What is the impact of giant cell arteritis on patients’ lives? A UK qualitative study

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ABSTRACT

Objectives Clinical management of giant cell arteritis (GCA) involves balancing the risks and burdens arising from the disease with those arising from treatment, but there is little research on the nature of those burdens. We aimed to explore the impact of giant cell arteritis (GCA) and its treatment on patients’ lives.

Methods UK patients with GCA participated in semi-structured telephone interviews. Inductive thematic analysis was employed.

Results 24 participants were recruited (age: 65–92 years, time since diagnosis: 2 months to >6 years). The overarching themes from analysis were: ongoing symptoms of the disease and its treatment; and ‘life-changing’ impacts. The overall impact of GCA on patients’ lives arose from a changing combination of symptoms, side effects, adaptations to everyday life and impacts on sense of normality. Important factors contributing to loss of normality were glucocorticoid-related treatment burdens and fear about possible future loss of vision.

Conclusions The impact of GCA in patients’ everyday lives can be substantial, multifaceted and ongoing despite apparent control of disease activity. The findings of this study will help doctors better understand patient priorities, legitimise patients’ experiences of GCA and work with patients to set realistic treatment goals and plan adaptations to their everyday lives.

INTRODUCTION

Giant cell arteritis (GCA) is the most common form of primary systemic vasculitis and primarily affects older people.1 2 The vasculitic process may result in ischaemic manifestations such as anterior ischaemic optic neuropathy or jaw claudication, which may produce groups of characteristic symptoms leading to clinical diagnosis. Presentation may, however, be non-specific with systemic features such as fever and weight loss and in this case diagnosis is facilitated by laboratory, histological and imaging tests.

The mainstay of treatment remains high-dose glucocorticoids (initially 40–60mg of prednisone equivalent), aiming to control disease activity. The dose is subsequently tapered gradually over several years but is increased in the face of relapse. Glucocorticoid-related adverse effects result in considerable morbidity in this patient population.3 Thus, clinical management of GCA involves a balance between the risks and burdens of the disease, and the risks and burdens of the treatment. Much has been written about this from the medical perspective; the sparse literature about patient priorities in GCA suggests that patient priorities for GCA include vision, control of arms and legs and personal care abilities.1 Qualitative research to develop patient-relevant outcome measures in large-vessel vasculitis has been conducted with patients with Takayasu arteritis, a rarer form of large-vessel vasculitis that affects younger adults,5 but the experience of older patients...
with GCA remains relatively unexplored. According to Borg and Davidson, ‘when it comes to understanding recovery, the trivialities of everyday life must be seen as anything but trivial’. In order to understand how best to help patients recover from their illness, we aimed to examine GCA and its treatment from the patient perspective, through the lens of its impact on patients’ everyday lives.

METHODS

Design

This was a qualitative study using semi-structured telephone interviews and inductive thematic analysis of data. The study received ethical approval from Keele University’s Research Ethics Committee (Ref. ERP2254) and verbal and written consent was obtained from all participants (a completed paper consent form was posted back to the research team by the participant after each interview).

Participants and data collection

Participants were recruited using two approaches. First, letters were sent to patients with GCA who had taken part in a cross-sectional survey, recruited through general practice medical records, and who had consented to further contact. Second, an email was circulated by the UK charity PMRGCAnk to its regional groups and members, inviting patients to contact the research team for further information. Only patients who reported that a clinician had diagnosed GCA were included. Purposive sampling categories included age, gender and time since diagnosis. JL and CDM developed a list of topics and prompts to guide interview discussions.

Following informed consent, RB conducted and audio-recorded semi-structured telephone interviews with recruited patients with GCA until the point where the research team agreed there were ‘diminishing returns’ from further data collection and that data saturation was sufficient. Brief fieldnotes were written after each interview to record thoughts about emerging analytic themes and data coding.

Analysis

All interview recordings were transcribed and pseudonyms used to preserve participant confidentiality. An inductive thematic approach was taken to analysis. RB completed an initial categorising and line-by-line coding of all data from the transcripts using QSR NVivo V.10 and discussed the development of codes and themes with JL. JL then continued with additional analysis (in discussion with JR and CDM), developing codes and themes focusing specifically on the impact of symptoms and treatment on patients’ everyday lives. After further discussion, JL and JR developed a visual representation of these themes (figure 1).

RESULTS

Participants’ ages ranged from 65 to 92 years and time since diagnosis ranged from 2 months to over 6 years. All participants were White British (table 1). Interviews lasted between 29 and 128 min. One transcript was excluded from analysis because the patient contacted the research team to say that her diagnosis of GCA had been changed to a diagnosis of lymphoma.

Patients did not conceptualise the impact of GCA as a set of discrete symptoms or side effects, but as an ongoing experience, changing over time, resulting from the combination and co-occurrence of multiple factors. Figure 1 is a visual representation of subthemes and codes within the data, demonstrating the psychological impacts, symptoms and side effects that patients experienced, and the aspects of their everyday lives requiring adaptation as a result. Patients were often unable to distinguish between disease-related symptoms and treatment-related side effects and did not make a distinction in terms of impact; the impact and combination of the experiences was most important to patients, regardless of the cause. Presentation of findings reflects this.

Two overarching themes from the qualitative data are presented: ongoing symptoms of the disease and its treatment and ‘life-changing’ impacts.

Theme 1: ongoing symptoms of the disease and its treatment

Patients gave detailed accounts of the symptoms of their disease and its treatment that impacted on their everyday lives, ranging from extreme to minimal. The data in tables 2 and 3 illustrate the extent to which the experience of GCA and its treatment varied between patients, in both type and duration.

Types of symptoms

“The effects it had on me, my body and my mind as well...”

Fatigue, pain, sight loss, other visual symptoms, changes in mood and changes in physical appearance and sleep (table 2) were particularly reported as having implications for the extent to which patients could continue living their lives in the same way as they had done before the onset of GCA. The experience of permanent visual loss was associated with feelings of bereavement and vulnerability. Other generalised, persistent symptoms such as dizziness and loss of strength were also reported by patients.

Duration of impact

“He says, ‘I’m going to give you a course of treatment’, he says, ‘which is gonna last for some time—more like years than weeks’, he says, ‘but it will control it and hopefully we can stop it’.”

The experiences of patients varied widely, with some reporting that the impact of GCA and/or its treatment on their everyday lives had continued for many years after diagnosis (up to 5 years, and longer for those who developed new features such as sight loss), while others reported that the impact of GCA and/or its treatment on their lives had been relatively short-lived.

The impact of symptoms could be categorised as: a) minimal or no long-term impact; b) continuing symptoms over time periods ranging from weeks to years or c) changes in health as a result of permanent visual loss and/or new health problems that now required management (table 3). There were no particular differences between the impacts or types of symptoms that were experienced minimally and those that became long-term.

Some patients had both long-term and permanent impacts. While some of those who experienced long-term impacts and symptoms reported that these resolved or diminished in the months and years following the initiation of treatment, others had not yet perceived such improvements. In particular, the continuation of non-specific symptoms (table 2) caused confusion and frustration for patients, especially in the context of being told that their inflammatory marker test results were within the normal range.

Theme 2: ‘life-changing’ impacts
Patients whose symptoms had resolved quickly did not feel that GCA had changed their lives. However, the ongoing impacts of GCA symptoms and treatment side effects were described as being ‘life changing’ (Cressida, 62, 5 years 5 months since diagnosis) and ‘restricting my life totally’ (Dorothy, 78, 2 years 11 months since diagnosis).

Activities, behaviours and circumstances
“I just used the energy on what I absolutely had to do and everything else was on hold”
Those patients with ongoing symptoms of GCA and its treatment generally described how these had substantially affected their everyday lives including aspects of life such as: work and voluntary roles; relationships; hobbies, social and leisure activities; household tasks, daily routines and personal care; financial circumstances and driving (table 4).
Impacts could be direct (eg, as a result of fatigue or visual loss making activities unmanageable) or indirect (such as the fluctuating nature and unpredictability of symptoms affecting an individual’s ability to plan or commit to future activities or events). Both types of impact required patients to adapt, consequently losing or reducing the sense of normality in their everyday lives. Patients also reflected on the feelings of guilt and regret that they had when their relationships with other people were affected.

Thoughts and feelings
“\textit{To be able to live a normal life, I suppose, is the thing that is desirable}”

Frustration arose as a result of patients being unable to continue with activities and tasks in the same way as they had before the onset of GCA (table 5). Patients talked about how these unwanted adaptations to their everyday lives affected the extent to which they felt independent, and the need to rely on others or ask for help was particularly unwelcome. Such reductions in independence or being unable to continue with everyday life as normal resulted in some patients feeling that they were not coping or managing the situation as well as they believed they should be able to. Their accounts demonstrated tendencies towards self-criticism rather than self-compassion, particularly when a less active, less mentally positive or less independent role was not congruent with their established perceptions of themselves and their identity.

Other psychological impacts were also prominent in patients’ accounts of living with GCA. These included symptoms of low mood or depression mentioned earlier (see table 2), but reduced confidence, fear and uncertainty were also common themes in patients’ accounts (table 5). Visible bodily changes resulting from glucocorticoid treatment and visual loss were two specific causes of feelings of reduced confidence and/or low mood, again impacting on perceptions of self and identity. While the actual experience of symptoms like permanent visual loss was frightening, being afraid of what might happen (ie, losing vision, experiencing a relapse of symptoms and of the potential future side effects of treatment) was a strong theme in the data. This was not exclusive to patients who had experienced ongoing or permanent symptoms.

For those who did express fears about the future, these fears were compounded by the uncertainty that patients felt about the likelihood of events such as visual loss occurring, along with their other unanswered questions about whether their symptoms would improve and which of their symptoms were due to GCA and/or its treatment or other conditions. Reassurance from clinicians sometimes helped to reduce anxiety (table 5). However, the lack of a clear-cut or predictable relationship between the length of time since the onset of symptoms and the impact of GCA and its treatment on patients’ lives (table 3) was a strong feature in the data.

**DISCUSSION**

GCA and its treatment present ongoing physical and psychological problems for patients, affecting their everyday lives in a wide variety of ways. As in a recent study of patients with polymyalgia rheumatica, another inflammatory condition of older people that is primarily treated with glucocorticoids, patients in our study described their experience in terms of collective impacts, rather than focusing on localised symptoms. Practical, social and psychological support may be valuable therapeutic interventions to help patients recover or maintain a sense of normality in everyday life tasks, skills and activities. Patients will likely view recovery as linked with undertaking activities of value and ‘re-assess...
<table>
<thead>
<tr>
<th>Ongoing symptoms reported by patients treated for giant cell arteritis</th>
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<tr>
<td><strong>Fatigue</strong></td>
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<td><strong>Pain</strong></td>
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<td><strong>Sight loss</strong></td>
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<td><strong>Visual symptoms</strong></td>
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<td><strong>Awareness of bone thinning</strong></td>
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Changes in mood

I’m a little bit fed up. I get very fed up because… just fed up with my body really (mmm) and it has debilitated my whole life now. (Sheila, 73, 11 months since diagnosis)

I thought my life was over actually, I thought I can’t go on living like this, I think I’d rather just die, it was no life at all. (June, 75, 2 years since diagnosis)

I think I might have been marginally buoyed along by the steroid pills as well. […] I think also that it made me quite – I wouldn’t say happy but, settled in a funny sort of way, you know? (Barbara, 71, 2 years 10 months since diagnosis)

Psychologically, I suppose, you just feel down a bit and you’re really fed up […] I’m afraid, under the steroids it was really nasty. I’m normally a happy, probably as you gather, chatty bunny. I became quite an intolerant bastard and wouldn’t put up with anything […] I honestly believe that when they upped the dose I should have been locked up […] kept out of people’s way. (Peter, 70, 6 years 8 months since diagnosis)

Changes in appearance

I think at first you are a bit shaken because, err, your face does get a bit bloated and I’ve got some photographs I won’t let anyone see, err, because my face does—I don’t look like myself. My face looks too bloated. (Rose, 73, 1 year since diagnosis)

I’m huge now […] I’ve now put on two and a half stone […] The sweating was constant. That was awful. It was worse—far worse than the menopause ever was. Because I used to use a bath sheet to save washing the sheets—lie on a bath sheet and wear a T-shirt, cotton T-shirt, to soak the sweat up. […] and I didn’t really want to go anywhere because my head was wet, you know, my hair was wet, sweating from my head. (Linda, 68, 8 months since diagnosis)

The skin seems to be that thin it seems to be that it’s almost like tissue so that if I do get just a small bang on it I’ve got a huge bruise there so all my arms are covered in bruises. (Robert, 92, 2 years since diagnosis)

Just seeing my, my face - not so much my body at that point but my face morphing into a frog or a chipmunk. And then the hair down the sides of my face […] I had fat round, round the bottom of my neck […] It was just life, life changing. And my hair then went into—I’ve got curly hair but it went into wiry, very tight curls. It was the most peculiar thing but that was the steroids again… (Cressida, 62, 5 years 5 months since diagnosis)

With the steroids […] I blew up like a balloon. […] It was the face, really. I mean I - my collar size went up about three sizes in a very short time. […] It was a damn nuisance. I had to buy a load of new shirts. […] I mean I’d got a football on my shoulders really. […] I felt embarrassed, really […] As I say, I couldn’t fasten my shirt collars. (Keith, 71, 3 years 6 months since diagnosis)

Changes in sleep

Probably asleep by 10ish and then about half eleven, or midnight, I get—my feet are boiling hot and throbbing like billy-o and a hideous rash. […] In the daytime, when I’m walking around, my feet, although they look pretty hideous with a bit of a rash on and that, they don’t seem to swell up and throb so much. […] So that goes on nearly all night, every night. Consequently, I’m tired in the day. (Sheila, 73, 11 months since diagnosis)

When I was on the 60mg, I’d, I’d get an hour and half, if I was lucky, and then I’d be awake for nearly half an hour and a half and then, you know, maybe another hour; something like that, so really bad sleeping patterns right the way through. (Barbara, 71, 2 years 10 months since diagnosis)

I couldn’t sleep at high doses. It was a bit, yeah, wearing. But then, when I got below—when I got to 20 and below, that got a lot better. (Yvonne, 65, 4 years 7 months since diagnosis)
**Table 2 Continued**

Not feeling normal

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<tr>
<th>Case</th>
<th>Length since diagnosis</th>
<th>Description</th>
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<tr>
<td>Dennis, 69, 2 years</td>
<td>6 months since diagnosis</td>
<td>I do have, I wouldn’t what I call headaches, they are more of a fuzziness, I get dizziness. But is it related to that, I don’t know. (Dennis, 69, 2 years since diagnosis)</td>
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<td>Robert, 92, 2 years</td>
<td>2 months since diagnosis</td>
<td>I seem to have lost some strength in my arms, the strength that I did have [...] I don’t seem to have full control of my legs. (Robert, 92, 2 years since diagnosis)</td>
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<tr>
<td>Clare, 75, 2 years</td>
<td>2 months since diagnosis</td>
<td>My feet—I don’t know what it is; they’re very strange [...] they just feel tight; that’s the only—best way I can describe it really, [...] my feet... heavy is the word. (Clare, 75, 2 years since diagnosis)</td>
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<td>Mary, 72, 2 months</td>
<td>7 months since diagnosis</td>
<td>I just do feel weak somehow. It’s hard to describe. (Mary, 72, 2 months since diagnosis)</td>
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<td>Iris, 74, 4 years</td>
<td>7 months since diagnosis</td>
<td>I really can’t understand why my bloods are normal and yet [...] I still feel not normal. (Iris, 74, 4 years since diagnosis)</td>
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continually and monitor their current well-being’, comparing this with their perceptions of normality before diagnosis.12 13

Besides the expected impact of permanent visual loss on patients’ lives,14 it is important to note the extent to which other symptoms including fatigue, pain and ‘not feeling normal’ continued to affect multiple aspects of the lives of patients with GCA many years after their diagnosis. In addition, psychological consequences such as reduced confidence, anxiety and feelings of reduced independence could extend beyond the duration of the physical symptoms. Thus, the status of a patient in terms of coping, recovery and/or sense of normality in everyday life is somewhat unpredictable and does not necessarily correspond with the length of time since diagnosis/completion of treatment or clinical severity.

Ongoing adaptations were made by patients both as a direct consequence of their symptoms and as a strategy for self-management. Hall et al describe these strategies as part of ‘the fight to maintain normality’.12 An increased sense of independence may arise from being able to plan changes in advance. Furthermore, ‘maintaining the appearance of normality’12 can be challenging when glucocorticoid treatments cause visible bodily changes, impacting on self-image, mood and confidence, with resulting effects on activities and behaviours.

Finding the optimal balance of information provision is challenging, and by educating patients about the risks of visual loss with GCA, an additional psychological burden is introduced. GCA presents considerable risks in terms of visual loss if left untreated,15 16 consequently clinicians may emphasise these risks to maximise patient adherence to glucocorticoid treatment. Yet fears about the possibility of visual loss can be very distressing for patients, continuing long after diagnosis. In our study, patients who had lost vision were also concerned about relapse causing further visual loss in the future. In addition, changes in vision from other conditions such as cataract and glaucoma, usually attributed to glucocorticoid therapy, heightened patients’ existing anxieties about experiencing permanent visual loss as a result of GCA.

This study provides the first qualitative analysis of the impact of GCA and its treatment on patients’ everyday lives. Interviews were conducted with a sample of people from different social backgrounds and age groups. The findings are compatible with existing models of health experiences and research from other chronic conditions. The data presented are based on patients’ retrospective accounts of their experiences, which may change with time.

It was not the intention of this study to specifically explore ethnic or cultural factors that may impact on experiences of GCA, but future research might actively aim to recruit people from a range of ethnic groups. In addition, the impact of GCA for people of different ages and/or before and after transition points in the life-course such as retirement, and of patients who undergo treatment with evolving biologic regimens, could be
explored in the future. The relationship between clinical presentation and/or comorbidities at diagnosis and the subsequent impact on life could also usefully be explored in more detail through a mixed-methods study, particularly given the clinical heterogeneity of GCA at diagnosis and the potential mediating factors such as treatment timing and approach, and individual patient behaviours and psychological responses. This could facilitate identification in advance of patients at higher risk of impacts such as anxiety and loss of normality, who might benefit most from potential support or educational interventions.

Two approaches to sampling were adopted in recognition that those GCA patients who were associated with the charity PMRGCAuk were unlikely to be representative of all patients with GCA. The sample included patients who described minimal impacts, although we acknowledge that those patients who felt that GCA had a large impact on their lives may have been more likely to volunteer to take part in the study. In our view, this does not diminish the importance of our findings about the experiences of patients who do experience ongoing impacts, despite the fact that the prevalence of these experiences has not yet been established in larger populations.

Purposive sampling is not intended to be numerically representative, but instead allows in-depth exploration and insight into experiences of patients. Consequently, the use of relative frequencies is avoided in the text to avoid confusion. Finally, our methodology did not allow us to verify the clinical diagnosis of GCA from participants’ medical records or the results of medical tests they had undergone; however, the fact that all participants were able to describe their glucocorticoid treatment provided reassurance that our sampling strategy identified individuals from the population of interest.

### CONCLUSIONS

This study demonstrates that GCA presents patients with considerable ongoing physical and psychological symptoms that affect their everyday lives in a wide variety of ways. These experiences vary over time according to the combination of multiple factors including symptoms, side effects, new health conditions and adaptations and impacts on normality in everyday life. Visible body changes attributed to glucocorticoid therapy and fear of future visual loss were important contributors to the loss of normality reported by patients.

This new understanding of the impact of GCA on patients’ lives has important implications for measurement/capture of truly patient-relevant outcomes, both in clinical trials and clinical practice. It also suggests that many patients with GCA would benefit from additional psychological support, whether from peers or professionals.

Clinical management of GCA often focuses on medical concepts such as disease activity, relapse, remission and the prescribing of further medications to mitigate against the consequences of glucocorticoid toxicity. We suggest that an understanding and acknowledgement of the very different ways patients experience GCA and its treatment will help clinicians negotiate patient-centred treatment plans, including planning adaptations to their lives to...
Table 4  Impacts of symptoms of giant cell arteritis and its treatment on activities, behaviours and circumstances

<table>
<thead>
<tr>
<th>Work and volunteering</th>
<th>I've given up a lot of my commitments. I've had to give up a lot of my voluntary commitments, trusteeships of this and that, and doing refereeing. (June, 75, 2 years since diagnosis)</th>
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<td>I did used to play the organ at church and various things but I can only play now to amuse myself because I can’t read the music. (Clare, 75, 2 years since diagnosis)</td>
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<td>It was hard to keep working when I wasn’t sleeping very well. That was probably the main thing [...] I had had almost 3 months off from work [...] and I’d just – I didn’t want to be retired on the grounds of ill health. I love my job. I wanted to get back to it. (Yvonne, 65, 4 years 7 months since diagnosis)</td>
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<td>Having taken the steroids, you know, after my breakfast, my head was buzzing, I couldn’t concentrate and I was - it was like I was having an out-of-body experience. And, and I said to my boss, ‘I need to go home,’ [...] I sent in doctor’s notes for about two or 3 months [...] I don’t think I could have gone back. [...] there is no way on God’s earth that I could have worked. I couldn’t, I couldn’t have done it physically [...] I was sending in sick notes and [...] in the end [...] they just let me go. (Cressida, 62, 5 years 5 months since diagnosis)</td>
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| Relationships | How my husband’s stuck with me this last year, I don’t know sometimes because I have – I’ve been, I’ve been spiteful to him for no reason because I’m – don’t feel quite so good and I’m ratty [...] it’s horrible and it’s pathetic and I hear myself doing it and I know I’m doing it and I feel like really mean for doing it to him [...] and the granddaughter’s been [...] staying here and [...] I love her so much – she’s irritated me as well. [...] and I said, ‘Clear off. Go away’ [...] and it’s because I’m irritable and I’m miserable. (Sheila, 73, 11 months since diagnosis) |
|               | I became quite an intolerant bastard and wouldn’t put up with anything and my poor old wife of 40 years had to put up with it. And I—I honestly believe that when they upped the dose I should have been locked up. I think I should have been kept out of people’s way. (Peter, 70, 6 years 8 months since diagnosis) |
|               | None of (my family) really knew what I was going through [...] I know that my niece was a bit sceptical when I didn’t got to her daughter’s wedding [...] And it wasn’t until she saw me getting slightly better about a month, 6 weeks ago that she then realised how poorly I’d been. (Linda, 68, 8 months since diagnosis) |
|               | I get a little bit short tempered than I used to be [...] I react more than I used to, you know I shoot off a bit quicker. (Anne, 85, 2 years 6 months since diagnosis) |

Continued
I can't do my hobbies like I used to. I used to embroider, I used to sew. I used to knit and crochet. I can't do that [...] I just can't do my hobbies. And I used to enjoy cooking [...] I can't go on holiday like I want to and I can't plan anything. I don't know how I'm going to be the next day. I get up, I feel all right. We start to go out and I'm out and I'm getting bad and you know, the headaches start and my sight starts to get very deteriorated, blurred, and my joints ache. (Dorothy, 78, 2 years 11 months since diagnosis)

One can't make plans. One can't say, 'Well, I'm going to go to (city) tomorrow and meet so-and-so and so-and-so,' [...] You have to make a decision on the day, which is not always possible [...] because you don't know how you're going to feel. (Rose, 73, 1 year since diagnosis)

The steroids have made me shake. [...] My whole body trembles and I, I'm—all my life, I've been a patchwork and quilter and sewer, clothes dress making and I, I can't thread a needle now [...] I've had to give up my classes. [...] I can't read a book. I've lost the concentration [...] I'm not a person who likes to be on my own an awful lot. That's why I join clubs for sewing and grouping and photographing because I like to talk to other people and have a bit of fun and a few smiles and everything. (Sheila, 73, 11 months since diagnosis)

What I have found, of course, is that I'm not covered by travel insurance, and I used to do an awful lot of travelling [...] they won't insure – cover it [...] I mean I like to go to Africa and places like that off the beaten track, but I'm a bit hesitant about that now. I suppose that is a big impact on my life. (Mary, 72, 2 months since diagnosis)

If, for example, I go to a restaurant, I need to sit by a window so that I have the light. So it does have an impact on my life, certainly. I also find going from sunlight into a dark room very, very difficult now because I can't immediately adapt to the light changes. (Gloria, 72, 6 years since diagnosis)

I struggle to cook. I struggle to do housework. I struggle with everyday living. (Dorothy, 78, 2 years 11 months since diagnosis)

When I go shopping [...] I can sort out the, the notes but it, it's the change that I have difficulty with [...] My jewellery, necklaces [...] I use the ones that I can put over my head that I don't have to try and fasten, but that's difficult. And I can manage to make a cup of tea and that sort of thing but, you know, it's obviously not as easy as it was, but everything takes a lot longer. [...] Obviously, when you've only got part sight in the one eye, your focusing isn't right at all [...] I go out in the garden now and I go to pick up some weeds and, and it takes me quite a while to get my hand on, onto the weed; I think I'm there to pick it up and I'm not [...] picking it up at all. (Clare, 75, 2 years since diagnosis)

Some days I, I would try and do supper, make supper but more often than not I couldn't do it. (Cressida, 62, 5 years 5 months since diagnosis)

I feel very weak actually; and not a tremor but shaky. My handwriting was never brilliant but it is dreadful now. I have to type everything because it's so awful. (Mary, 72, 2 months since diagnosis)

When I get up in the morning, I can't dress myself properly [...] changing your underwear; I have to hang on, onto the bed, side of the bed with one hand while I negotiate the underpants and the underwear with the other hand. (Laurence, 72, 1 year 7 months since diagnosis)

I was on alendronic acid for, to protect the bones but I stopped that because I found it so difficult [...] even though it was only once a week [...] you have to take it before anything else and not have anything to drink for at least half an hour and I found that really difficult because when I wake up I'm ever so thirsty and to have to take this pill and then wait half an hour before I could have a cup of tea I found really horrible. (June, 75, 2 years since diagnosis)

I've got no osteoporosis but I do take a tablet each week for that. I have to take one a week, on the same day, every week and sit for half an hour after I've taken it. (Clare, 75, 2 years since diagnosis)
I'm now paying for somebody to clean the house. They come in fortnightly and have a good go through for me. (Dorothy, 78, 2 years 11 months since diagnosis)

Well for one thing it's the cost really of employing people, you know, it's becomes quite expensive at times. I mean we get a female into once a week to help with housework, house cleaning, things like that. (Robert, 92, 2 years since diagnosis)

At the end of the medical, he said I passed the medical, I wouldn't be entitled to any employment support allowance because, according to the medical, I had no descriptors of scored points for disability. [...] What it really meant was that none of the descriptors that they worked on to see how ill you were, applied to me. [...] they'd answer the questions on the computer and there was nothing in there for anybody with PMR and GCA. [...] I'd passed the test, but I pointed out I could only work for 90 min. (Peter, 70, 6 years 8 months since diagnosis)

I went and got myself a bigger screen for my television, a bigger screen television, so I can watch the television. (Clare, 75, 2 years since diagnosis)

Well, I’m, I’m more cautious actually, especially if I’m driving. Although my — what I see, I see quite well now I’ve got my new glasses, but the actual blind area is a little…. It’s not a problem, but I have to be careful with traffic lights for instance, because I can be going along and for one brief second the traffic—the red light isn’t there. Then if I change just slightly my range, or look just slightly to the left or up or down, then the light is there and I know it’s there and I keep my eye on—at that level then. (Mary, 72, 2 months since diagnosis)

I do drive locally and some long distance but, you know, I, I don’t do anything for a long period of time. That’s as a result of the illness really, I think. (Barbara, 71, 2 years 10 months since diagnosis)

It took me a long time to learn to go back to driving and I still won’t drive on the motorway because it’s my right eye that’s affected and I’m frightened that I shan’t see cars if I pull out. So I’m very careful. (Gloria, 72, 6 years since diagnosis)

The only thing that I really miss is being able to drive…so I have to—obviously have to rely on friends and family. (Clare, 75, 2 years since diagnosis)
Table 5  Thoughts and feelings in everyday life with giant cell arteritis

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<td><strong>Frustration</strong></td>
<td>It is <strong>frustrating</strong>; there's no doubt about it. I can't say it isn't. (Clare, 75, 2 years since diagnosis)</td>
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<td>It's very frustrating, because you—your mind still thinks you can do things, but actually [...] when I try, my body flags out very quickly. (Sue, 67, 3 years 9 months since diagnosis)</td>
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<td>I get frustrated because [...] I think, 'This has got to be done.' Dinners got to start and if I'm not well I say, 'Can you give me ...?' 'In a minute. In a minute.' I'm not that type of person. I want to get up and it get done and sorted. And I'm getting very frustrated that way. (Dorothy, 78, 2 years 11 months since diagnosis)</td>
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<td>Oh frustrated, I suppose, really, you know. I, I want to be doing things but you know very well that you can't. (Keith, 71, 3 years 6 months diagnosis)</td>
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*Continued...*
Fear and anxiety

That is something I'm really worried about because I'm petrified of going blind. 

...I've had a cataract in one eye for about five or six years; very slow growing. 

...then, in February this year, I just thought it was getting a bit worse. 

...I went three times to the opticians because I was worried about my sight. 

...I was sort of semi-paranoid about losing my sight. The consultant assured me that I couldn't lose my sight once I was on the steroids and so I felt quite brave then. 

...I'd heard so many stories; they (people) say, ‘Oh, my granny went blind with that,’ and all this business. 

...then about four weeks ago, my eye started to fade and fade and fade and fade and today, as we speak, in my right eye, I can only distinguish light and dark. I can't distinguish any shapes or people or anything. 

...the cataract has suddenly just grown right across my eye and it’s gone like that in a matter of weeks. 

...my biggest fear is having another relapse. (Sheila, 73, 11 months since diagnosis)

...I do worry about my vision and glaucoma can be affected by GCA as I understand. Certainly within the last few months, since I've been diagnosed, my vision has changed quite a lot. 

...I found out about GCA and prednisolone and that sort of thing, and the risk of blindness, and then there's the devil and the deep blue sea, I don't want to lose my sight but I don't want to take the tablets either. 

...I'm always in the edge in case I lose more sight, and I think that's understandable. Frankly, I'm reducing my steroids, I'm on three milligrams a day at the moment and I'm reducing down to 2.5 over a period of many weeks. I'm concerned that when I finally come off the steroids, is it all going to come back? That is a fear I have. (Gloria, 72, 6 years since diagnosis)

...I'd looked after patients on steroids and their skin was so fragile and bones crumbling, and I was thinking, 'Oh no. It's all going to happen to me.' 

...it was just the fear of the side effects of steroids. 

...I'm always in the edge in case I lose more sight, and the risk of blindness, and that's why I find it hard to read my papers. 

...I'm in the middle of a caseload of more sight, and I think that that's understandable. Frankly, I'm reducing my steroids, and I'm wondering if it's going to come back. That is a fear I have. (Gloria, 72, 6 years since diagnosis)

...I was having all these effects and worried if doing my exercises is doing this visibly to the skin and the hair? That was a worry. (Joan, 81, 1 year 4 months since diagnosis)

...I'm just puzzled sometimes as to whether I would have been like this whether I had this other thing, or whether, you know, it's all part of it. (Robert, 92, 17 months since diagnosis)

...I don't know whether it's just the tablets or if it's just the whole steroid regime that we're going now and I got down to zero steroids, is that it or is it knowing to be unwell? My only concern is that I've been told how severe that the condition can be and is it something you can expect to keep reoccurring. You know, a little my heart's in fear. 

You only have to look at you, know, have had it a lot longer (Louise, 54, 4 years 7 months since diagnosis)

...Uncertainty

...I'm just puzzled sometimes as to whether I would have been like this whether I'd got this other thing, or whether, you know, it's all part of it. (Robert, 92, 17 months since diagnosis)

...I don't know whether it's just the tablets or if it's just the whole steroid regime that we're going now and I got down to zero steroids, is that it or is it knowing to be unwell? My only concern is that I've been told how severe that the condition can be and is it something you can expect to keep reoccurring. You know, a little my heart's in fear. 

...Fear and anxiety

...That is something I'm really worried about because I'm petrified of going blind. (Sheila, 73, 11 months since diagnosis)
help them maintain independence and retain or restore a sense of normality.

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