

Original article

Addressing the transition to a chronic condition: exploring independent adoption of self-management by patients with ANCA-associated vasculitis

Ian Litchfield ¹, Sheila Greenfield¹ and Lorraine Harper^{1,2} and the FAB(V) Trial team

Abstract

Objective. Improvements in care have led to the recognition of ANCA-associated vasculitis (AAV) as a chronic condition; however, the self-management strategies considered a crucial component of the care model for patients with more prevalent chronic conditions are yet to be integrated formally into the treatment of AAV patients. The aim of the work we present here is to identify those self-management processes and tasks already being adopted by patients with AAV to help inform existing care and the development of a structured self-management programme.

Methods. We conducted a series of focus groups and semi-structured interviews with AAV patients, collating the data and performing a *post hoc* deductive analysis based on a consolidated framework of self-management processes.

Results. Despite the unique attributes and demands of AAV, patients adopted self-management behaviours previously identified and supported in patients with more prevalent chronic diseases. They accessed information on their disease proactively and learnt to mitigate their symptoms and side-effects. They pursued a range of health-promotion activities and accessed support from their social network and beyond and, ultimately, learnt to integrate the condition into their everyday life.

Conclusion. Our work has highlighted some key areas of self-management that might be addressed usefully and immediately, including the provision of more consistent information relating to evolving symptoms and side-effects, additional support in accessing both appropriate care and community-based resources, and the use of interventions to bolster resilience. Our findings will inform the development of a tailored self-management programme, but in the meantime provide a more contemporary context for current clinician–patient conversations.

Key words: ANCA-associated vasculitis, self-management, chronic care, personalized care

Key messages

- In established chronic conditions, supported self-management is a key component of successful long-term care.
- We have described how ANCA-associated vasculitis patients have adopted many of these self-management strategies independently.
- This work has enabled more relevant clinician–patient conversations and provided a basis for facilitated self-management in ANCA-associated vasculitis.

¹Institute of Applied Health Research, College of Medical and Dental Sciences, University of Birmingham and ²University Hospitals Birmingham NHS Foundation Trust, Edgbaston, Birmingham, UK
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Correspondence to: Ian Litchfield, Institute of Applied Health Research, College of Medical and Dental Sciences, University of Birmingham, Birmingham B15 2TT, UK. E-mail: i.litchfield@bham.ac.uk

Introduction

Ongoing improvements in technology and medical care have led to transitions of disease states whereby conditions formerly considered terminal are now recognized as chronic [1, 2]. Such changes require adaptations from patients, health-care professionals, commissioning bodies and policy-makers in terms of how the condition is viewed and managed. What has remained consistent across similar shifts in priorities of care for more established chronic conditions is enabling patients to share greater responsibility for maintaining their long-term health [3] and increasing their self-efficacy to do so [4, 5]. This self-management has become integral to the health and social care policies adopted for a range of chronic conditions [6], including arthritis [7], diabetes [8] and HIV [9]. It is supported by facilitated self-management programmes [10] that provide patients with the generic skills necessary to manage the symptoms, treatment and physical and social consequences of living with their condition alongside content specific to the requirements of each particular disease [6]. The onset of the coronavirus disease 2019 (COVID-19) pandemic and the ensuing restrictions on access to health care have highlighted the importance of greater patient autonomy for those managing their chronic condition [11, 12].

ANCA-associated vasculitis (AAV) is an autoimmune disease characterized by the inflammation and necrosis of blood vessel walls, with potentially life-threatening outcomes. Symptoms are systemic and wide-ranging, including skin rash and complications to the upper respiratory tract or the renal system, often combined with muscle pain and persistent and debilitating fatigue [13]. It can lead to reduced quality of life, lowered levels of social participation [14], fewer employment opportunities [15] and poor mental health [16]. It is also an example of a condition whose treatment has improved to the extent that it can now be defined as chronic [17]. Although this extended longevity is ostensibly positive, it means that AAV patients are faced with the long-term management of a chronic condition that is disabling, painful and stigmatizing [18], treated as if acute [19].

Despite the increasing recognition of the role that self-management can play in AAV [3, 20], more must be done to relate what we know of the experiences and needs of patients living with AAV [21] in developing the tailored content of effective self-management programmes [22, 23]. As part of the recent Treatment of Fatigue with physical Activity and Behavioural change support in Vasculitis (FAB-V) study [20], we undertook a nested qualitative study that explored participant experiences of the intervention [24] but also enquired of their initial and persistent AAV symptoms, the impact of subsequent treatments and any measures taken in mitigation.

Here, we present a structured analysis of these data, specifically examining the self-management processes and tasks independently adopted by AAV patients [25]. We highlight areas of priority that can contribute immediately to current conversations between providers and

patients but also inform long-term development of a tailored self-management programme.

Methods

Study design

The study used focus groups to collect qualitative data on patient experiences of living with AAV as part of a feasibility trial designed to explore whether a physical activity intervention can help to combat chronic fatigue (FAB-V trial) [20]. The West Midlands–Black Country Research Ethics Committee (ref. 16/WM/0374) approved the study protocol. All participants provided written informed consent.

Recruitment

All 43 patients recruited to the trial were invited to participate in focus group discussions by clinical staff. Those who accepted gave written informed consent, which was verbally reaffirmed before the beginning of each focus group. Individuals who declined to participate in the trial were invited to complete a ‘consent to be contacted’ form. Those who had done so were subsequently contacted by a member of the research team and verbal consent provided before the interview. The focus groups with participants in the FAB-V trial took place 18 months after the study began. All who were part of the intervention had participated in the prescribed physical activity. Those who declined to take part in the FAB-V trial (whom we have named non-participants for the purposes of this study) were interviewed during the same time period and some 24 months after they were first invited to participate in the FAB-V trial. Further details on the recruitment process and the aims of the trial are provided in the published protocol paper [20].

Data collection

We aimed to collect data from four focus groups, each consisting of the recommended four to six members [26]: two with participants who received the physical activity intervention, one with participants receiving standard care and one consisting of non-participants. We also offered non-participants unable to attend a focus group a one-to-one semi-structured telephone interview [26].

The group discussions were facilitated by I.L., a member of the research team, a research fellow and experienced qualitative researcher, using the same topic guide for each, which included questions on patients’ experience of both initial and persistent AAV symptoms, the subsequent treatment and its side-effects, and any measures taken in mitigation. The same questions were asked of non-participants by the same researcher (I.L.) via a series of semi-structured telephone interviews. All discussions were digitally audio-recorded and transcribed verbatim by a specialist company, abiding by the recommended confidentiality agreement [27] and managed using NVivo.

Analysis

We analysed the data using the consolidated framework developed by Schulman-Green *et al.* [25] that describes the range of self-management processes and tasks systematically. This was chosen from among other potentially suitable frameworks [5, 28, 29] because it is comprehensive (based on a meta-synthesis of 104 qualitative research papers) but also describes self-management solely from the perspective of patients and is therefore directly relevant to our aim of understanding the extent to which self-management strategies have been adopted independently by patients with AAV from the perspective of patients. The Schulman-Green self-management framework (SMF) identifies a comprehensive range of tasks that patients complete and groups them within three broad processes of self-management: focusing on illness needs, activating resources and living with a chronic condition. These processes and tasks are defined and described in Fig. 1.

All data were collated and analysed using a *post hoc* deductive approach [30] whereby we populated the processes of the framework with examples of tasks described by our study participants. To this end, the transcripts were analysed independently by I.L. and S.G., with the data searched for text relating to the framework and any discrepancies regarding the allocation of the data to a specific task discussed, and the overall interpretation agreed with all authors. We did not seek data saturation in respect of participants using every self-management task found within the original framework [31] but instead to provide a more systematic understanding of the strategies that AAV patients are using that have been conceptualized previously as self-management in other chronic disease areas.

Results

Three focus groups were conducted: two consisting of those randomized to the trial intervention and one with those randomized to standard care, totalling 15 participants (P). Of these, nine were male and six female, and at the point of interview the duration of diagnosis ranged from 1.5 to 27 years. The focus groups lasted between 61 and 72 min. Twelve individuals who did not participate in the trial signed the 'consent to contact' form, of whom eight ultimately agreed to be interviewed. These non-participants (NP) had been diagnosed with AAV for a longer duration (a mean of 13.2 years) than participants (a mean of 7.2 years). The telephone interviews lasted between 16 and 37 min. The characteristics of focus group participants and one-to-one interviewees are summarized in Table 1.

Below, we present the self-management tasks we identified within our group of AAV patients grouped within the three key self-management processes described by the SMF: focusing on illness needs, activating resources and living with a chronic illness [25].

Each task is described in the context of AAV and illustrated with exemplar quotes below.

Focusing on illness needs

In managing their condition, chronically ill patients are required to understand the parameters of their disease, its symptoms, their treatment and any potential side-effects. The SMF describes this process within three tasks: learning about the disease, taking ownership of health needs and performing health-promoting activities [25], all of which were identified within our data.

Learning

If patients are to self-manage their chronic disease successfully, they must gather information about their condition [25]. Although a number of patients spoke about this, the extent to which it was achieved successfully varied, with more proactive patients accessing relevant information independently; for example, via their (Vasculitis UK) support group.

Vasculitis UK gave us—we go to their meetings—there's a table full of booklets and all the information you could possibly want!
P08, female, 11 years diagnosed, standard care

Other, more passive, patients were less inclined to seek additional information, evidenced by their reluctance to determine which aspects of their health were symptoms attributable to AAV.

I do feel tired, but then all my friends of the same age group, they feel tired and they haven't got vasculitis, so I don't know whether it's the illness or whether it's old age.
P15, female, 10 years diagnosed, standard care
I find I don't know how I feel down to whether it's this disease, the Parkinson's or just being old—because I've never been old before to understand it.
P13, male, 6 years diagnosed, standard care

Taking ownership of health needs

The task of taking ownership requires patients learn to recognize symptoms, manage treatment and understand any side-effects [25]. Patients we spoke to described a number of wide-ranging health effects, in particular distinguishing the debilitating fatigue resulting from AAV from the occasional bouts of weariness that many experience when well.

The fatigue is all engulfing when you get it; it's right down to your fingertips, and you ache all over and your body doesn't want to do anything but sit there. There's a difference between that and then times when you just don't feel like doing it because whatever reason.
NP02, female, 14 years diagnosed

Another symptom commonly associated with AAV and described by several of our patients was nausea, but as one patient described, they grew to understand the pattern of its presentation over the course of the day.

Since I've had this, I get feeling sick all the while. I wake up in the morning and I am just feeling like I want to vomit all the time. I feel a bit now, but then it goes off and then it comes on...
P11, male, 5 years diagnosed, standard care

Fig. 1 The key processes, tasks and definitions of self-management adapted from Schulman-Green *et al.* [25]

Key process	Definition	Tasks	Definition
1. FOCUSING ON ILLNESS NEEDS	Self-management tasks and skills necessary to take care of their bodies and the illness-specific concerns of chronic illness. The amount of time and attention depends on illness trajectory and the individual's life context.	1.1 Learning	Acquiring information about the illness and learning requisite regimens, skills, and strategies, in order to manage daily illness needs.
		1.2 Taking ownership of health needs	Learning about and managing body responses, completing health tasks and becoming an expert.
		1.3 Performing health promotion activities	Changing or maintaining health behaviours to minimise the impact of the illness and adopting health promotion activities.
2. ACTIVATING RESOURCES	Utilising resources integral to optimal self-management including family members, friends, healthcare providers and community resources and services. Can be used to assist individuals to manage various aspects of their illness, including medical, psychosocial, spiritual, and financial facets.	2.1 Healthcare resources	Contact with appropriate providers at the correct time.
		2.2 Psychological resources	The inner psychological reserves drawn upon by individuals.
		2.3 Social resources	The support of relatives and friends.
		2.4 Community resources	Resources established within the local community, for example peer support groups.
		Spiritual resources	Sustaining spiritual self
3. LIVING WITH A CHRONIC ILLNESS	The ability to cope with the illness, grow as a person. Involves a transition from focussing on the needs of the illness to its integration into the context of the individual's life.	3.1 Processing emotions	Includes exploring and expressing various emotions in response to the diagnosis and loss of health or functioning.
		3.2 Adjusting	Coming to terms with a changed life and a changed self as a result of the illness.
		3.3 Integrating illness into daily life	Seeking normalcy in life through modifying lifestyle and balancing the pursuit of meaningful activities with appropriate attention to illness needs.
		3.4 Meaning making	Re-evaluating life in the context of the illness and the search for personal growth and satisfaction.

TABLE 1 Characteristics of qualitative study population

Individual identity	Biological sex	Years diagnosed	Data collection	Role in study
P01	Male	5	Focus group 1	Intervention
P02	Male	4	Focus group 1	Intervention
P03	Female	14	Focus group 1	Intervention
P04	Female	12	Focus group 1	Intervention
P05	Male	3	Focus group 2	Intervention
P06	Male	4.5	Focus group 2	Intervention
P07	Female	3	Focus group 2	Intervention
P08	Female	11	Focus group 3	Standard care
P09	Male	1.5	Focus group 3	Standard care
P10	Male	12	Focus group 3	Standard care
P11	Male	5	Focus group 3	Standard care
P12	Male	6	Focus group 3	Standard care
P13	Male	6	Focus group 3	Standard care
P14	Female	11	Focus group 3	Standard care
P15	Female	10	Focus group 3	Standard care
NP01	Female	4	Telephone interview	Non-participant
NP02	Female	14	Telephone interview	Non-participant
NP03	Female	10	Telephone interview	Non-participant
NP04	Male	18	Telephone interview	Non-participant
NP05	Male	13	Telephone interview	Non-participant
NP06	Male	27	Telephone interview	Non-participant
NP07	Male	13	Telephone interview	Non-participant
NP08	Male	6	Telephone interview	Non-participant

Another aspect of the concept of ownership of their own health required patients to gain confidence in undertaking a range of tasks related to maintaining their health complexity [25], such as taking their medication.

I just take the medications I am prescribed. I don't take supplements of any sort. I try not to take anything, not even a paracetamol, not unless I am desperate. I just stick to the medical regime.
NP04, male, 18 years diagnosed

The ability of chronically ill patients to manage their condition frequently improves with the understanding of their body's response to the disease and its treatment [25]. As a result, they learn to adjust their behaviour accordingly; for example, reducing the exposure to sunlight owing to the increased photosensitivity related to certain immunosuppressants.

Touch wood, I haven't had any problems with the azathioprine. It's just like P05 says; you do have to worry about skin cancer, and so when you're abroad, instead of just lying there and soaking up the sun you're constantly putting on sun screen and covering up.
P07, female, 3 years diagnosed, intervention

Again, in recognition of their compromised immune system, a patient had modified their social interaction to minimize contact with those who appeared unwell.

If I'm walking around and if there's someone coughing, I don't breathe in; I just stop breathing, just clear the area. If there's anybody at work who is huffing and puffing or something, I don't go anywhere near them. It makes you feel like you're being rude, but at the same time you think, 'Well, I don't want to be at risk—where it can end up?'
P06, male, 4.5 years diagnosed, intervention

Health-promoting activities

The individual behaviours undertaken to improve the health and well-being of individuals, such as eating healthily or exercising regularly [32], are frequently adopted by the chronically ill to help manage their condition. For example, one patient described how, post-diagnosis, they had adopted measures typically associated with a healthy lifestyle.

I certainly do try and eat more healthy, do more exercise, not drink as much as I ... you can't drink more than you used to, you just can't do it.
P10, male, 12 years diagnosed, standard care

Activating resources

Self-management requires the activation of a variety of resources that help to manage the various medical, physical and psychosocial aspects of their condition [25]. Our patients activated numerous resources identified by the SMF, including those associated with the health-care system, their internal psychological reserves or 'inner strength', the social resources relating to their friends or family, and the community resources found within their local area [25]. The one previously identified task within this process that we did not find in our data was the activation of spiritual resources [25].

Health-care resources

Although the frequency with which health-care resources are accessed by the chronically ill is dependent upon the severity and progression of their illness or condition, it remains a consistent component of self-

management [25]. In doing so, patients spoke of the supportive relationship that had developed with key care providers; for example, one patient described the reassurance gained from the availability of a known and knowledgeable clinician.

Within the team, [Clinical Nurse Specialist] is so easy to get hold of, if there was anything worrying me about what I could do or anything, I would have been able to pick up the phone or email and get an answer really quick.

NP01, female, 4 years diagnosed

Accessing the most appropriate clinical resource relies to some degree on the ability of an individual to navigate the health-care system [33]. For one patient, this involved discovering that the best setting to receive treatment for their vasculitis-related diabetes was secondary care.

I have my diabetic assessments here at the [hospital] now, not so much at the doctor's surgery, only simply because it's steroid induced and they have got all my notes here, and it just ... I am on much better drugs for my diabetes now than I was when I was at the doctor's, so that's been an improvement for me really, for diabetes.

P14, female, 11 years diagnosed, standard care

Psychological resources

To sustain the management of their condition, chronically ill individuals often draw on their own psychological resources and resilience [25]. Some of our patients did so, conceptualizing their relationship with the disease as a conflict they were not prepared to lose.

But like I say, I made this rocking chair. I've made chairs for my other grandchildren as well. I can knock one out in ~3–4 days. That rocking chair, since I've had vasculitis, took me >3 weeks to do. But I have vowed that it's not going to beat me. I think you've got to get a frame of mind, because there are people that—I am not bragging for us lot—but I've met people who are not so ill as us, and it's, 'Oh, I give up, I can't do it, I don't want to do it'. But you've got to get it in your mind, I think, that it's not going to beat you; you're going to beat it and keep going at it!

P09, male, 1.5 years diagnosed, standard care

Social resources

The support provided by family, friends and peers is another valuable resource, yet personal circumstances differ, and it is not available to the same degree for all [25]. Our patients reflected on the important role this support had played, with one explaining how their spouse had motivated them to participate in regular group exercise.

It's my husband that gets me out. I saw my husband was doing Park Run, and it just seemed like a nice thing to be involved in, and so I started the couch to 5k. I have got to the stage it still takes me 50 min to an hour to do 5k, but I can get round it, and I quite like going to the Park Run and being part of it ... apart from my husband kicking me out of bed and going, 'Come on, we're going today now!' ... So, I have signed up for a 7k in July, and that means I have to keep going, I have to keep practising.

P04, female, 12 years diagnosed, intervention

Another patient described how they had maintained their friendship group by attending the same activities despite being unable to participate.

I love exercise, I love the camaraderie, all the rest of it that goes with it, and now I go and watch badminton with my mates who I used to play with ...

P05, male, 3 years diagnosed, intervention

Community resources

There are a number of useful resources available through the local community that can bolster self-management [25], such as peer support groups or organized communal activities. The benefits obtained from attending a local keep-fit class were described.

...so, we do all these exercises with our arms and legs, bending and stretching and everything. We have a cup of tea and chat at the end of it, and that's twice a week, and I find that is a lifeline for me ... I recommend to everybody, find a class for elderly people or if you're not old a seated class for exercise, and it lifts your spirit, it really does. It makes you feel so much better.

P08, female, 11 years diagnosed, standard care

Others were unaware of the opportunities available, as this exchange between two near neighbours who hadn't met before the focus group demonstrates.

I go to two [keep-fit] sessions. Once a fortnight, I go to a dedicated [disease] group where we're all in the same boat, and that has a trained physiotherapist run it, and the other one is through our local council. I go to keep fit every week, and I find I sit there and I am surrounded by people who are a lot older than me and a lot fitter than me.

P13, male, 6 years diagnosed, standard care

You will have to tell me about that then

— and I live on the same estate, would you believe!'

P14, female, 11 years diagnosed, standard care

Living with a chronic illness

In the long-term self-management of illness, the SMF identifies four key tasks. Examples of each were referenced within our group, namely processing and sharing emotions, adjusting to changed circumstances, integrating the illness into everyday life and seeking for meaning from their experience [25].

Processing and sharing emotions

As individuals come to terms with their diagnosis, they explore and express a range of emotions [25]. One patient spoke of the impact on their confidence of being diagnosed with a serious chronic disease.

...after I was diagnosed with vasculitis ... my confidence went out the window. I think if you've never been ill before, seriously ill, when you have something like that it does knock your confidence, and it was a lot at the beginning, I didn't want to go out ...

P07, female, 3 years diagnosed, intervention

Another patient explained how they had to come to terms with feelings of guilt for not being as active as they once were.

...I have still got the mind of what I had before I had caught it. I used to do yoga and swimming and all sorts of exercises regularly every week, and I still have got this, 'I want to go! I want to do things!', but it cramps your style tremendously. And to feel tired all the time, and it gives me a sense of guilt.

P08, female, 11 years diagnosed, standard care

Adjusting

Successful self-management requires individuals to learn to adjust to their changed circumstances. As one patient who had lived with AAV for a number of years described, their condition had become an accepted part of their everyday life.

...I've grown so used to my situation, having amended my lifestyle to the way I am, and things have had to change at home, and the family work round me very often ... but now I have got so used to what we do—it's just like a normal situation now.

NP06, male, 27 years diagnosed

Integrating illness into everyday life

The process of integrating illness into daily life requires patients to strike a balance between the activities they are often obliged or expected to pursue as individuals and the need to manage the impact of their illness [25]. For example, one patient spoke about how they adopted a flexible approach to fulfil routine household activities.

Usually, I work in the morning, do all the jobs, do whatever they have got to do around the garden and round the home, and then afternoon, usually, I sit down for quite a long time ... usually, I can do 3 or 4 h, and then I make a point of stopping if I can. Anything I can't do today I will do tomorrow, it's quite as simple as that.

NP07, male, 13 years diagnosed

Another patient described how, in order to continue working, she voluntarily had to reduce their responsibilities and the hours worked.

I've had to reduce my working hours; I work part time now, I've also dropped down from my position of responsibility, because I was a head of a sixth form in quite a large comprehensive, and now I just teach part time.

NP01, female, 4 years diagnosed

Seeking for meaning

Over time, patients with chronic diseases attempt to make sense of what has happened to them. Imbuing their changed circumstances with meaning helps them to move forward with their lives [25]. Those who had experienced the most severe or inexplicable set of symptoms within our group expressed a similar appreciation for the life they have.

...if you think about it, it is sad, but we're sitting round this table now and thank God they diagnosed us when they did; we wouldn't be here, would we? I have to keep reminding myself of that ... and you think to yourself, well if I hadn't have gone to the doctors that day and if he hadn't have been on top form and said, 'Right you're going straight to the hospital!', we wouldn't be here now talking, would we?

P07, female, 3 years diagnosed, intervention

Discussion

General findings

Advances in clinical science and care have improved survival rates for patients with AAV, challenging the existing care model to reflect this longevity and acknowledge the potential role of patient self-management [21, 22]. The SMF has provided a valuable insight into how the self-management strategies supported by care providers and

used by patients with recognized chronic conditions [6], including those until recently considered acute [1, 2], are being adopted independently by AAV patients. Examples specific to our AAV patients included: alleviating symptoms by staggering activity or mitigating the side-effects of treatment by reducing social contact; using a range of resources, including family and friends and specialized care and community services; and the adjustments made to their professional and personal lives, being grateful for the opportunity to accommodate living with AAV.

In practical terms, our findings have indicated several areas that clinicians might address in their consultations with AAV patients. These include offering guidance on diet and exercise, directing patients to reliable sources of further information about their condition that might also be shared with friends and relatives unaware of AAV and its implications, and signposting patients to peer groups that can offer support and shared activities.

Strengths and limitations

A significant challenge in studying vasculitis is how the illness can manifest, with wide-ranging symptoms and severity dependent on which organs are affected. Consequently, capturing a representative view of the illness or of how patients are dealing with it is a difficult undertaking. In an attempt to address this, the patients we interviewed were recruited through one of the largest treatment centres in the UK, which draws patients from across the diverse and heavily populated Midlands region. They had lived with the condition for different lengths of time and described a range of symptoms and side-effects of varying severity, although all participants were continuing to experience fatigue. In contrast, many non-participants had been diagnosed for longer, and their symptoms were being managed successfully at the time of recruitment, hence their reluctance to commit to the resource-intensive trial (patient experiences specific to taking part in the FAB-V trial or reasons for non-participation are presented in more detail elsewhere [24]). The focus of this analysis was the independently adopted self-management processes, not those raised, encouraged or facilitated by the involvement or otherwise in the FAB-V trial. All patients reported using a range of self-management strategies previously unrecognized in AAV patients.

The intention of this work was not to produce a definitive description of the self-management strategies used by all AAV patients but instead to instigate a more systematic understanding of their nature to inform future facilitated self-management support.

Specific findings

Focusing on illness needs

Successful self-management is predicated upon independent decision-making informed by an understanding of a patient's current health and the physiology of their disease [6]. The degree to which the parameters of AAV were understood appeared to vary, with more proactive patients independently seeking additional information,

whether from the Internet or through peer support groups.

The importance of independent access and assimilation of dependable clinical information is widely recognized in other chronically ill patient groups [34], and two interrelated factors are at play: how practiced patients are in seeking this information [33], and their comprehension and assimilation [35]. Both can be promoted in AAV patients by consistent and culturally sensitive messaging from care providers and the written materials they provide [36].

Our patients described a number of beneficial lifestyle activities long recognized as important elements in self-management across numerous chronic diseases [3]. These ranged from modest dietary adjustments to concerted efforts to increase levels of physical activity. However, in the UK there are no recommendations within care guidelines for clinicians to promote or support such activities [19].

Activating resources

Chronically ill patients need to identify and access a variety of health-service resources during the course of managing their condition [25, 37]. Nevertheless, the ability to do so is inhibited by the combination of a complex health-care system and the effects of their condition [38]. Some of our patients were more successful than others in accessing the care they required, and in the future such differences might be reduced by the use of care navigators trained to help patients overcome modifiable barriers to accessing care [39]. In their absence, secondary care providers need to remain sensitive to patients who might receive more appropriate care in other settings.

Our patients described the importance of family and friendship groups, both practically and emotionally, and a patient's integration with their social network is a recognized determinant of health-related outcomes in the chronically ill, reducing the psychological and physiological effects of stress and isolation and increasing well-being [40]. However, these positive effects are dependent upon individual circumstances, and for those without social support networks the availability of community resources becomes more important. Where accessible, these have also been shown to improve health outcomes among the chronically ill [41]. The finding that some of our patients were unaware of the opportunities presented by public or third-sector-funded programmes is a recurrent issue across many patient groups [42].

In terms of drawing on their own psychological resources, some described a refusal to be beaten by the disease, and this positive mental attitude is an important component of successful self-management [43] and has led to the emergence of a number of interventions designed to empower and mobilize personal strengths that could be applicable equally to patients with AAV [44].

Living with a chronic illness

Over time, patients diagnosed with a serious chronic condition re-evaluate their priorities and, in the process, can develop optimism and self-worth [45]. Some of our patients had adjusted to the long-term implications of the disease, able to place in context the constraints of their immediate future within the potentially fatal outcomes they contemplated throughout their diagnosis. However, we did not explore how long it took to arrive at this acceptance. Some described how their confidence and self-belief were shaken, exacerbated by the diagnosis of a little-known disease and the lack of a wider understanding among family and friends of its implications [21].

Conclusions

Our findings suggest that AAV patients have initiated independently many of the same self-management behaviours as those used in other, more common chronic conditions, for which there are routine and formal self-management programmes. This is an important finding for the ongoing service design, content, management and patient empowerment of a condition such as AAV, which has transitioned from being thought of as terminal, where formal self-management is not a focus of management, to chronic where self-care is a major emphasis.

It appears inevitable that supported self-management will become intrinsic to the treatment of AAV [46], particularly in the post-COVID landscape, where routine access to services is expected to remain limited. The latest National Health Service advice on developing facilitated programmes to support self-management recommends that commissioners work closely with 'people with lived experience' [47, 48]. This work has met this aim by providing a patient voice that can inform the future development of a tailored self-management programme, but these patients have highlighted areas of care that might be addressed immediately and usefully and present a more contemporary context for clinician-patient conversations.

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Data availability statement

The data that support the findings of this study are available on request from the corresponding author (I.L.). The data are not publicly available as they contain information that could compromise the privacy of research participants.

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