

Qualitative study: the experience and impact of living with Behcet's syndrome

Vicky Tai, Karen Lindsay, Joanne Sims, Fiona McQueen

ABSTRACT

AIM: Behcet's syndrome is a rare chronic multisystemic vasculitis of unknown aetiology, is unpredictable and can cause life-threatening complications. This qualitative study aims to explore the experiences of patients living with Behcet's syndrome in New Zealand.

METHODS: Eight English-speaking patients participated in in-depth semi-structured interviews about their experiences of living with Behcet's syndrome. Interviews were recorded and transcribed. Data were analysed using a general inductive thematic approach.

RESULTS: Five themes related to the experience of Behcet's syndrome emerged from the interviews: diagnosis (diagnostic challenge and closure), impact of disease (pain, fatigue, reduced vision, fear and uncertainty), loneliness and isolation (lack of support and information, invisible illness), acquiring resilience (coping, gaining sense of control, support group) and ongoing interactions with health system (specialist care, primary care, need for multidisciplinary care, doctor-patient relationship).

CONCLUSIONS: Behcet's syndrome patients experience difficulties in obtaining a timely and correct diagnosis and contend numerous physical and emotional challenges, often experiencing loneliness and isolation. Establishing trusting doctor-patient relationships, allowing timely access to specialist care and recruiting psychosocial supports will help patients better cope with their illness. Diagnosis and management of Behcet's syndrome requires close collaboration and communication among specialists and general practitioners and improved education on Behcet's syndrome.

Behcet's syndrome is a rare, chronic, multisystem vasculitic disorder of unknown etiology. Patients are commonly affected by recurrent oral and genital ulcers, skin lesions, thrombophlebitis and arthritis. In addition, they may develop sight-threatening uveitis and organ-threatening complications from gastrointestinal, vascular or neurologic disease. Onset of Behcet's syndrome is usually in the third decade, with both sexes being equally affected, and the disease runs a course with unpredictable exacerbation and remission periods.^{1,2}

Behcet's syndrome patients in New Zealand contend with the rarity and chronicity of their disease, and significant challenges may arise due to unfamiliarity among clinicians. At their 2014 meeting, the Outcome Measures in Rheumatology

(OMERACT) vasculitis working group emphasised the importance of incorporating the perspectives, concerns and ideas of Behcet's syndrome patients into outcome measure development for future Behcet's syndrome research.³ This qualitative study sought to explore the experiences and challenges faced by patients living with Behcet's syndrome, and to identify potential management strategies to enhance resilience.

Methods

Study participants

Patients with a physician diagnosis of Behcet's syndrome, who attended Auckland District Health Board for review, were invited to participate in this study. Eligible participants were enrolled after providing written informed consent.

Study design

One-on-one, 90-minute, in-depth semi-structured interviews with open-ended questions were conducted, audio-recorded and transcribed by the principal investigator (VT), and transcripts were then verified by the participants. Interview questions were developed following consultation with experienced clinicians involved in the management of Behcet's syndrome (KL, FM, JS), and explored personal experiences of receiving the diagnosis, ongoing disease management, symptoms/flares-ups and the impact on quality of life.

Data analysis

Transcripts were uploaded onto NVivo 10 software and analysed to extract themes by a general inductive thematic approach. Two investigators (VT, KL) independently reviewed the responses and grouped them into common ideas or patterns, before collectively agreeing on the development of themes and subthemes.⁴ Hospital clinical records were also examined to triangulate data collected during the interviews, and collate data on ethnicity, disease onset and progression, medication history and comorbidities.

Ethical committee approval

This study was approved by the University of Auckland Human Participants Ethics Committee (reference number 011604).

Results

Patients

Demographics

Eight patients (six female, two male) with a median (range) age of 51 (24–67) years were recruited. The ethnic breakdown included four New Zealand European, one South African European, one Māori, one Armenian and one Korean patient.

Disease course/symptomatology

A summary of the disease course of patients is presented in Table 1. The median (range) age of disease onset was 32 (14–49) years, and the median (range) disease duration was 16.5 (1–32) years. All patients suffered from mouth and genital ulceration and 7/8 patients had experienced at least one episode of uveitis. There were, however,

considerable variation in the range of symptoms experienced and the frequency and severity of flares. For most patients, a severe acute flare (of uveitis, gastrointestinal bleed, pustular skin rash) initiated investigations which led to diagnosis. However, many patients identified, retrospectively, that their first manifestation of the disease was mouth or genital ulceration, which preceded the acute flare by weeks to years.

Themes

Five main themes emerged from this study: Diagnosis, Impact of Disease, Loneliness and Isolation, Acquiring Resilience and Ongoing Interactions with Health System (Figure 1). Each of these themes were further categorised into subthemes.

Diagnosis

Diagnostic challenge

For five of the eight patients interviewed, getting a diagnosis was a long and difficult journey. The multiplicity of symptoms caused patients to see many specialists and undergo numerous investigations prior to diagnosis. Some even required a period of hospitalisation for investigation. Life revolved around specialist appointments. The difficult diagnostic process created frustration for patients and tension with the medical profession. Two patients described encounters with doctors who didn't believe them and criticised them.

"I felt like I wasn't getting anywhere with the medical profession. They seemed to think I thought I was sick and I wasn't really... even when I came up to Hospital X they put me under a psychiatrist because they thought it was all in my head. They told me, 'You know there is nothing wrong with you, you know you aren't sick, just get on with life!'" (Patient 6)

One patient also felt diagnosis was hindered by doctors who failed to listen or inquire about symptoms outside their specialty.

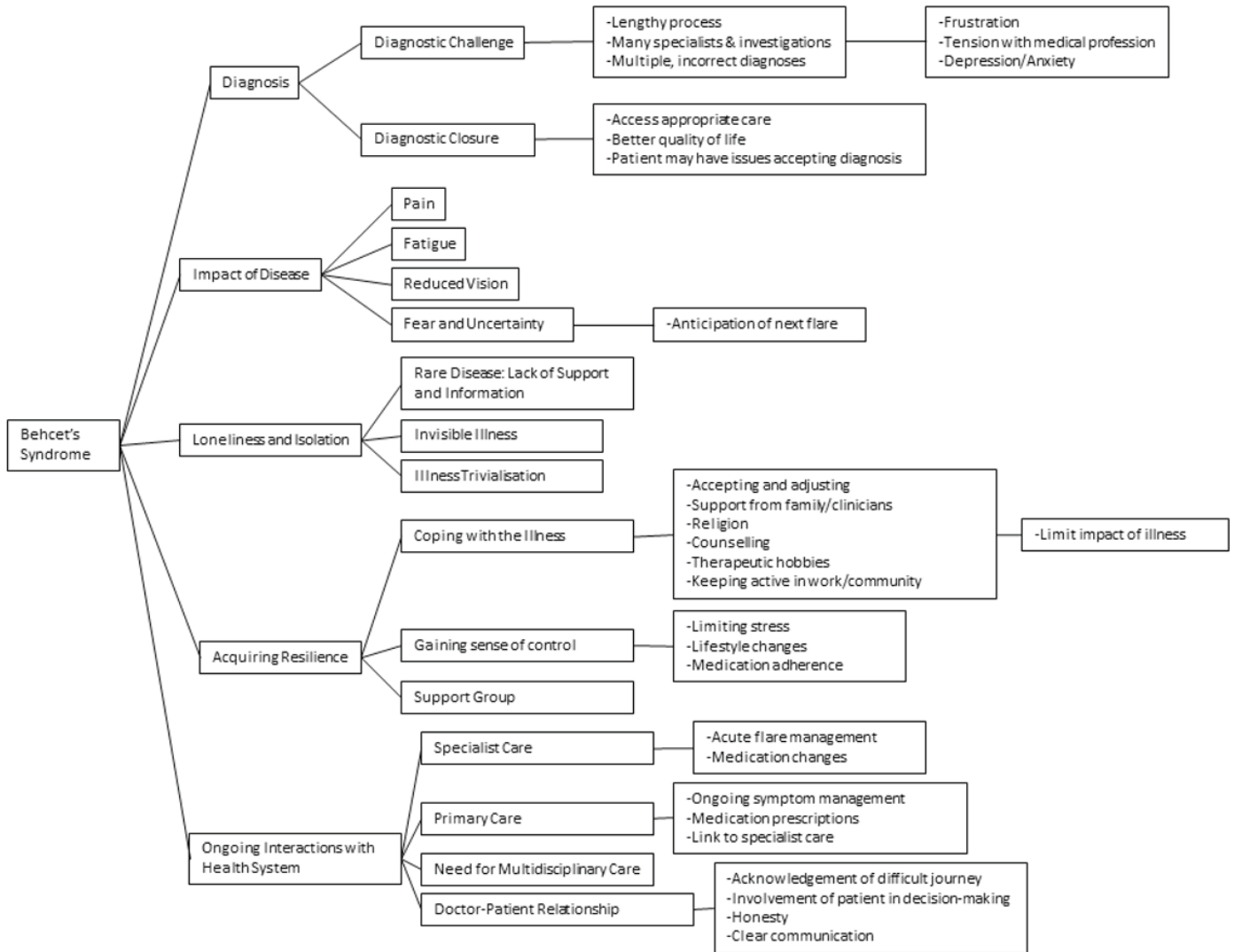
"I got frustrated because I know very well that ulcers in the mouth and ulcers down below have nothing to do with the eye. But if you have a patient saying to you I also have this and during coming to the eye clinic, I also had the swelling of the arm... I mean something's going on but they were like, 'Oh that's not our department.'" (Patient 1)

Table 1: Disease course of patients.

Patient	Gender	Ethnicity	Age at onset (years)	Disease duration (years)	Clinical manifestations
1	F	NZ European	33	8	Mouth ulcers ^a Genital ulcers Uveitis ^b Arthritis Widespread musculoskeletal pain Pustular skin rash Headaches
2	F	NZ European	49	19	Mouth ulcers Genital ulcers Gastrointestinal symptoms ^{a,b} Widespread musculoskeletal pain Pustular skin rash ^{a,b} Pathergy Headaches Neurological symptoms Fatigue
3	M	South African European	22	2	Mouth ulcers ^a Genital ulcers ^a Uveitis ^b Headaches
4	F	NZ European	35	23	Mouth ulcers ^{a,b} Genital ulcers Uveitis ^{a,b} Arthritis Pathergy Fatigue
5	M	Armenian	28	1	Mouth ulcers ^a Genital ulcers ^a Uveitis ^b Arthritis Fatigue
6	F	NZ European	31	32	Mouth ulcers Genital ulcers Uveitis Gastrointestinal symptoms ^b Arthritis Pustular skin rash ^a Thrombophlebitis Headaches
7	F	Korean	43	14	Mouth ulcers ^a Genital ulcers Uveitis ^b Erythema nodosum
8	F	Māori	14	31	Mouth ulcers ^a Genital ulcers ^a Uveitis Gastrointestinal symptoms ^b Widespread musculoskeletal pain Headaches

^aPatients' first clinical manifestation of Behcet's syndrome.^bPatients' first severe acute flare.

Figure 1: The experience and impact of living with Behcet's syndrome.



On the other hand, diagnosis was facilitated by doctors who wanted to “know about everything” and “listened to see what else is actually going on.” Patients also felt that there was a lack of inter-disciplinary communication. This resulted in patients receiving multiple, incorrect diagnoses. For some patients, the difficulty in getting a diagnosis led to anxiety, ‘breakdowns’ and depression.

“It (the long diagnostic process) did eventually get me quite depressed... everything was just so long and hard.” (Patient 4)

Importance of diagnostic closure

A diagnosis came as a relief for some patients as it provided an explanation for their suffering and validated their symptoms. These patients felt that a diagnosis helped them to be believed and allowed them to “get into the (medical) system” to access appropriate care to control the illness. Diagnostic closure allowed patients to move on and learn to deal with the disease.

“The diagnosis meant that I would finally get the help that I so needed... I now have a better quality of life and could then go on to study as a teacher.” (Patient 6)

On the other hand, receiving the diagnosis was difficult for some patients. They struggled to accept they had an incurable illness.

“Once you have diagnosis, it’s some relief but at the same time it can be more depressing because you do know that at this point, there is no such a thing which can make you completely healthy...” (Patient 5)

Impact of disease

Pain

All patients experienced pain from mouth ulcers, genital ulcers, joint inflammation or headaches, with considerable variation in severity and degree of debility. Pain from mouth ulcers ranged from being ‘annoying’ to very severe where the patient could not eat, drink, talk or socialise.

“Well if I get the mouth ulcers, especially if I get two on each side of the mouth, they’re not just tiny ulcers, they’re quite big and vicious and last a week or more and you know eating food or just putting anything in the mouth, it hurts! They’re painful. To talk is painful! When I had given up smoking and I had that many in my mouth I was dribbling, constantly. Had to have my tissue when I spoke to somebody... I couldn’t move my mouth, it was so sore!” (Patient 1)

Patient 1 experienced a major flare-up of her mouth ulcers a few months after smoking cessation. These mouth ulcers were refractory to medical treatment. Eventually, the unbearable pain caused her to recommence smoking, which she reports helped keep the ulcers under control.

For another patient, pain from genital ulcers made it difficult to walk and urinate and caused her to take a lot of time off school. Joint pains, described by one patient as “having somebody with a hammer and chisel hitting a piece of wood”, reduced patients’ ability to engage in exercise. Pain became a part of everyday life and patients learnt to endure their pain through taking pain relief and “just getting on”. Two patients required pain management education to help them cope.

Fatigue

Patients spoke of becoming fatigued easily and having to adjust and re-pace their lives. Some felt that fatigue limited their engagement in household responsibilities and work, and one patient ceased contribution to the workforce.

Reduced vision

Patients who suffered uveitis were left with permanent partial loss of vision. Reduced vision limited patients’ ability to read for long periods and caused challenges including being unable to drive.

Fear and uncertainty

The unpredictable, remitting-relapsing course of Behcet’s syndrome meant that patients lived in uncertainty of when they would suffer another flare and what system this flare would affect. Patients were particularly fearful of sight-threatening uveitis and life-threatening neurological complications.

“I don’t really know what would happen tomorrow. I’ve looked on the internet and

people have died from it. There’s been things where people have suffered from Behcet’s and they’ve had so much swelling and stuff that they’ve died!... So it’s just a bit of a fear thing. Like what if I had another episode (uveitis) like I did? What if they can’t stop it? Stop the eyes from swelling... What if I’ve got swelling in the brain and what if...” (Patient 1)

The constant anticipation about the possible onset of flares meant patients felt perpetually worried.

Loneliness and isolation

Rare disease: lack of support and information

Patients spoke about the challenges of acquiring support and information for their rare illness. Many did not know anyone else with the disease and were not aware of a support group. They reported that most doctors had little knowledge on Behcet’s syndrome and perceived that some were not interested in learning about it as it was a rare disease. This meant patients had to do their own research on the illness. They were ‘alone’.

“There were so few people who had it and there was no support group. Like for a lot of people, if you have a stroke, there’s a support group. There was nobody to talk to.” (Patient 4)

“They (doctors) are not interested in looking it up! I used to be very angry about it and I guess underneath I still am very angry about it. But there are a lot of other diseases in the world and we are the rare ones, the minority.” (Patient 2)

Invisible illness

Many of the symptoms of Behcet’s syndrome (mouth/genital ulcers, musculoskeletal pain, headaches, uveitis) were not visible to those around the patient. The invisibility of symptoms made the illness difficult to explain to others and difficult for others to understand.

“Like people looked at you and you weren’t sick. Like if I came out of the hospital with my leg in plaster or if I’d had a stroke like that... There was no support system.” (Patient 4)

Patients were also determined to lead a ‘normal’ life. Most carried on their usual activities and did not dwell on or talk about their illness, which perpetuated the invisibility of their disease.

“To be honest with you, if you saw my daily life you’d think that she can’t have any joint pain, she does that. I just do it. Yea, it really hurts to pick the baby up but I’m his mother so I’ve got to pick him up.” (Patient 1)

Awareness of the illness was often confined to the patients’ immediate family.

Illness trivialisation

The invisibility of Behcet’s syndrome symptoms and the complex disease course meant that often, patients’ family members, friends and treating physicians lacked understanding of their disease experience. They labelled patients as hypochondriacs or psychologically impaired and accused them of feigning symptoms.

“They (family) think it’s hocus pocus. If you have a stroke, they understand that, if you have a heart attack, they understand that. It’s too technical for them. So I don’t bother to talk about it...” (Patient 4)

The perceived trivialisation of their symptoms caused patients to doubt their own perception of suffering and increased their sense of isolation as they felt they could not talk to others about their illness.

“I try not to talk to people about it because do you know if you talk to people about being sick they think you’re a hypochondriac. So you can’t, you really can’t... I am petrified of becoming a hypochondriac!” (Patient 2)

Acquiring resilience

Coping with the illness

Patients coped with Behcet’s syndrome by accepting and adjusting to the restrictions posed by their illness and developing positive mental attitudes. Emotional and physical support offered by family members and clinicians encouraged them to persevere and maintain a positive outlook. For some patients, religious connection and prayer gave them hope for a better future. Others sought counselling to help them cope emotionally with the challenges of Behcet’s syndrome. Many patients engaged in therapeutic hobbies such as exercise, painting, gardening, meditation and kept active in their work and in the community to ‘escape’ from their illness. Many were strong-willed and strived to lead a ‘normal life’.

“It’s not something which should stop me to be who I am.” (Patient 5)

Gaining sense of control

For all patients, keeping their Behcet’s syndrome in remission was a top priority. Patients adjusted their lives to prevent triggering flares. This included pacing their life, limiting stress, “listening to what the body wants” and making lifestyle changes such as stopping smoking, reducing alcohol consumption and adopting a healthier diet. Patients reported high adherence to medications despite unpleasant side effects and most believed their medications were working well to keep the disease under control.

Support group

Two patients with longstanding Behcet’s syndrome founded a support group in the early 2000s in conjunction with a rheumatologist. The support group offered an environment where patients could share their experiences and coping strategies and receive encouragement. For some, the support group was the only place where they could talk about their illness and receive mutual understanding. Patients found comfort in knowing they were not alone. However, the rarity of Behcet’s syndrome meant the group struggled to acquire members, organise meetings and to find specialists who had an interest in the disease to support them. Some patients who were not aware of the local Behcet’s syndrome support group joined international support groups online.

Ongoing interactions with health system

Specialist care

Behcet’s syndrome patients were often under the care of multiple specialists. Specialist appointments tend to be infrequent, occurring every three to six months, or yearly. Patients stressed the importance of being managed by a specialist who is knowledgeable or interested in the disease and willing to learn about it. Many had to ‘navigate specialists’ in order to find appropriate help. Patients were reliant on their specialists to make the important decisions regarding their care (acute flare management and medication changes) and felt that a good specialist enabled them to “get on with life”. Patients also emphasised the importance of being able to access timely specialist care during a flare-up. For one patient, this was facilitated through a

priority card for the eye clinic and being given the contact number for the rheumatology department.

Primary care

Between specialist appointments, patients sought care from their general practitioners (GPs) for ongoing symptom management and medication prescriptions. In addition, GPs were often the first point of contact when flare-ups occurred or when new symptoms appeared, and provided the link to accessing specialist care. Patients had varied experiences of primary care. Some patients reported excellent care under GPs who researched the disease, communicated with specialists and worked closely with them.

“I was spoilt by my first GP, because when I’d come up with the symptoms he’d always had his books and computer out and he was always checking on it and he worked in conjunction with the specialists.” (Patient 2)

On the other hand, some patients struggled to get appropriate help from GPs who were not interested in the illness, too busy and reluctant to contact specialists for the patient, even when they were experiencing flares.

“The specialist I’m seeing now says the GP just needs to fax or ring him if I’ve said I’m having a flare but the GP won’t always do that, he’ll say, ‘Oh no we can deal with it.’ And that’s a big thing... Because I think people with Behcet’s know themselves when they’re having a flare more than the doctor.” (Patient 4)

These patients felt they had to become their own doctor.

Need for multidisciplinary care: communication and collaboration among doctors

Patients felt that their diagnosis could have been sped up if the various doctors they saw had come together to discuss their case. Patients also felt that lack of collaboration between doctors caused disagreement on the management plan, which manifested in their medications being constantly changed. This had led to some patients being criticised by subsequent doctors for not following instructions and left feeling confused and frustrated.

“You go to one doctor and they say, ‘Oh why are you taking that medication?’ And then you go back to the other one and stop taking

it and they say, ‘Why did you stop taking that medication?’ But that one said to not... And they didn’t treat it as a whole. Everybody was treating their little bit but not coming together.” (Patient 4)

One patient had been given a letter from her rheumatologist, which explained that she had Behcet’s syndrome, outlined the flares she experiences and her medications, and provided advice on how to manage her flares. This helped the patient receive appropriate care when she saw new doctors in the emergency setting.

Doctor-patient relationship

Patients valued doctors who listened to their complaints, believed them and acknowledged their difficult journey. Acknowledgement of their struggles helped patients feel understood, which was emotionally therapeutic and enabled them to trust the doctor.

“The absolute best thing is when a doctor acknowledges what you are going through. Yesterday a GP said to me he has read my file and I must be a very strong-minded woman to deal with this disease as well as my back and not crawl into surgery feeling sorry for myself. I actually felt as if he had given me a medal because he acknowledged what I was going through.” (Patient 2)

Patients also felt empowered by doctors who encouraged them to “ask questions” and involved them in decision-making regarding medication and treatment options. They appreciated honesty regarding doctor’s knowledge level and their prognosis and valued clear communication on the management plan.

Discussion

This qualitative study on patient experiences of Behcet’s syndrome has uncovered many challenges of living with this rare, chronic, multisystem disease.

The challenges experienced by Behcet’s syndrome patients are both physical and emotional.

Behcet’s syndrome patients contend daily with pervasive pain, fatigue, loss of vision and organ failure, which cause physical and social limitations. Patients live with considerable anxiety due to the unpredictable course of their illness. In addition,

they experience isolation due to the invisibility of many symptoms and consequent trivialisation of their condition. These experiences share similarities with those of other chronic rheumatologic conditions, including systemic lupus erythematosus (SLE).⁵ However, the rarity of Behcet's syndrome means that the isolation experienced by patients is more profound. Behcet's syndrome patients experience a lack of 'priority' for them in the health system. They may feel alone as doctors lack knowledge and interest in the disease and support networks are not readily available.

The difficulty in obtaining a correct diagnosis is another challenge experienced by many patients. This study revealed that there is considerable delay between disease onset and correct diagnosis, by which time the patient has consulted numerous specialists and received various incorrect and sometimes psychiatric diagnoses before being diagnosed with Behcet's syndrome. Several factors may contribute to this. The lack of pathognomonic signs, or specific laboratory, radiologic or histologic findings for Behcet's syndrome means that the diagnosis relies heavily on clinical assessment.⁶ Moreover, the disease is episodic, with long intervals between initial onset and secondary manifestations.⁷ Finally, the rarity of the condition means that many physicians are not familiar with Behcet's syndrome and its presentations. Delayed diagnosis causes distress for patients and tension with the medical profession. In patients with rare diseases, delayed diagnosis can lead to deleterious consequences such as delayed appropriate treatment, with consequent worsening disease state and possibly death, psychological distress and loss of confidence in the healthcare system.⁸

Despite facing numerous challenges, Behcet's syndrome patients in our study were determined to limit the negative impact of their illness. Efforts should thus be placed on helping Behcet's syndrome patients acquire resilience to cope with the condition. Building a trusting doctor-patient relationship, fostered through listening, empathy, acknowledgement and involving patients in treatment decision-making may be therapeutic, and the first step to enhancing capacity of patients to cope with Behcet's syndrome. Facili-

tating access to appropriate care during acute flare-ups may also help patients feel in greater control of their illness and reduce anxiety levels. This may be achieved through giving patients priority access to eye clinics and rheumatology departments, and an official document explaining their condition and management plan to other health professionals. One patient in our study experienced complete resolution of mouth ulcers on recommencing smoking. Similar cases have been reported in the literature and it has been suggested that nicotine-replacement therapy may be useful for treating aphthous ulceration in Behcet's syndrome.⁹ Interventions such as counselling, stress management programmes and cognitive behavioural therapy have been shown to improve anxiety, depression, stress and disease activity in SLE, and may have similar benefits in Behcet's syndrome.¹⁰ Support groups have also been shown to improve patients' perceived quality of life in other chronic rheumatologic conditions such as rheumatoid arthritis.¹¹ Efforts should be made to raise awareness of Behcet's syndrome support groups and to organise regular meetings and education sessions for patients, families and doctors via such groups. Better understanding of the illness by family and doctors may also increase the support they are able to provide patients.

This study also provides insight into the complexity of interactions Behcet's syndrome patients have with the health system. As Behcet's syndrome attacks multiple organs, ongoing management may require input from many health professionals. Providing consistent quality care for Behcet's syndrome patients requires collaboration and clear communication between the various members of the multidisciplinary team. In some European countries, this has been facilitated through the establishment of Centres of Expertise for Rare Diseases, where patients with rare conditions such as Behcet's syndrome can be followed for medical advice, treatment, tests and check-ups by various specialists who work in close proximity and cooperate with one another.¹² While such centres are not widely found, collaborative care for Behcet's syndrome patients may be promoted through regular multidisciplinary meetings, ideally involving GPs, to discuss patients or through holding

combined specialist clinics to evaluate patients. A combined ophthalmology and immunology clinic is held at our centre and has facilitated swifter diagnosis and medication adjustments among Behcet's syndrome patients with ocular manifestations.

Delays in diagnosis remain a challenge to be addressed for Behcet's syndrome. Providing more education on Behcet's syndrome to primary care providers and specialists who are more likely to encounter Behcet's syndrome patients (rheumatologists, ophthalmologists, dermatologists, neurologists, sexual health physicians, gastroenterologists) may prompt better recognition of the disease and earlier referral to a rheumatology specialist. Increasing education during medical training may also be of benefit.

Our study is not without limitations. The rarity of Behcet's syndrome in New Zealand

is acknowledged to limit the sample size. Nevertheless, the use of semi-structured interviews and qualitative analysis allowed an in-depth exploration of patient experiences. Furthermore, our study strived to minimise interviewer bias, a limitation inherent to qualitative studies, through the use of consensus groups to formulate research questions and to review the themes uncovered in the analytic process.

In summary, this qualitative study highlighted the numerous challenges faced by Behcet's syndrome patients, and identified strategies to improve diagnosis and disease management. Future qualitative studies conducted on patients' families and health professionals are required to explore the impact of Behcet's syndrome on family members and to further characterise and understand the barriers to diagnosis and effective medical management.

Competing interests:

Nil.

Author information:

Vicky Tai, Final Year Medical Student, University of Auckland, Auckland;
Karen Lindsay, Rheumatologist and Immunology Fellow, Department of Rheumatology, Auckland District Health Board, Auckland; Joanne L Sims, Ophthalmologist, Department of Ophthalmology, Greenlane Clinical Centre, Auckland; Fiona M McQueen, Professor of Rheumatology, Department of Molecular Medicine and Pathology, University of Auckland, Auckland.

Corresponding author:

Vicky Tai, University of Auckland, 85 Park Road, Grafton, Private Bag 92019, Auckland 1142.
tai.vicky18@gmail.com

URL:

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