



Support available for and perceived priorities of people with polymyalgia rheumatica and giant cell arteritis: results of the PMRGCAuk members' survey 2017

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Abstract

Polymyalgia rheumatica and giant cell arteritis are relatively common, but under research inflammatory rheumatological conditions. This survey aimed to ascertain the matters in which patients feel they need support with these conditions and appraise how the Charity PMRGCAuk currently supports these needs and could do so in the future. PMRGCAuk members ($n = 910$) were invited to complete an on-line survey. The survey requested the respondent's history of PMR and or GCA, their perceived priorities for support for people with PMR and or GCA and views on the services already provided by the Charity. A total of 209 people completed the survey. Less than 24% had heard of either PMR or GCA before their diagnosis. Priorities in supporting people with PMR and or GCA included: being on and tapering off glucocorticoids (76.6%), specifically, length of treatment and the risks versus benefits and managing side effects. Respondents generally reported satisfaction with the services currently provided by PMRGCAuk. The support provided by PMRGCAuk is very helpful to members and fills an important gap in provision for people with PMR and or GCA. The areas in which the greatest proportions of participants requested support do not have an evidence base to underpin them. It is incumbent on the research community to address patients' concerns and provide an evidence base where it is required by those affected.

Keywords Giant cell arteritis · Patient involvement · Polymyalgia rheumatica

Introduction

Polymyalgia rheumatica (PMR) and giant cell arteritis (GCA) are closely associated inflammatory rheumatological conditions affecting older people. PMR can cause pain and stiffness in the shoulders and hip girdles, whilst GCA classically presents with a headache, scalp tenderness and sometimes jaw or tongue claudication and can, if not treated, cause irreversible blindness.

Both conditions are usually accompanied by raised inflammatory markers (e.g. ESR, CRP) and can also occur with systemic symptoms such as fever, unintentional weight loss and fatigue [1]. PMR and GCA commonly co-exist and are often thought of as being part of a disease spectrum. Estimates vary, but 16 to 21% of those with PMR will go on to develop GCA, whilst 40 to 60% of those with GCA will also have symptoms of PMR during their illness [2].

Although relatively common, with a lifetime prevalence of 2.4% in women and 1.7% in men [3], PMR has received little research attention, particularly in the primary care setting, where over 80% of patients are exclusively diagnosed and managed [4]. Currently, the recommended first-line treatment for PMR in international guidelines remains medium- to low-dose oral glucocorticoids, which are not always popular with patients [5]. Other treatments for refractory disease and those

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with an intolerance to glucocorticoids have been suggested (e.g. methotrexate, tocilizumab) [6, 7], but the evidence for these is still limited.

Although less common than PMR, GCA has potentially serious complications (e.g. irreversible sight loss if left untreated) and requires higher doses of glucocorticoids for successful treatment. There has recently been a trial of tocilizumab as a glucocorticoid sparing agent in GCA [8], prompting guidance from the National Institute for Health and Care Excellence in the UK [9].

In order to support people with PMR and GCA, the charity PMRGCAuk was formed in 2010 after a group of patients contacted each other via an Internet forum. It now has over 900 members, with others having signed up via the website to receive regular newsletters. The charity provides invaluable education, advice and peer support to those people with PMR and/or GCA and their carers. This fills an important gap where research evidence is limited and pragmatic advice, through traditional medical routes, on living with PMR and or GCA and managing its treatment is lacking. Support is available via four main routes: local support group meetings, a telephone helpline, a web forum (hosted by the HealthUnlocked website [10]) and the charity's own dedicated website. The Charity also produces a regular newsletter, called NewsWire. NewsWire details recent and upcoming events, as well as new developments in health services and research for PMR and GCA.

In the spring/summer of 2017, PMRGCAuk conducted a survey of its membership and other interested parties known to the charity and receiving regular updates from them. The aims of this survey were to understand more fully the priorities of their membership in terms for support for living with PMR and or GCA, to evaluate the services provided by the charity and the impact they were having, and to provide an opportunity for interested parties to suggest improvements to their services. In this paper, we summarise the results of the survey and its potential implications for the rheumatology research community.

Methods

Study design

The cross-sectional survey of 13 questions was conducted by PMRGCAuk using [SurveyMonkey.com](https://www.surveymonkey.com). A link to the survey was emailed to all members ($n = 910$) and other contacts on the charity mailing list with a valid email address in April 2017. The survey was also advertised in the NewsWire newsletter, which was sent by post to all members in the same month, and via the Charity's website and social media outlets including Facebook, Twitter and the HealthUnlocked forum [10]. Potential participants were also able to contact the

Charity to ask for paper copies of the questionnaire to be sent in the post and responses were entered manually into SurveyMonkey on their return to the Charity's office. The survey was closed at the end of July 2017.

As this was a service evaluation conducted by the Charity, ethical approvals were not required.

Data collection

The survey collected information in three broad areas, as outlined below.

Background information on PMR/GCA

Survey participants were asked to indicate whether they had PMR, GCA, both or had recovered from their condition. Where these responses were not applicable, a text box was available for the respondent to give their chosen response. They were also asked how long ago they were diagnosed, whether they had heard of PMR and or GCA before they received their diagnosis and how they had become aware of the Charity.

Priorities for supporting people with PMR and GCA

Respondents were asked in the survey to choose up to five of 14 pre-defined aspects of supporting people with PMR and or GCA that they felt were most important. One of these options was "being on and tapering off steroids". Respondents who chose this option were then asked to complete a further item to provide more detail on their response. This additional detail was added after treatment with glucocorticoids was established as a major concern for the Charity's members in a previous survey [5].

Satisfaction with services provided by the Charity

Participants were asked to consider their use of each of the avenues of support provided by the Charity (local groups, helpline, forum, website) and to rate their agreement with various statements regarding each form of support on a four-point Likert scale (strongly disagree, disagree, agree, strongly agree), with a fifth option of "don't know/not applicable". For each of the avenues of support, there was also a free text option to invite respondents to comment on how the service provided by the Charity could be improved.

In addition, this section contained items asking respondents if they did not attend a support group meeting, what their reasons were for not attending and asked would they like to join a telephone support group if one were available. There were also specific questions regarding use of the telephone helpline.

Data analysis

For the purpose of analysis, the Likert scales were categorised to ‘Agree’ (strongly agree, agree) versus ‘Disagree’ (disagree, strongly disagree). “Don’t know/not applicable” was treated as missing, because these respondents did not express an opinion. Closed questions were analysed using frequencies and percentages. For items relating to current status of the respondents PMR and or GCA, how they found out about PMRGCAuk and why they do not attend a support group in person, where possible the responses in the text box were transposed into the pre-defined response options. Where this was not possible, the additional responses are noted in the footnotes to the tables.

Data from the text boxes relating to how each avenue of support could be improved were analysed independently by two researchers (SM, CAH) to identify recurring themes.

Data availability All data generated or analysed during this study are included in this published article [and its supplementary information files].

Results

A total of 209 surveys were completed: 206 online via SurveyMonkey and three via printed versions of the questionnaire. The majority of respondents reported having PMR ($n = 120, 57.4\%$), whilst approximately equal numbers reported having GCA, both conditions or being a recovered patient (Table 1). A total of 4.8% ($n = 10$) reported their condition having started in the previous 3 months and 20.3% ($n = 42$) between 3 and 12 months prior to response. A fifth of respondents reported the time since diagnosis as more than 5 years ($n = 41, 19.8\%$). Less than a quarter of people reported having heard of PMR or GCA before their diagnosis ($n = 48, 23.3\%$). The majority of people reported having found out about the Charity through an Internet search ($n = 110, 64.7\%$). A fifth were told about it by a doctor ($n = 45, 26.5\%$). The next largest groups were those reading about the group in a magazine/newspaper, or being told by word-of-mouth, which was not an option on the survey, but frequently given as a response in the accompanying free text item.

The priority for supporting people with PMR and or GCA most often chosen as important by respondents was “being on and tapering off steroids” ($n = 160, 76.6\%$) (Table 2). The aspect of glucocorticoid treatment that respondents were most concerned about was the tapering of the dose, with over 90% ($n = 145$) of people identifying this as an issue. A total of 63% ($n = 101$) wanted information on the duration of treatment with over 61% of people ($n = 99$) endorsing items relating to benefits and side effects of treatment and how to manage side

Table 1 Characteristics of respondents

	<i>n</i> (%)
PMR/GCA status	
Have PMR	120 (57.4)
Have GCA	32 (15.3)
Have PMR and GCA	30 (14.4)
Recovered patient (either condition)	21 (10.1)
Other ^a	6 (2.9)
Time since diagnosis	
> 5 years	41 (19.8)
3–5 years	39 (18.8)
2–3 years	41 (19.8)
1–2 years	34 (16.4)
3–12 months	42 (20.3)
< 3 months	10 (4.8)
Had heard of PMR/GCA before diagnosis	48 (23.3)
First became aware of PMRGCAuk	
Reading magazine/newspaper	8 (4.7)
Poster	2 (1.1)
Internet search	110 (64.7)
Doctor	45 (26.5)
Calling a helpline	1 (0.6)
Facebook/Twitter	0 (0.0)
Local support group	3 (1.8)
NewsWire ^b magazine	1 (0.6)
Conference/exhibition	0 (0.0)

^a Includes 5 people where diagnosis is unclear/changed from PMR/GCA and 1 carer

effects. The need for information on how to take steroids was less widely requested ($n = 56, 35.0\%$).

Approximately half of patients reported “managing fatigue and debilitation” and “knowing whether what is happening to me is ‘normal’” to be important. New research ($n = 95, 45.5\%$) and the outlook for recovery ($n = 83, 39.7\%$) were the next two most highly prioritised aspects. With the exception of diet and nutrition (13.4%) and work and employment (2.4%), all aspects of which the survey enquired were endorsed by at least 20% of respondents.

Respondents were generally very positive about support provided by the Charity (Table 3). However, 25.7% of people ($n = 27$) reported being confused by other people’s responses on the HealthUnlocked forum. Additional suggestions for the support groups included trying to boost attendance at meetings, having more structure/national input and external speakers. Also, comments were made regarding the website to improve user-friendliness, especially on a tablet/mobile device, which was targeted as a point for improvement. For the helpline, there was a suggestion to have an alternative for those who cannot use a telephone (e.g. hearing impairment). Across the local group meetings, forum and website, there

Table 2 Important aspects in supporting people with PMR/GCA

	<i>n</i> (%)
Being on and tapering off steroids	160 (76.6)
Information on additional/alternative medication (e.g. pain relief, methotrexate)	60 (28.7)
Outlook for recovery	83 (39.7)
Sight loss caused by undiagnosed GCA	58 (27.8)
Managing pain	50 (23.9)
Managing fatigue and debilitation	108 (51.7)
Regular contact with people with similar condition	65 (31.1)
Knowing whether what is happening to me is 'normal'	105 (50.2)
Diet and nutrition	28 (13.4)
Relationships with doctors	55 (26.3)
Support with identifying options and choices	42 (20.1)
Exercise and mobility	50 (23.9)
New research	95 (45.5)
Work and employment	5 (2.4)
Priorities specific to steroid treatment ^a	
Information on how to take steroids	56 (35.0)
Information the benefits and side effects of steroids	99 (61.9)
Information and support on how to manage steroid side effects	110 (68.8)
Information on how long I can expect to be on steroids	101 (63.1)
Information and support on how to taper the steroid dose.	145 (90.6)

^a Only in those reporting "being on and tapering off steroids" as a priority

were suggestions that PMR and GCA should be more separated, as GCA appears not to get the same 'coverage' as PMR.

The majority of people, who did not attend a local support group, did not do so because there was not one close by ($n = 63$, 64.3%) (Table 4). However, there was some interest in the idea of a telephone support group, with 43.3% of those responding to the question ($n = 81$) reporting that they might join if one were available.

Discussion

Discussion

This survey has provided contemporary insights into the areas in which members of a PMR and GCA support charity think support and further research are important. These areas were broadly around management and prognosis. It also identified that members of PMRGCAuk are largely very satisfied with the support they receive from the Charity.

At the time of the survey, membership of PMRGCAuk was approximately 910, but the survey was also sent to other contacts of the Charity who were not members and there is the possibility that the survey may have reached other people as well. Hence, there is no denominator population against which to compare survey responders. However, we do not expect the reach to be large, as this

is a relatively small patient community. Furthermore, the Charity did not request demographic information in the survey, and so, the respondents cannot be compared to a 'classical' PMR or GCA population. However, whether or not the sample is in any way 'representative' is largely irrelevant for the purposes of this paper and indeed includes one person who was a carer, rather than patient or former patient. It would seem unlikely that the survey has been completed by anyone who does not have an interest in either or both of the conditions, and the focus was to recognise what is important to a range of people with an interest in the conditions and to understand whether the charity is fulfilling its objectives. In this setting, the engagement of interested parties is seen by advisory groups, such as INVOLVE, as more important than representativeness [11]. Results from this survey give an insight into the opinions of those who seek help in managing these conditions over and above what has been offered by their usual health services. The completion of the survey by at least one person who reported themselves to be a carer is important for the Charity, who suspect that this is a growing group of people that needs their support. It should also therefore be a relevant group of people for clinicians, as they work with friends and relatives in caring for patients.

As populations age and the number of health conditions to be managed grows, collaboration between formal

Table 3 Services provided by PMRGCAuk

	<i>n</i> (%)
Usefulness of support group (<i>n</i> (%) agree/strongly agree)	
Helpful to meet other people with same condition	92 (96.8)
Guest speakers give useful information	56 (96.6)
Being part of group helps manage condition	81 (93.1)
Being part of group helps to feel more in control of treatment	76 (90.5)
Being part of group improves optimism for recovery	69 (80.2)
Group is well organised	82 (95.4)
Group members give personal support by phone/email	30 (73.2)
Usefulness of helpline (<i>n</i> (%) agree/strongly agree)	
Number easy to find	49 (96.1)
Person who answered was helpful	49 (100.0)
Person who answered was good listener	46 (100.0)
Person who answered was knowledgeable	46 (97.9)
Received useful information during call	46 (97.9)
Good to talk to someone with experience of condition	45 (97.8)
Felt less anxious after call	39 (92.9)
Usefulness of web forum (<i>n</i> (%) agree/strongly agree)	
Helpful to meet other people with same condition	98 (96.1)
Helps to feel less alone with condition	106 (95.5)
Helps to manage condition	102 (96.2)
Helps to feel more in control of treatment	101 (96.2)
Improves optimism for recovery	87 (86.1)
Reading other people's experiences is reassuring	99 (90.0)
Reading other people's experiences is confusing	27 (25.7)
Helpful to feel better equipped to ask right questions of doctor	102 (94.4)
Usefulness of website (<i>n</i> (%) agree/strongly agree)	
Easy to find	161 (98.2)
Easy to navigate	150 (95.5)
Visually attractive	143 (98.0)
Appears up to date	146 (98.0)
Found what was looking for	138 (92.6)
Would go back again if needed more information	152 (95.0)
Would rather use a different site to get information	27 (19.2)
Website creates good impression of the charity	146 (97.3)

PMRGCAuk members' magazine

health services and the third sector (especially those promoting self-management strategies) will be key to providing comprehensive care to patients with a wide range of conditions. For example, The King's Fund's number 1 priority for commissioners is to provide active support for self-management [12] and the recent NHS "Realising the Value" programme [13] to support active patient self-management has been in partnership with a number of voluntary organisations. This type of partnership is likely to continue. As such, evaluations of the services provided by charities, such as PMRGCAuk, are relevant to clinicians so that they can ensure they signpost their patients to relevant sources of support.

The administration of the survey via SurveyMonkey may have impeded its completion by those without internet access, or the "knowhow" to complete the survey. According to recent data from the UK Office for National Statistics, which reports that 90% of those aged 55 to 64 years, 78% of those aged 65 to 74 and 41% of those aged 75 or over have used the Internet in the last 3 months [14], this is only likely to be a problem for those people at the older end of the PMR/GCA spectrum [15]. However, due to financial restrictions, an online survey was the only viable method of large-scale administration. To mitigate this problem as far as possible, the survey was also advertised via in the Newswire magazine. Three people requested and completed paper copies of the survey and some

Table 4 Other aspects of the services provided by PMRGCAuk

	<i>N</i> (%)
Why do not attend groups ^a	
No knowledge of them	14 (11.8)
Cannot make the meeting time	12 (10.1)
No group close enough	64 (53.8)
Have mobility problems	11 (9.2)
Do not want to attend a group	11 (9.2)
Other	7 (5.9)
Would attend telephone support group if available	81 (43.3)
What happened when you called the telephone helpline?	
Answered straightaway	25 (12.0)
Left message on answering machine	18 (8.6)
Did not leave message on answering machine	5 (2.4)
Call returned promptly	15 (7.2)
Requested information pack during call	16 (7.7)
Received information pack after call	17 (8.1)

^a Only in those people who do not currently attend a group

respondents stated in their responses to the open questions that they had made the effort to get someone else to help them complete the survey online.

PMRGCAuk is a UK-based charity and its provision is therefore aimed at patients living in the UK, who will be most likely be treated, at least in part, by the National Health Service (NHS), unless they have chosen to seek exclusively private treatment. This is relatively rare in the UK [16], as the general practitioner still has a gatekeeper role and glucocorticoid prescriptions would still be available on the NHS. However, there was evidence in the survey responses that at least one person completed their survey from the USA. It could be that more people than this were based outside the UK. In addition, many of the results regarding what is important to patients will be relevant to clinicians working outside the UK and in other healthcare settings. For researchers, the lack of an evidence base for elements of care that patients highlighted as important is an international issue, although potentially the importance of those aspects of care will differ.

There are few examples of charities and other patient organisations attempting to share their findings with the research community in as direct a way as a publication such as this. It is encouraging to see that the areas of highest concern to patients align with those highlighted in recent publications from experts in the field as requiring further research (e.g. [17, 18]), as this suggests that this is not a disconnect between theoretical knowledge and clinical practice. However, this is also a major concern, as it highlights gaps in the research field that are perceived, not only by experts, but by patients. Even with funding available to conduct research into these areas (e.g. prognosis, ideal glucocorticoid regimens), which in itself

may be difficult to find in the current climate, recruitment to studies and follow-up to fill these knowledge gaps may take many years.

The majority of respondents thought information surrounding glucocorticoid treatment was important to people diagnosed with PMR and GCA. This is not to say that this information is not currently provided, but specific research evidence is lacking. Respondents reported that information on taking, reducing and the side effects of glucocorticoids was important. The current findings concur with a recent qualitative study with general practitioners [19] and highlight glucocorticoid management as a major area in which the evidence base is lacking and should be improved. For example, the EULAR/ACR guidelines for the treatment of PMR recommend a starting dose of 12.5 to 25 mg of prednisolone daily, and individualised tapering of the dose [7]. This is largely on the basis of expert consensus, rather than empirical evidence, and there is very little to guide the clinician in tapering the dose of an individual patient.

Other factors important to respondents were the outlook for recovery and knowing whether what they were experiencing was ‘normal’. It was also clear that many people do not know about these conditions until they are diagnosed, which may make the process of receiving a diagnosis more difficult and confusing for the patient [20]. While some people reported that the local support groups and the HealthUnlocked forum provided them with reassurance and guidance, it is not scientific, generalizable data that are provided via these media, and reliance on anecdotes could prove problematic. Indeed, around a quarter of respondents reported that they found the discussions on the HealthUnlocked forum confusing. What is required is an evidence base of outcomes in PMR to guide health professionals when discussing prognosis with patients and from which clinicians can provide the information that individual patients want. In order to fully provide for this need, a qualitative study of patients’ needs in relation to information provision is likely to be required.

The other major area of importance to respondents was the management of fatigue. This is something that is well-discussed in other rheumatological conditions (e.g. rheumatoid arthritis), but less so in PMR or GCA. Current EULAR/ACR guidelines conditionally recommend “an individualised exercise programme for PMR patients aimed at the maintenance of muscle mass and function, and reducing risk of falls...” [7]. Such provision of physiotherapy, education relating to pacing or similar graded exercise therapy for those with PMR or GCA, may help patients to pro-actively manage fatigue and debilitation. Further related research is overdue to guide health professionals to select suitable treatments.

Conclusions

Survey respondents highlighted areas of importance to those with PMR and or GCA, emphasising the importance of holistic care and not just medical management, although glucocorticoid treatment and tapering is a key priority. The services provided by PMRGCAuk are generally well received and are important to their members.

Practice implications

The research community should be aware that for many of the aspects of care for those with PMR and or GCA that were highlighted by survey respondents, there is little evidence base from which to provide information or change in practice. This should be addressed as a matter of urgency to improve the quality of life of those diagnosed with these conditions. Specifically, evidence is needed on optimal glucocorticoid regimens, prognosis, and the additional information and guidance that patients require from their doctors and other health professionals. Whilst such evidence is generated, clear and relevant information to aid self-management should be available to those who desire it.

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Compliance with ethical standards

Disclosures None.

Ethics approval and consent to participate Ethical approval was not required for this study as it was a survey of members of the charity PMRGCAuk in order to better inform the services that they provide.

Consent for publication Not applicable.

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