


Original article

Psychological and self-management support for people with vasculitis or connective tissue diseases: UK health professionals' perspectives

Joanna C. Robson^{1,2}, Michael Shepherd^{1,2}, Lorraine Harper^{3,4}, Mwidimi Ndosi ^{1,2}, Keziah Austin^{1,2}, Caroline Flurey⁵, Sarah Logan⁴ and Emma Dures^{1,2}

Abstract

Objectives. CTD and systemic vasculitis impact on health-related quality of life. Treatment can be complex, involving multiple medical specialities. The aim of this study was to investigate psychological and self-management support for patients in secondary care.

Methods. An online survey of health professionals in the UK, including 45 multiple-choice and free-text questions, was analysed descriptively. Free-text survey responses were analysed thematically to identify health professionals' perceptions of best practice and unmet needs.

Results. The online survey included 120 health professionals (34% specialist nurses, 51% doctors and 12% allied health professionals), predominantly working in rheumatology (52.9%) and nephrology (21.5%) departments. Access to self-management programmes or clinics for people with CTD or vasculitis was available in 23% of rheumatology and 8% of nephrology departments. In response to 'How well is your team providing self-management support to people with CTD or vasculitis?', 38% of respondents reported 'not very well' or 'not well at all'. Direct access to psychological support was available in 76.9% of nephrology and 32.8% of rheumatology departments. More than 80% of respondents would like additional training. Key themes from the qualitative data (free-text survey responses) included the importance of: dedicated psychological support and self-management programmes for people with CTD and vasculitis, a whole-team approach (specialist teams empowering people to manage their own care), staff training (e.g. brief psychological interventions) and signposting to resources, including patient charities.

Conclusion. People with CTD and vasculitis have complex needs, and improvements in self-management and psychological support are required in UK rheumatology and nephrology departments.

Key words: self-management, psychological, lupus, vasculitis, myositis, rheumatology, nephrology, health professionals, education

Introduction

The rare autoimmune rheumatic diseases include the systemic vasculitides (e.g. ANCA-associated vasculitis, Behçet's disease, polyarteritis nodosa, Takayasu arteritis and GCA) and the CTDs (e.g. SLE, inflammatory muscle diseases, SSc, aPL disease and SS) [1].

People with CTD and vasculitis present with multi-organ disease, which can require complex treatment regimens, including glucocorticoids, chemotherapy and biological medications; many of these therapies can cause significant morbidity to patients [2–4]. These

¹Department of Nursing and Midwifery, Faculty of Health and Applied Science, University of the West of England, ²Rheumatology Research, Rheumatology Department, University Hospitals Bristol NHS Foundation Trust, Bristol, ³Institute of Clinical Sciences, College of Medical and Dental Sciences, University of Birmingham, ⁴Nephrology Department, University Hospital Birmingham NHS Foundation Trust, Birmingham and ⁵Department of Health and Social Sciences, Faculty of Health and Applied Science, University of the West of England, Bristol, UK

Submitted 28 January 2020; accepted 23 April 2020

Correspondence to: Joanna C. Robson, Academic Rheumatology Unit, The Courtyard, Bristol Royal Infirmary, Bristol BS16 1QY, UK. E-mail: jo.robson@uwe.ac.uk

Key messages

- CTDs and systemic vasculitis impact on peoples' health-related quality of life.
- Two-thirds of rheumatology professionals report no psychological support available for people with CTD/vasculitis.
- Eighty per cent of health professionals report no self-management support available for people with CTD/vasculitis.

diseases can be life and organ threatening; 25% of patients with ANCA-associated vasculitis will die within 5 years of diagnosis [5], a higher proportion than that seen with breast and prostate cancer. Care is usually led by rheumatology or nephrology teams, but a range of medical and surgical specialists can be involved depending on the nature of the person's specific disease [6]. The care available to people with CTD and vasculitis is often fragmented across different medical specialities and hospitals, and people can find it difficult to navigating the health-care system [7]. The impact of fatigue is consistently ranked as a key aspect of health-related quality of life in people with CTD or vasculitis [8–11]. Having a rare autoimmune disease can also be isolating [12, 13]; family, friends and health-care professionals can lack detailed knowledge and understanding [14]. These factors can contribute to the high levels of distress seen in this group of patients [15, 16]. The Rare Autoimmune Rheumatic Disease Alliance (RAIRDA) UK survey ($n=2000$) of people with SLE, scleroderma and vasculitis highlighted that 61% struggle to cope with their condition [14].

Lorig *et al.* [17] conceptualized self-management as three aspects of management that patients must address when dealing with having a chronic disease: medical (e.g. interacting with health-care professionals, adhering to medications); role (e.g. adapting to changes in relationships and social roles); and emotional (e.g. processing negative emotions, such as anger and anxiety). A Europe-wide survey (EURODIS) found that 42% of people who live with rare diseases spend >2 h a day in tasks related to their illness, and 25% spend >6 h [18]. The need for better patient support to manage their own care and to navigate through complex care pathways are key recommendations from the 2013 Department of Health Strategy for Rare Diseases and the 2014 British Society of Rheumatology Workshop on autoimmune rheumatic diseases [19, 20]. The UK National Health Service (NHS) 5-year forward plan also highlights self-management as a key element in the care of patients with long-term conditions [21].

Psychological need can be conceptualized as a pyramid; the majority of people will have lower levels of need, whereas a smaller proportion will have greater needs, as represented by the top of the pyramid [7]. For many patients who have psychological symptoms, self-management programmes can provide information about their condition and coping strategies to help with

anxiety, depressive symptoms and disease activity [22–25]. Those with more severe emotional or mental health problems require specialist psychological interventions that take account of their physical health status [7, 18].

The RAIRDA and EURODIS surveys [14, 18] have highlighted the range of unmet needs of importance to people with CTD and vasculitis, including peoples' views on what their support needs are from health professionals.

The aims of the present study were to identify health professionals' perceptions of the presence and quality of self-management and psychological support available to people with CTD and vasculitis in secondary care in the UK, to explore best practice and potential improvements in terms of self-management and psychological support for people with CTD and vasculitis, and to explore the training needs of health-professionals in terms of self-management and psychological support for people with CTD and vasculitis.

Methods

Design

This project comprised an online cross-sectional survey including closed and short-answer questions. The survey was designed by the steering committee (including health professionals from rheumatology and nephrology, researchers and methodologists) and piloted by rheumatology specialist nurses and clinicians at the Bristol Royal Infirmary.

The study was given ethical approval by the Faculty Research Ethics Committee at the University of the West of England, Bristol (reference: HAS.19.03.152). Participants were informed that by completing and submitting the online survey they were giving their implied consent. No personally identifiable data were used, although to enable late withdrawal requests, the online system randomly assigned an identifier to each participant, which they were asked to quote if they wished to withdraw.

Participants

Health professionals [including specialist nurses, clinicians, allied health professionals (AHPs), psychologists and pharmacists] working with people living with CTD or vasculitis in secondary care in the UK were invited to participate in the online cross-sectional survey.

The survey

The survey questionnaire was developed in Qualtrics[™] [26], an online survey platform that enables survey construction and hosting of the data on secure servers during data collection. The survey comprised 45 items including multiple choice response and open-ended questions. The regional location was compulsory in order to ensure that the response was limited to UK-based staff. The items were divided into three sections: participant demographics, including professional background, experience and geographical region; questions related to self-management support for people with CTD and vasculitis in their service; and questions related to psychological support for people with CTD and vasculitis in their service.

During the online survey, participants were shown the definition of self-management as provided by Lori *et al.* [17] (i.e. the medical, role and emotional management required of people when adapting to a chronic disease) to refer to when answering questions related to self-management.

Items on the ability of the team to provide self-management and psychological support services were designed as five-point Likert scales ranging from extremely well to not well at all. Participants were also asked to rate their own confidence in providing self-management support and in recognizing a patient's need for psychological support (four-point scale, from 'completely confident to not at all confident).

Seven free-text, open-ended questions were used to explore current provision and best practice and potential improvements identified by health professionals working with people with CTD and vasculitis. These included questions about current self-management clinics or programmes for people with CTD or vasculitis held in their department; what worked well and what could be improved; what was available in terms of psychological support, including what was good about the support and what could be improved; and the training needs for staff in terms of self-management and psychological support for people with CTD and vasculitis.

Data-collection procedures

Health professionals from different medical specialities (particularly, rheumatology and nephrology), professional background, geographical regions and type of hospital setting [district general hospitals (DGHs) and NHS England Specialist Centres] were actively targeted to ensure a broad representation of experiences and views.

Participants were recruited via social media with the post: 'Are you a nurse, doctor, AHP or psychologist who has ever worked with people with Vasculitis or CTD? Please complete our quick survey of psych and self-management support in the UK. Interested in renal/rheum/DGH or specialist opinions'. A link was provided to the Qualtrics[™] survey [26]. The post was tweeted via the study account (@SelfSurvey) and the British Society of Rheumatology account (@RheumatologyUK), posted

on the Royal College of Nursing Rheumatology nursing forum and distributed via the United Kingdom and Ireland Vasculitis Registry (UKIVAS) and UK GCA Consortium email lists. The survey was also advertised during a talk at the British Society for Rheumatology Conference, 2019 [27].

Data analysis

For statistical analysis, the following combined items were defined: Doctors, combining Consultants and Registrars; Nurses, combining Advanced Nurse Practitioners, Nurse specialists and Staff Nurses. Allied Health Professionals were also defined as including Occupational Therapists, Physiotherapists, Pharmacists and Podiatrists.

Analysis of survey data was initially undertaken within Qualtrics[™] [26], with further analyses in IBM SPSS for Windows (v.25.0; IBM Corp., Armonk, NY, USA). Data were summarized and analysed descriptively, with categorical data presented as proportions. Contingency tables with χ^2 statistics were used to test the significance of the association between categorical variables. Where appropriate, odds ratios (ORs) were calculated to quantify the magnitude of the association [28]. Analysis of the Likert scale questions used the Kruskal–Wallis test [29] to assess differences between groups.

Free-text survey responses were organized using NVivo v.12 [30] software. A combined inductive and deductive approach was used [31]. Themes of importance were identified by three independent researchers (M.S., J.C.R. and K.A.), including key elements of good practice, how self-management and psychological support could be improved, and health-professional training needs. The chronic care model (CCM) [32] was chosen as the framework for the deductive analysis. The CCM is an evidence-based framework that highlights the key modifiable components of a health-care system that can support high-quality, patient-centred chronic disease management. The CCM accounts for the many factors that influence clinical practice and care in real-world settings.

Results

Participant characteristics

A total of 120 responses were received from the online survey, which was open for 6 weeks from 16 April to 31 May 2019.

Table 1 describes the professional background and demographic details of the survey participants. Most of the health professionals worked in either rheumatology (52.9%) or nephrology (21.5%) departments. There was a range of participants with different professional backgrounds (specialist nurses, allied health professionals and doctors) and types of hospitals (DGH vs teaching and NHS England specialist centres). Most participants (86%) reported that they regularly saw patients with CTD or vasculitis. Survey participants were from across

TABLE 1 Description of online survey participants

Speciality, <i>n</i> (%)			
Nephrology		26 (21.7)	
Rheumatology		64 (53.3)	
Other speciality	Research (4) Psychiatry (1) Podiatry (2) Anaesthesia (1) Respiratory (1)	9 (7.5)	
Specialty not given		21 (17.5)	
		Rheumatology	Nephrology
Type of hospital, <i>n</i> (%)			
District general hospital		19 (30.2)	3 (11.5)
Teaching hospital		23 (36.5)	17 (65.4)
NHS England specialist centre		21 (33.3)	6 (23.1)
Professional background, <i>n</i> (%)			
Nurses	Nurse specialists (31) Staff nurses (2) Research nurses (2) Advanced nurse practitioner (1)	24 (38.1)	5 (19.2)
Allied health professionals	Physiotherapists (4) Podiatrists (3) Occupational therapist (3)	9 (14.3)	2 (7.7)
Doctors	Consultants (41) Doctor in training (10)	30 (47.6)	19 (73.1)
Others	Psychologists (1) Pharmacists (1)		
Experience in specialty, <i>n</i> (%)			
<5 years		8 (12.7)	5 (19.2)
5–10 years		17 (27)	2 (7.7)
10–20 years		23 (36.5)	10 (38.5)
>20 years		15 (23.8)	9 (34.6)
Level of experience and interest in working with patients who have CTD and vasculitis, <i>n</i> (%)			
Regularly see patients and have a special interest		27 (43.5)	20 (76.9)
Regularly see patients, but not a special interest		26 (41.9)	5 (19.2)
Do not regularly see patients, but interested		6 (9.7)	0 (0.0)
Rarely see patients with CTD or vasculitis		3 (4.8)	1 (3.8)

the UK, although most came from English hospitals ([Supplementary Table S1](#), available at *Rheumatology Advances in Practice* online).

Who is providing self-management and psychological support for patients with CTD and vasculitis?

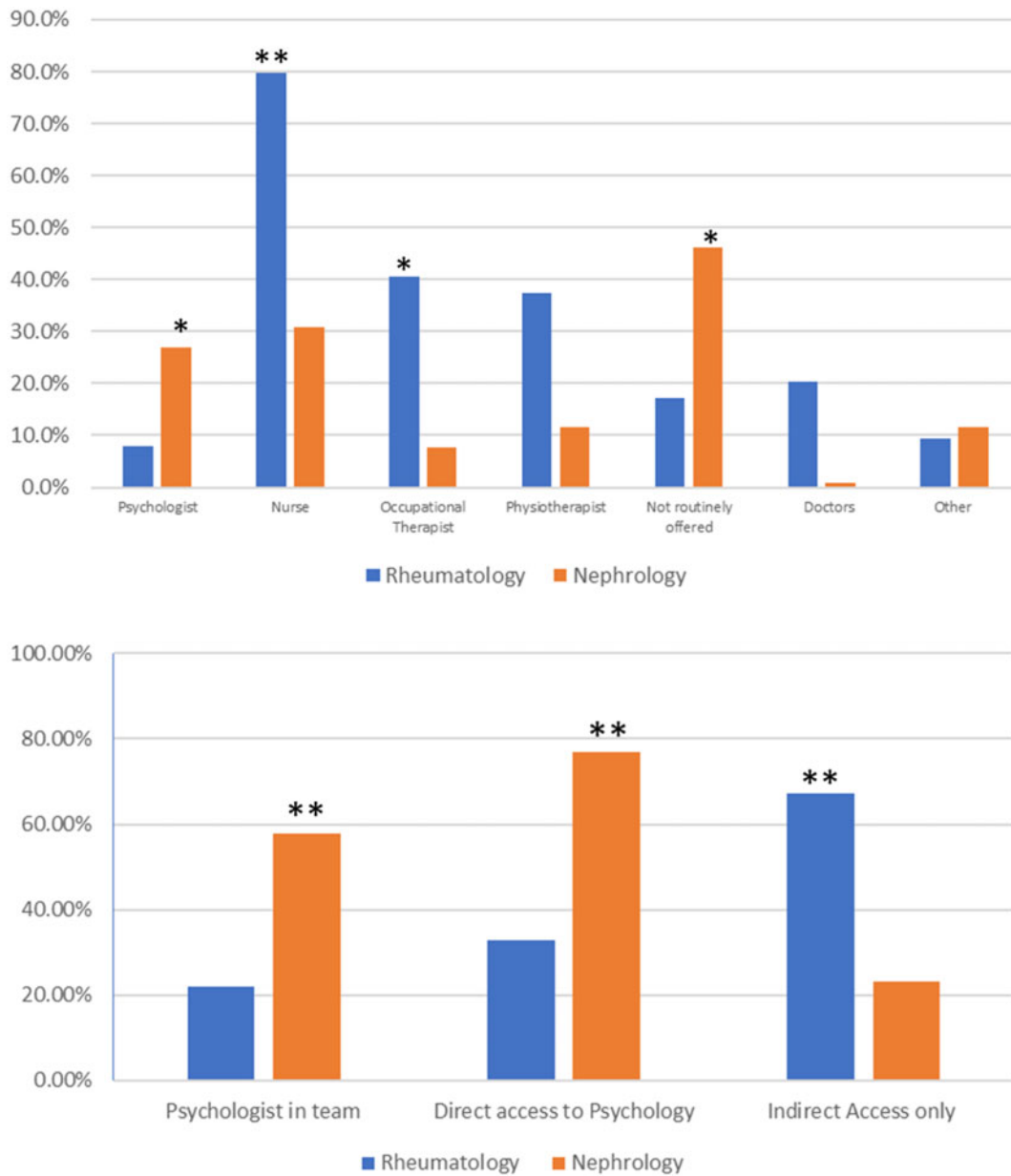
Overall, 18.3% of participants ($n = 17$) reported having self-management clinics (i.e. one-to-one support) or group programmes in their department that included people with CTD and vasculitis (14 from rheumatology and 2 from nephrology).

Health professionals reported that the self-management support currently provided is delivered by AHPs (53%), nurses (52.5%), doctors (12.5%) and psychologists (10%). Differences were seen between rheumatology and nephrology departments in terms of who provided self-management support, with a higher proportion of nurse specialists and AHPs in rheumatology ([Fig. 1A](#)).

Approximately 40% of health professionals were able to provide direct access to psychological support for their patients with CTD or vasculitis, either in their department or hospital. There was greater access within nephrology (20/26; 76.9%) compared with rheumatology departments (21/64; 32.8%; $\chi^2 = 19.10$, $P < 0.001$, OR = 6.8). Health professionals in nephrology were also more likely to have a psychologist in their team (15/26; 57.7%) than in rheumatology departments (14/64; 21.9%; $\chi^2 = 13.83$, $P < 0.001$, OR = 4.9). Health professionals working in rheumatology departments were more likely than those in nephrology departments to rely on indirect referrals for psychological support (signposting to general practice or self-referral to community providers; $\chi^2 = 14.93$, $P = 0.001$, OR = 4.82; [Fig. 1B](#)).

Health professionals' ratings of self-management support provision for people with CTD and vasculitis

The quality of the self-management support provided was rated by 61.8% of respondents as providing

Fig. 1 Who is providing self-management and psychological support for people with systemic vasculitis or CTD?

(A) Comparison between health professionals. Other is defined as including podiatrists, pharmacists and wellness team. **(B)** Comparison between rheumatology and nephrology departments. Direct access is defined as a psychologist available to patients with CTD or vasculitis within the team or hospital. Indirect access to a psychologist is defined as health professionals either signposting patients back to general practitioners or advising self-referral to community providers. * $P < 0.05$, ** $P < 0.001$

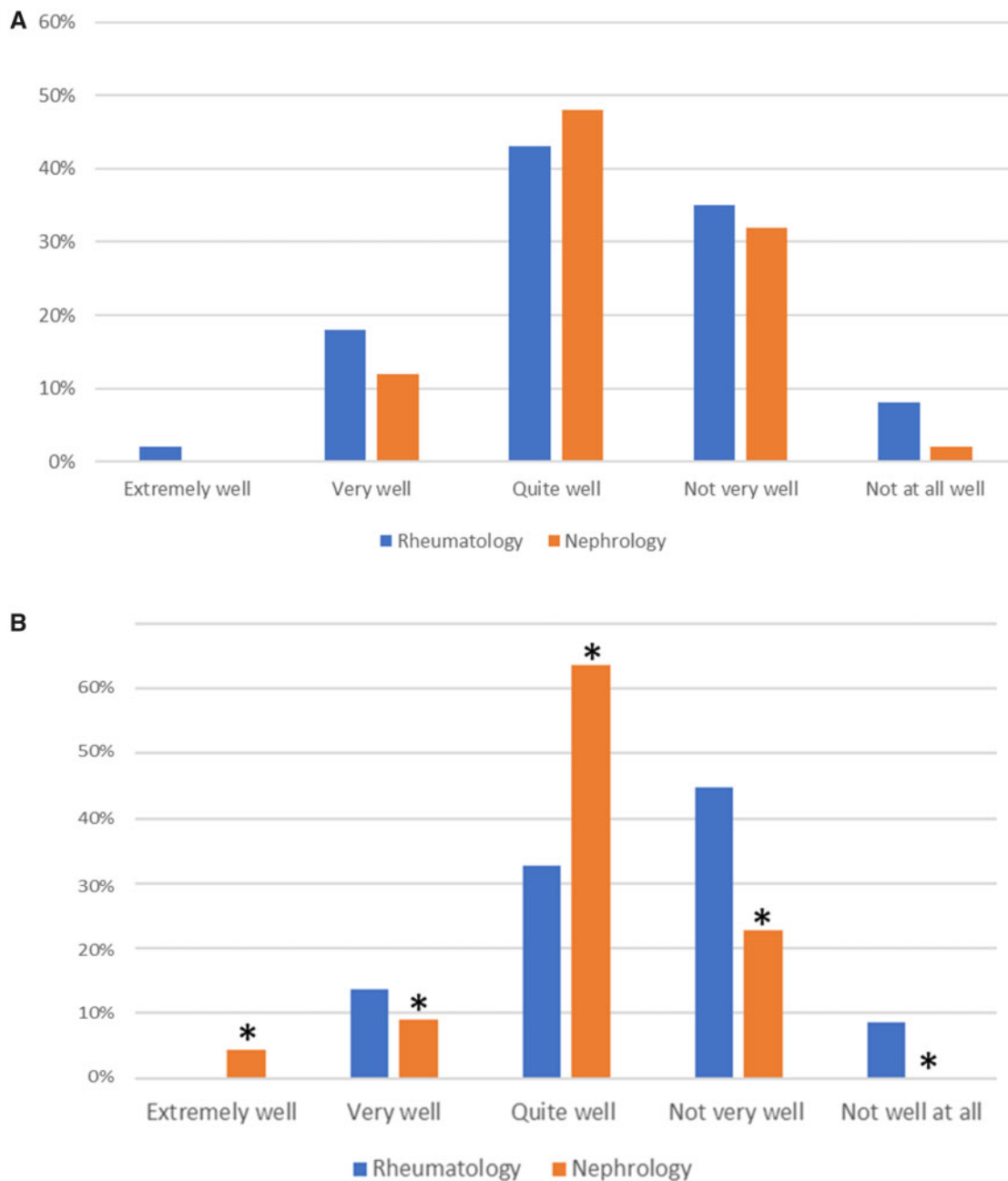
support extremely well, very well or quite well; 38.2% rated their service as providing support not very well or not well at all. There were no differences between those working in nephrology and rheumatology ($\chi^2 = 0.036$, $P = 0.982$) nor between those working in DGHs and those in teaching hospitals or NHS England specialist centres ($\chi^2 = 0.308$, $P = 0.579$). There were no differences in ratings between the assessments given by doctors (57.1% rated self-management provided quite well

or better), nurses (64.3%) and allied health professionals (57.1%, $\chi^2 = 2.39$, $P = 0.495$; Fig. 2A and B).

Health professionals' ratings of psychological support provision for people with CTD and vasculitis

Psychological support was assessed as being provided quite well, very well or extremely well by 53% of those responding overall. Nephrology staff rated the provision

Fig. 2 How well is self management and psychological support provided for people with CTD and Vasculitis?



(A) How well is self-management provided and **(B)** How well is psychological support provided? * $P < 0.05$.

as better, with 77.3% rating their provision as quite well or better, whereas 46.6% of rheumatology staff gave this rating ($\chi^2 = 0.431, P = 0.014, OR = 3.90$).

Where referrals were direct, within the department itself, within the hospital or directly to psychologists or counsellors in the community, more respondents (31/42, 73.8%) rated the quality of the service as higher (well or extremely well provided) than respondents (14/42,

33.3%) in departments where the referrals were indirect ($\chi^2 = 13.832, P < 0.001, OR = 5.6$).

Health professionals from DGHs assessed their psychological support as not very well or not at all well provided in 16/22 (72.7%) of cases, compared with 15/40 (37.1%) of those from teaching hospitals or NHS England specialist centres ($\chi^2 = 8.288, P = 0.004, OR = 4.4$). There were no significant differences between

professional groups; doctors assessed psychological support as being provided quite well or better in 52.1% of cases; nurses assessed support at this level in 53.8%, and allied health professionals assessed it at this level in 50% ($\chi^2 = 1.82$, $P = 0.611$).

Health professionals' confidence and training needs

Self-management support was a role that health professionals undertook regularly (36.5%) or occasionally (48.2%), whereas a smaller number of respondents rarely or never (10.9%) provided support. Fifty-two per cent of nurses, 71.4% of AHPs and 61.2% of doctors said that they felt confident in delivering self-management support. As expected, those who provide self-management support regularly were more likely to be confident in undertaking this task than those who do not do this regularly ($\chi^2 = 26.0$, $P < 0.001$, $OR = 44.2$).

More than 80% of respondents reported that they would like additional training in self-management support for people with CTD and vasculitis. Those less confident were more likely to see training as a priority ($\chi^2 = 4.36$, $P = 0.037$, $OR = 3.9$). Free-text responses showed that training might include brief psychological interventions, communication skills and how to set up a self-management programme (Table 2).

Most professionals felt that they were confident in recognizing patients who would benefit from psychological support (76.9% of nurses, 87.5% of AHPs and 79.2% of doctors).

Analysis of short answer responses

Responses to individual open-ended questions varied from a single phrase or sentence to several paragraphs, with many of the responses being three or four sentences for individual questions. Deductive analysis using the chronic care model as a reference framework was used to analyse the data across responses to these questions. After discussion between the three researchers, 162 individual items were organized into 13 key overarching themes and aligned with one of the six interrelated elements of the CCM [health systems (Table 2), decision support, clinical information systems, patient self-management support, community resources and delivery system design (Table 3)]. No themes were identified in relationship to clinical information systems. Key themes included the importance of a positive departmental ethos towards supporting self-management (particularly in terms of investment in training and resources), multiple benefits of having psychological support embedded within rheumatology and renal departments, and the importance of multidisciplinary working. Developing a self-management programme specifically for people with CTD and vasculitis or sharing resources provided to people with other conditions, plus staff training to improve confidence in short psychological intervention within clinic appointments were identified as areas of potential service improvement.

Discussion

This is the first study to examine the provision of self-management and psychological support for people with vasculitis and CTD within secondary care in the UK.

More than 80% of health professionals reported that they had no self-management clinics or programmes that catered for patients with CTD or vasculitis in their centres; within nephrology, this rose to >90%. The RAIRDA survey of people with vasculitis and CTDs highlighted that 60% struggle to cope with their disease and 40% felt that they did not have enough information and support from the hospital in living with their condition [14]. In the present survey, almost the same proportion of health professionals (also 40%) felt that self-management was not provided well to people with CTD and vasculitis in their secondary care departments. These results highlight the unmet needs in terms of support for people with rare rheumatic diseases.

Access to specialist psychological support was identified as a key requirement by health professionals in the present survey, in the support of people with CTD and vasculitis. This survey demonstrates some inequalities in access across secondary care attributable to location and speciality. Direct access to psychological support for patients with vasculitis or CTD was available in almost 80% of nephrology departments, but in only one-third of rheumatology departments. Psychological support provision in DGHs was reported as worse (rated as not well provided by 72.7% of health professionals in those centres) compared with that available in teaching hospitals and NHS England specialist centres (rated as not well provided by 37.1%). Health professionals identified similar barriers to providing self-management and psychological support to people with CTD and vasculitis (lack of time, skills and management support) as previously highlighted by a survey of psychological support provision for people with RA in the UK [33].

The main strength of the present survey is the breadth of health professional participants: from a range of medical specialties (predominantly rheumatology and nephrology), with a range of professional backgrounds (nurses, allied health professionals and doctors), from different types of hospitals (teaching, district general and specialist centres for CTD and vasculitis) and from geographical regions across the UK. This study also used mixed methods, using survey data to gain a breadth of perspectives and then short-answer and in-depth interviews to explore topics of greatest interest in more depth.

Although online surveys have advantages in terms of cost and timeliness, there are also disadvantages in control over samples and selection bias [34, 35]. One limitation in this survey is that a higher proportion of participants were from rheumatology departments compared with other departments, and a higher proportion of renal physicians vs renal nurses was included. This might be attributable to the fact that renal nurses are less likely to see patients with CTD/vasculitis unless

TABLE 3 Self-management and psychological support for people with CTD/vasculitis, mapped to chronic care model (elements B–F)

B. Decision support Decisions based on evidence and patients' preferences and needs	Patient centred <ul style="list-style-type: none"> • Use agenda-setting tool within clinic appointments • Engage with patients to understand psychological impact • Training health professionals on what support is available • Variety of options to suit different patients Evidence required <ul style="list-style-type: none"> • Understanding and prioritizing main issues faced by patients (as a group) • Understanding how disease affects individual patients to support them better • Evidenced-based interventions to support self-management • Interventions tailored with disease-specific components 	Decision support requirements <ul style="list-style-type: none"> • <i>Engage with patients and understand psychological impact due to their condition.</i> (Doctor, Rheumatology, Northwest England) • <i>More variety of options to offer people who need help (not everyone responds to the same approach), better links with primary care to join up care and step-down support from hospital to community.</i> (Consultant, Northeast England, Rheumatology) • <i>Develop a more comprehensive, structured approach, supported by evidence for demonstrably effective interventions.</i> (Consultant, Nephrology, Wales) • <i>Tailoring more to disease-specific components. Service design to facilitate referral in all team same message.</i> (AHP, Yorks & Humber, Rheumatology) 	9
D. Patient self-management support Self-management support to enable patients to manage their health-related quality of life and health care	Potential methods of support for self-management within secondary care <ul style="list-style-type: none"> • Specific self-management programmes for people with CTD and vasculitis • Opening up generic self-management programmes • One-to-one self-management support • Written information • Online self-management programme Specific topics: <ul style="list-style-type: none"> • Managing pain • Managing fatigue • Managing symptoms of disease • Guidance to patients on navigation through the NHS system 	Quotes related to self-management support in secondary care <ul style="list-style-type: none"> • <i>The initial approaching of the patient and making him/her realize that their role is vital and empower them to take a leading role for certain aspects of their care.</i> (Consultant, West Midlands, Rheumatology) • <i>We have a multidisciplinary team who deliver self-management support for a wide range of rheumatology conditions. Self-management support for patients with CTD/vasculitis is offered on a 1:1 basis at present; however, we are looking into adapting our current 'living well with arthritis' programme to offer a more tailored programme to patients with CTD/vasculitis.</i> (AHP, Rheumatology, Southwest England) 	15
E. Personal and community resources Assets and resources available to help mobilize patient action	Community resources – what is helpful? <ul style="list-style-type: none"> • Peer support • Local support groups • National patient charities • Online and written information Staff knowledge needed <ul style="list-style-type: none"> • Awareness of support options • How/where to signpost to for support 	Quotes related to accessing community resources <ul style="list-style-type: none"> • <i>Online support via charities and mental health charities/NHS Choices anxiety and depression, Mind, Mindfulness, mood gym etc.</i> (Specialist Nurse, Rheumatology, West Midlands). • <i>We don't have a specialist nurse with an interest in vasculitis – I think this would help. We do refer to a peer support group and Web-based resources, but don't have specific written information.</i> (Consultant, Wales, Nephrology) • <i>Patient-centred team approach, knowledge of local services and resources for signposting patients.</i> (Specialist Nurse, Southwest England, Rheumatology) 	12
F. Delivery system design Design of clinical care and self-management support, including team care and preparation	Design of delivery systems to support people with CTD and vasculitis <ul style="list-style-type: none"> • Pathway for people with CTD/vasculitis • Timely access to services at diagnosis and during flare/rapid review • Advice line support • Continuity of care Multidisciplinary approach is important for people with CTD and vasculitis <ul style="list-style-type: none"> • Specialist nurse with interest in CTD/vasculitis to act as key contact for people • Access to occupational health, physiotherapy and psychological support when needed • Embedded psychologist has multiple benefits 	Importance of service design <ul style="list-style-type: none"> • <i>A pathway for patients with CTD/vasculitis and making appropriate services available to all inflammatory rheumatic diseases rather than disease specific or just inflammatory arthritis.</i> (Specialist Nurse, Rheumatology, Southwest England) • [importance of] <i>Specialist teams rather than individual clinicians, nurse specialist for vasculitis.</i> (Consultant, Nephrology, Southwest England) • <i>Psychologists as part of the team. MDT approach facilitating a joined-up approach. Working with psychologists in group programmes.</i> (AHP, Yorks & Humber, Rheumatology) 	51

Chronic care model (elements B–F): B, decision support; D, patient self-management; E, personal and community resources; F, delivery system design. No themes mapped to C, clinical information systems; AHP, allied health professional; MDT, multidisciplinary team.

they are on dialysis, because they do not tend to do outpatient clinics, as opposed to rheumatology specialist nurses, who may lead or work in parallel with rheumatologists in the outpatient clinics. There was also a higher proportion of allied health professionals working within rheumatology, as would be expected for a speciality focused on musculoskeletal conditions.

The biggest limitation to this survey is that it is likely to have been completed by health professionals with an interest in these topics; therefore, the survey might not capture the full breadth of views and experiences. However, 80% of health professionals were keen to receive further training specific to self-management in CTD and vasculitis. There was also a higher proportion of respondents from teaching hospitals/specialist CTD or vasculitis centres than from DGHs. Specialist centres might potentially benefit from an increase in psychological and self-management provision because they have a greater pool of patients with these diseases. The true provision across DGHs across the UK might therefore be much lower outside these centres. In order to maintain anonymity, we did not record the exact institution each health professional came from; this could be a limitation of the survey if more than one respondent came from the same hospital. We did, however, record respondents' geographical distribution ([Supplementary Table S1](#), available at *Rheumatology Advances in Practice* online). Respondents were from nine different English regions, plus Wales, Northern Ireland and Scotland, and this supports the generalizability of the findings across the UK.

Management guidelines for treatment of people with CTDs and vasculitis focus mainly on treatment of physical symptoms, although patient education and care within a wider multidisciplinary team are also highlighted [2, 36–39]. This survey demonstrates the range of health professionals who are currently delivering self-management support for people with CTDs and vasculitis in the UK, primarily within individual clinic appointment settings. Evidence from studies in SLE and RA has demonstrated the potential positive impact of self-management programmes on patient wellbeing and reduction in resource utilization [17, 40–44]. Current research studies targeting fatigue include a remotely delivered cognitive behavioural and graded exercise programme for people across the inflammatory rheumatic diseases [45, 46] and a disease-specific feasibility study of a combined physical activity and behavioural support intervention in ANCA-associated vasculitis [47].

This study highlights a range of proposals on how to improve provision of self-management and psychological support, identified by health professionals working with people with CTD and vasculitis. These include broadening access to generic self-management courses, developing new courses specifically designed for people with CTD or vasculitis, or use of brief psychological interventions for use within routine clinic appointments by all health professionals. Development of future interventions will need to include all stakeholders, including

patients, staff and funders. The key finding in terms of psychological support is the broad-ranging benefits of having an embedded psychologist within the clinical team for people with CTD and vasculitis, by contributing to a supportive team ethos focused on self-management and psychological support, delivery of specialist group and one-to-one interventions, and by practical support and training of the wider multidisciplinary team.

Funding: This work was supported by a grant from the Faculty of Health and Applied Sciences (HAS) Quality-Related Research (QR) Fund for Cross-Research Centres/Groups Collaboration, University of the West England, Bristol.

Disclosure statement: The authors have declared no conflicts of interest.

Supplementary data

Supplementary data are available at *Rheumatology Advances in Practice* online.

References

- 1 NHS England. NHS standard contract for specialised rheumatology services (adult). London: NHS England, 2014.
- 2 Ntatsaki E, Carruthers D, Chakravarty K *et al.* BSR and BHPR guideline for the management of adults with ANCA-associated vasculitis. *Rheumatology* 2014;53: 2306–9.
- 3 Denton CP, Hughes M, Gak N *et al.* BSR and BHPR guideline for the treatment of systemic sclerosis. *Rheumatology* 2016;55:1906–10.
- 4 Gordon PA, Winer JB, Hoogendijk JE, Choy EHS. Immunosuppressant and immunomodulatory treatment for dermatomyositis and polymyositis. *Cochrane Database Syst Rev* 2012;(8):CD003643. doi: 10.1002/14651858.CD003643.pub4
- 5 Flossmann O, Berden A, de Groot K *et al.* Long-term patient survival in ANCA-associated vasculitis. *Ann Rheum Dis* 2011;70:488–94.
- 6 Quaresma M, Coleman MP, Rachet B. 40-year trends in an index of survival for all cancers combined and survival adjusted for age and sex for each cancer in England and Wales, 1971–2011: a population-based study. *Lancet* 2015;385:1206–18.
- 7 Fellow-Smith E, Moss-Morris R, Tylee A *et al.* Investing in emotional and psychological wellbeing for patients with long term conditions. London: NHS Confederation, 2012.
- 8 Basu N, Jones GT, Fluck N *et al.* Fatigue: a principal contributor to impaired quality of life in ANCA-associated vasculitis. *Rheumatology* 2010;49:1383–90.
- 9 McElhone K, Abbott J, Gray J *et al.* Patient perspective of systemic lupus erythematosus in relation to health-

- related quality of life concepts: a qualitative study. *Lupus* 2010;19:1640–7.
- 10 van Lankveld WGJM, Vonk MC, Teunissen H, van den Hoogan FHJ. Appearance self-esteem in systemic sclerosis—subjective experience of skin deformity and its relationship with physician-assessed skin involvement, disease status and psychological variables. *Rheumatology* 2007;46:872–6.
 - 11 Leclair V, Regardt M, Wojcik S *et al.* Health-related quality of life (HRQoL) in idiopathic inflammatory myopathy: a systematic review. *PLoS One* 2016;11: e0160753.
 - 12 Sutanto B, Singh-Grewal D, McNeil HP *et al.* Experiences and perspectives of adults living with systemic lupus erythematosus: thematic synthesis of qualitative studies. *Arthritis Care Res* 2013;65:1752–65.
 - 13 Brennan KA, Creaven AM. Living with invisible illness: social support experiences of individuals with systemic lupus erythematosus. *Qual Life Res* 2016;25:1227–35.
 - 14 Feinmann J, Hopgood J, Lanyon P *et al.* Reduce, improve, empower: addressing the shared needs of rare autoimmune rheumatic diseases. Rare auto-immune rheumatic disease alliance, 2018. <https://rairda.org/our-reports/> (2 June 2020, date last accessed).
 - 15 Hyphantis TN, Tsifetaki N, Sifaka V *et al.* The impact of psychological functioning upon systemic sclerosis patients' quality of life. *Semin Arthritis Rheum* 2007;37: 81–92.
 - 16 Nguyen C, Ranque B, Baubet T *et al.* Clinical, functional and health-related quality of life correlates of clinically significant symptoms of anxiety and depression in patients with systemic sclerosis: a cross-sectional survey. *PLoS One* 2014;9:e90484.
 - 17 Lorig KR, Mazonson PD, Holman HR. Evidence suggesting that health education for self-management in patients with chronic arthritis has sustained health benefits while reducing health care costs. *Arthritis Rheum* 1993;36:439–46.
 - 18 Courbier S, Berjonneau E. Juggling care and daily life: the balancing act of the rare disease community. Paris: Eurodis, 2017.
 - 19 Department of Health, Northern Ireland Executive, Scottish Government *et al.* The UK strategy for rare diseases. London: Department of Health, 2013.
 - 20 Peter Lanyon on behalf of the British Society of Rheumatology. A collaborative approach to improving outcomes in rare rheumatic and musculoskeletal diseases: report from a national workshop. London: The British Society for Rheumatology, 2016.
 - 21 NHS England. Five year forward view. London: NHS England, 2014.
 - 22 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.
 - 23 Mooney J, Spalding N, Poland F *et al.* The informational needs of patients with ANCA-associated vasculitis—development of an informational needs questionnaire. *Rheumatology* 2014;53:1414–21.
 - 24 Waldron N, Brown S, Hewlett S *et al.* '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.
 - 25 Zhang J, Wei W, Wang CM. Effects of psychological interventions for patients with systemic lupus erythematosus: a systematic review and meta-analysis. *Lupus* 2012;21:1077–87.
 - 26 Qualtrics [program]. 01/19–08/19 Version. Provo, UT: Qualtrics, 2005.
 - 27 Robson J. Unmet needs of patients with rare rheumatic diseases. Birmingham: British Society for Rheumatology, 2019.
 - 28 Szumilas M. Explaining odds ratios. *J Can Acad Child Adolesc Psychiatry* 2010;19:227–9.
 - 29 Colman AM. A dictionary of psychology. 3rd edn. Oxford: Oxford University Press, 2008.
 - 30 Nvivo qualitative data analysis software [program]. Version 12. Doncaster, Victoria, Australia: QSR International, 2018.
 - 31 Thomas D. A general inductive approach for qualitative data analysis. *Am J Eval* 2006;27:237–46.
 - 32 Wagner E. Chronic disease management: what will it take to improve care for chronic illness? *J Eff Clin Pract* 1998;1:2–4.
 - 33 Dures E, Almeida C, Caesley J *et al.* A survey of psychological support provision for people with inflammatory arthritis in secondary care in England. *Musculoskeletal Care* 2014;12:173–81.
 - 34 Aerny-Perreten N, Domínguez-Berjón MF, Esteban-Vasallo MD *et al.* Participation and factors associated with late or non-response to an online survey in primary care. *J Eval Clin Pract* 2015;21:688–93.
 - 35 Arafa AE, Anzengruber F, Mostafa AM, Navarini AA. Perspectives of online surveys in dermatology. *J Eur Acad Dermatol Venereol* 2019;33:511–20.
 - 36 Gordon C, Amisshah-Arthur M-B, Gayed M *et al.* The British Society for Rheumatology guideline for the management of systemic lupus erythematosus in adults. *Rheumatology* 2018;57:e1–e45.
 - 37 Denton CP, Hughes M, Gak N *et al.* BSR and BHRP guideline for the treatment of systemic sclerosis. *Rheumatology* 2016;55:1906–10.
 - 38 Price EJ, Rauz S, Tappuni AR *et al.* The British Society for Rheumatology guideline for the management of adults with primary Sjögren's Syndrome. *Rheumatology* 2017;56:1828.
 - 39 Schmidt J. Current classification and management of inflammatory myopathies. *J Neuromuscul Dis* 2018;5: 109–29.
 - 40 Sharpe L, Sensky T, Timberlake N *et al.* A blind, randomized, controlled trial of cognitive-behavioural intervention for patients with recent onset rheumatoid arthritis: preventing psychological and physical morbidity. *Pain* 2001;89:275–83.
 - 41 Sharpe L, Sensky T, Timberlake N *et al.* Long-term efficacy of a cognitive behavioural treatment from a

- randomized controlled trial for patients recently diagnosed with rheumatoid arthritis. *Rheumatology* 2003; 42:435–41.
- 42 Hewlett S, Ambler N, Almeida C *et al.* Self-management of fatigue in rheumatoid arthritis: a randomised controlled trial of group cognitive-behavioural therapy. *Ann Rheum Dis* 2011;70:1060–1067.
- 43 Brady TJ, Murphy L, O’Colmain BJ *et al.* A meta-analysis of health status, health behaviors, and health care utilization outcomes of the Chronic Disease Self-Management Program. *Prev Chronic Dis* 2013;10: 120112–12.
- 44 Panagioti M, Richardson G, Small N *et al.* Self-management support interventions to reduce health care utilisation without compromising outcomes: a systematic review and meta-analysis. *BMC Health Serv Res* 2014; 14:356.
- 45 Thorpe CT, Devellis RF, Lewis MA *et al.* Development and initial evaluation of a measure of self-management for adults with antineutrophil cytoplasmic antibody-associated small-vessel vasculitis. *Arthritis Rheum* 2007; 57:1296–302.
- 46 Al-Janabi H, Flynn TN, Coast J. Development of a self-report measure of capability wellbeing for adults: the ICECAP-A. *Qual Life Res* 2012;21:167–76.
- 47 Harper L, Morgan MD, Chanouzas D *et al.* Treatment of fatigue with physical activity and behavioural change support in vasculitis: study protocol for an open-label randomised controlled feasibility study. *BMJ Open* 2018; 8:e023769.