion of knowledge tests unlikely. Nevertheless, there is currently no offer of a widely available educational programme for AAV patients in Germany, owing to limited staff capacity and lack of funding (10, 22).

In contrast to the educational programmes for patients with RA or AAV mentioned above, our patient information seminar was confined to one day. The group size, with up to 21 patients, was larger than in previous publications. In our study, we focused on the gain of knowledge without the inclusion of specific psychoeducational interventions (e.g. biofeedback, relaxation, exercise, cognitive techniques to manage pain, or strategies to effect behavioural change). Some reviews report the beneficial effects of psychoeducational interventions in rheumatic diseases on symptoms, physical functioning, and psychological status (23). Our results demonstrate that a comprehensive educational intervention limited to a single day is able to provide relevant information that is still retrievable by the patients several months later.

We used a reduced version of the SLENQ to assess the informational needs of AAV patients. Although unvalidated for AAV, the SLENQ was chosen owing to the comparable systemic course and multi-organ involvement of SLE. The need for help and support decreased after participation in our seminar, and this change was most pronounced in the domain of ‘disease-specific information’. This was the only domain of the SLENQ in which the majority of participants requested help before the seminar. This is in contrast with surveys of SLE patients published earlier. These studies indicated a strong need for help preferentially related to physical as well as psychological factors. Less helplessness was also observed in scleroderma patients attending a psychoeducational group programme (24). Scoring the need for disease-specific information by means of the SLENQ suggested that the programme satisfied the pre-existing unmet needs for a majority of participants.

Our results reveal that participants primarily relied on physicians, especially the treating rheumatologist, as a source of disease-specific information. The literature describes that the information received by physicians plays an essential role (25, 26). Websites, internet platforms, and books were also readily used, confirming the importance of written material, as described in other studies (25).

We did not measure any significant change in disease activity. For patients with RA, it has been reported that interventions that provide only theoretical information exert no effects on disease activity (27). However, our participants reported an insignificant increase in pain 3 months after the information seminar (data not shown). This is probably due to the fact that the last survey was performed in autumn or winter, rather than to the intervention itself. The seasonality of symptoms in AAV, suggesting a higher incidence of symptoms and recurrences in autumn and winter, has been described previously (28–30).

Three months after the seminar, there was a tendency to carry out disease-relevant behaviour more intensely in everyday life, at least regarding nasal care and dietary recommendations. There was no change in the level of physical exercise because the recommendations had already been implemented by most of the participants.

In the past, there was no consistent realization of outpatient training programmes for patients with AAV in Germany. Training seminars in small groups are time consuming, and funding agencies are reluctant to provide finance (22). A disease-specific information seminar for major groups at a specialized centre could serve as an option that is easier to finance.

The limited generalizability of the results to all patients with AAV may be a weakness of this study. Sampling bias may have occurred owing to the voluntary nature of participation. Patients without interest in empowerment, without sufficient organizational skills, and with mobility-imparing functional limitations are less likely to attend a one-day information seminar. Furthermore, our study criteria excluded AAV patients who were unlikely to comprehend or to fully attend the programme because of age, language barriers, or disease activity.

Nevertheless, by improving disease-specific knowledge in patients with AAV, we are confident that their health literacy and treatment adherence can be increased, thus contributing to better disease control.

Conclusion

Educating patients with AAV in a one-day seminar can increase disease-specific knowledge and behaviour for a longer duration. This training can be implemented at a medical centre with a moderate time investment for patients and medical professionals.

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References
1. Schirmer JH, Ariès PM, de Groot K, Hellmich B, Holle JU, Kneitz C, et al. S1-Leitlinie Diagnostik und Therapie der ANCA-assoziierten Vaskulitiden. Z Rheumatol 2017;76:77–104.
2. Basu N, McClean A, Harper L, Amft EN, Dhaun N, Luqmani RA, et al. The characterisation and determinants of quality of life in ANCA associated vasculitis. Ann Rheum Dis 2014;73:207–11.
3. Carpenter DM, Thorpe CT, Lewis M, Devellis RF, Hogan SL. Health-related quality of life for patients with vasculitis and their spouses. Arthritis Rheum 2009;61:259–65.
4. Joosten EAG, DeFuentes-Merillas L, de Weert GH, Sensky T, van der Staak CPF, de Jong CAJ. Systematic review of the effects of shared decision-making on patient satisfaction, treatment adherence and health status. Psychother Psychosom 2008;77:219–26.
5. Yates M, Watts RA, Bajema IM, Cid MC, Crestani B, Hauser T, et al. EULAR/ERA-EDTA recommendations for the management of ANCA-associated vasculitis. Ann Rheum Dis 2016;75:1583–94.
6. Mooney J, Poland F, Spalding N, Scott DGI, Watts RA. ‘In one ear and out the other’ - it’s a lot to take in’: a qualitative study exploring the informational needs of patients with ANCA-associated vasculitis. Musculoskeletal Care 2013;11:51–9.
7. Waldron N, Brown S, Hewlett S, Elliott B, McHugh N, McCabe C. ‘It’s more scary not to know’: a qualitative study exploring the information needs of patients with systemic lupus erythematosus at the time of diagnosis. Musculoskeletal Care 2011;9:228–38.
8. Feldman CH, Bermas BL, Zibit M, Fraser P, Todd DJ, Forlin PR, et al. Designing an intervention for women with systemic lupus erythematosus from medically underserved areas to improve care: a qualitative study. Lupus 2013;22:52–62.
9. Mattukat K, Boehm P, Raberger K, Schaefer C, Keyszer G, Mau W. How much information and participation do patients with inflammatory rheumatic diseases prefer in interaction with physicians? Results of a participatory research project. Patient Prefer Adherence 2019;13:2145–58.
10. Ehlebracht-König I. Patientenschulung in der Rheumatologie. Ein Überblick. Z Rheumatol 2003;62:116–9.
11. Schwarze M, Fieguth V, Schuch F, Sandner P, Edelmann E, Händel A, et al. Krankheitsbezogene Wissenserwerbung durch strukturierte Patienteninformation bei Rheumatoider Arthritis (StruPI-RA): erste Ergebnisse der StruPI-RA-Studie in Deutschland. Z Rheumatol 2021;80:364–72.
12. Ndosi M, Bremaender A, Hannes B, Horton M, Kukurajnen ML, Machado P, et al. Validation of the educational needs assessment tool as a generic instrument for rheumatic diseases in seven European countries. Ann Rheum Dis 2014;73:2122–9.
13. Moses N, Wiggers J, Nicholas C, Cockburn J. Development and psychometric analysis of the Systemic Lupus Erythematosus Needs Questionnaire (SLENQ). Qual Life Res 2007;16:461–6.
14. Broadbent E, Petrie KJ, Main J, Weimann J. The brief illness perception questionnaire. J Psychosom Res 2006;60:631–7.
15. Hu Y, Sparks JA, Malspeis S, Kostenbader KH, Hu FB, Karlson EW, et al. Long-term dietary quality and risk of developing rheumatoid arthritis in women. Ann Rheum Dis 2017;76:1357–64.
16. Morisky DE, Green LW, Levine DM. Concurrent and predictive validity of a self-reported measure of medication adherence. Med Care 1986;24:67–74.
17. Kottonen YT, Santavirta N, Honkanen V, Sandelin S, Schauman L, Gronblad M. Systemic lupus erythematosus patient guide: influence on knowledge of the disease. Ann Rheum Dis 1991;50:900–2.
18. Faller H, Ehlebracht-König I, Reusch A. Empowerment durch Patientenschulung in der Rheumatologie. Z Rheumatol 2015;74:603–8.
19. Hennell SL, Brownell C, Dawson JK. Development, validation and use of a Patient Knowledge Questionnaire (PKQ) for patients with early rheumatoid arthritis. Rheumatology (Oxford) 2004;43:467–71.
20. Das TK. SLE-Patientenschulungsprogramm – Programmumhalt und erste Evaluationsergebnisse. Akt Rheumatol 1997;22:98–104.
21. Herlyn K, Gross WL, Reinhold-Keller E. Longitudinale Effekte des strukturierten Patientenschulungsprogramms für Vaskulitispatienten. Z Rheumatol 2008;67:206–10.
22. Mattussek S. Patientenschulung in der Rheumatologie. Die Ist-Situation. Z Rheumatol 2003;62:1110–3.
23. Mulligan K, Newman S. Psychoeducational interventions in rheumatic diseases: a review of papers published from September 2001 to August 2002. Curr Opin Rheumatol 2003;15:156–9.
24. Kwakkenbos L, Bluyssen SJM, Vonk MC, van Helmond AF, van den Ende CHM, Van Den Hoogen FHH, et al. Addressing patient health care demands in systemic sclerosis: pre-post assessment of a psycho-educational group programme. Clin Exp Rheumatol 2011;29(S60–5.
25. Mooney J, Spalding N, Poland F, Grayson P, Leduc R, McAlear CA, et al. The informational needs of patients with ANCA-associated vasculitis-development of an informational needs questionnaire. Rheumatology (Oxford) 2014;53:1414–21.
26. Babac A, Frank M, Pauer F, Litzkendorf S, Rosenfeldt D, Lührs V, et al. Telephone health services in the field of rare diseases: a qualitative interview study examining the needs of patients, relatives, and health care professionals in Germany. BMC Health Serv Res 2018;18:99.
27. Riemssma RP, Kirwan JR, Taal E, Rasker JJ. Patient education for adults with rheumatoid arthritis. Cochrane Database Syst Rev 2002;(2):CD003688.
28. Tidman M, Olander R, Svalander C, Danielsson D. Patients hospitalized because of small vessel vasculitides with renal involvement in the period 1975-95: organ involvement, anti-neutrophil cytoplasmic antibodies patterns, seasonal attack rates and fluctuation of annual frequencies. J Intern Med 1998;244:133–41.
29. Pompermayer LE, Scolnik M, Scaglioni V, Gallardo MDLA, Soriano ER. Seasonality in ANCA-associated vasculitis. Arthritis Rheumatol 2015;67(Suppl 10).
30. Draibe J, Rodó X, Fulladora X, Martínez-Valenzuela L, Diaz-Escarceñal M, Santos L, et al. Seasonal variations in the onset of positive and negative renal ANCA-associated vasculitis in Spain. Clin Kidney J 2018;11:468–73.

Supporting information
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