



# Overlooked Symptoms in Autoimmune Hepatitis Negatively Impact Many Facets of Life

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## Abstract

**Background** Significant reduction in quality of life among patients with autoimmune hepatitis (AIH) patients has been observed in several studies. While acute symptoms associated with AIH have been well described, little is known about the overall impact of living with AIH on patients' quality of life. The aim of this qualitative descriptive study was to describe the impact of AIH and associated symptoms on quality of life from the perspectives of patients living with AIH.

**Methods** Patients from Autoimmune Hepatitis Association support groups were recruited to participate in one of five online focus groups conducted between August and September 2020. After enrollment, patients were asked to complete a brief demographic and disease history questionnaire. A single moderator conducted interviews with each group guided by seven questions focused on the impact of AIH on the participants' quality of life. Each session was recorded, transcribed, and verified. Content analysis was used to summarize the participants' responses.

**Results** The participants' discussed three overarching topics: (a) symptoms of AIH and medication side effects, (b) the impact the disease and symptoms/side effects on five domains of quality of life (work life, relationships with friends and family, social life, leisure activities, and diet and exercise) and (c) interactions with healthcare providers and recommendations for future research.

**Conclusions** Living with AIH can have profound effects on patients' quality of life in several domains. Healthcare providers and the AIH research community should focus on developing further strategies that can improve the quality of life in persons suffering from AIH.

**Keywords** Qualitative study · Autoimmune hepatitis · AIH · Depression · Fatigue · Focus group

## Abbreviations

AIH Autoimmune hepatitis  
AIHA Autoimmune Hepatitis Association  
Yrs Years

## Introduction

Autoimmune hepatitis (AIH) is a rare, often lifelong, auto-inflammatory liver disease that can result in progressive liver fibrosis and require liver transplant. Beyond hepatic injury, patients with AIH often suffer from extrahepatic effects of the disease or side effects from prescribed therapy, both of which have been reported to reduce overall quality of life. European and Asian studies have found that compared to the general population, quality of life among AIH patients is significantly reduced due to depression, anxiety, and fatigue as well as to corticosteroid use and advanced liver fibrosis [1–4]. Even among patients that have excellent biochemical control of liver inflammation with immunosuppressive therapy, reduction in life quality has been observed and linked to duration of disease [5].

Depression and anxiety are common in patients with AIH. A European study demonstrated five times the risk of major

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depressive syndrome and four times the risk of symptoms of severe anxiety in AIH patients compared to the general population [1]. These mental health symptoms are often related to worry regarding liver disease progression and thus possibly amenable to therapy and targeted counselling. In a Polish single center study, depression significantly affected the well-being of patients with AIH and was not linked to clinical or laboratory metrics of disease [4].

Because the clinical needs of AIH patients related to a variety of central (e.g., fatigue, depression, anxiety, poor sleep) and peripheral (e.g., joint pain, right upper quadrant pain, itch) symptoms are often unmet, research on the etiology and treatment of these symptoms is critical. While acute symptoms of patients with AIH have been well described [6], little is known about the overall impact of living with AIH on patients' quality of life. In particular, no studies have been conducted on how AIH affects patients' social, relational, and occupational day-to-day experiences.

Patients with AIH are in best position to inform other AIH patients, treating physicians, other healthcare providers, and the AIH research community about how living with the disease affects their quality of life. Moreover, their perspectives can inform the development or enhancement of AIH management paradigms which have remained unchanged for years. The aim of the current study, therefore, was to describe the impact of AIH and associated symptoms on quality of life from the perspectives of patients with AIH. We used a qualitative descriptive approach to collect and organize participant narratives [7].

## Methods

### Study Participants

Our group has leveraged social media platforms to conduct research in online cohorts of AIH patients by deploying surveys that have included confirmation of diagnosis by procuring medical records and biosamples [8–10]. In 2014, our on-going work with these cohorts led to the development of the Autoimmune Hepatitis Association

(AIHA, [www.aihep.org](http://www.aihep.org)). AIHA is a non-profit organization dedicated to providing support, education, and research opportunities to patients and families affected by AIH. In 2021, five online (Zoom platform) support groups were established for AIHA members living in the Midwest, Northeast, Northwest, and Indiana, and one for those diagnosed with AIH within the past 6 months. We recruited participants for this study from AIHA support groups. Between August and September 2020, a digital study announcement was sent to 116 registered AIHA support group users. This study was approved by the local institutional review board and no identifiable information was collected.

Consenting participants were provided a dedicated weblink to a REDCap survey. The survey collected demographic and AIH disease-specific information (e.g., disease duration, current medical treatment, results of most recent liver biopsy). Each potential participant was assessed for eligibility criteria. Participants were required to be aged 18 years or older and have been provided a diagnosis of AIH by a medical doctor. Eligible participants were provided a confidential Zoom meeting invitation. A total of five focus groups were hosted for a maximum of 1 h duration. In total, 46 individuals confirmed their participation, but only 30 participated (completion rate 65%). Each focus group ranged from four to seven participants.

### Focus Groups and Data Collection

In consultation with an expert in qualitative methods (CD), the study team developed an interview guide consisting of seven questions to provoke discussions about how AIH can affect patients' quality of life (Table 1). A single research team member (EA) led each focus group discussion. Each member of the focus group was given an opportunity to respond to each question. Focus group sessions were recorded without identifying information, and the transcripts were prepared with the Zoom platform software. Each transcript was reviewed for accuracy by at least one study team member (AJ, MW).

**Table 1** Focus group interview guide

#### Focus group Questions

1. Overall, how does autoimmune hepatitis influence your quality of life?
2. How does autoimmune hepatitis impact your immediate family (relationships with spouse and children)?
3. How does autoimmune hepatitis impact your social wellness, including relationships with friends, coworkers, and other distant family?
4. How does autoimmune hepatitis impact your work or ability to work?
5. How does autoimmune hepatitis impact what you do for entertainment or enjoyment?
6. What do you need from health care providers to improve your quality of life with autoimmune hepatitis?
7. What do you need from liver researchers to improve your quality of life with autoimmune hepatitis?

## Data Analysis

Three study team members (AJ, MW, CL) read all completed transcripts and divided responses into text units, which are words, phrases, sentences, or other segments of text that present discrete ideas related to the research aim. Each text unit was given a code, a short label that captured the essence of the text unit. The research team met often and reviewed the data and evolving codes across all patient responses. In the event of a disagreement of codes, the team reviewed the data and reached consensus via a group discussion led by the study team leader (CL).

The team developed a content analytic summary table, as described by Miles et al. [11] that had the summarized coded responses according to participants. These were grouped into topic categories and verified through discussion and consensus by study team members (EJ, MW, CL). Study team members then composed narrative descriptions of the categories related to each major topic. These narratives were reviewed and edited by other study team members based on a review of the data in the transcripts and a re-examination of the summary table.

## Results

### Participant Demographics

A total of 30 AIH patients from 16 different states in the United States (US) participated in this study (Table 2). The majority of participants were female (96.7%) and Caucasian (93.3%). Most participants were also married (73.3%) with children (76.6%) and completed at least some college education or more (93.3%). The average age at the time of study completion was 53 years (yrs.) old (standard deviation [SD] = 12.6 yrs.) and included an average AIH duration of 4.2 yrs. (SD = 4 yrs). Current medications used to treat AIH included prednisone (33.3%), budesonide (13.3%), azathioprine (53.3%), 6-mercaptopurine (3.3%), mycophenolate mofetil (30%), sirolimus (6.7%), tacrolimus (3.3%), and cyclosporine (3.3%). Twenty-two (73.3%) participants were aware of their most recent liver biopsy findings, and 22.7% reported no fibrosis, 18.2% stage I, 18.2% stage II, 27.3% stage III, and 13.6% stage IV fibrosis.

### Participant Experiences with AIH

Most participants discussed their experiences freely in response to the interview questions, often providing anecdotes of events in their lives that exemplified living with AIH. The participants' remarks could be divided into three overarching topics: (a) disease symptoms and medication side effects, (b) the impact of AIH and symptoms/side

**Table 2** Participant demographics and AIH-related disease attributes

	AIH patients (n = 30)
Age of survey completion, years*	53 (12.6)
AIH disease duration, years*	4.2 (4)
Gender, % female	96.70%
Race, % Caucasian	93.30%
Married, %	73.30%
Have children, %	76.60%
Education, % college or more	93.30%
Current medication, %	
Prednisone	33.30%
Budesonide	13.30%
Azathioprine	53.30%
6-mercaptopurine	3.30%
Mycophenolate mofetil	30.00%
Sirolimus	6.70%
Tacrolimus	3.30%
Cyclosporine	3.30%
Fibrosis on most recent liver biopsy, %	
Stage 0	22.70%
Stage I	18.20%
Stage II	18.20%
Stage III	27.30%
Stage IV	13.60%

\*Mean, standard deviation

effects on quality of life, and (c) interactions with healthcare providers and recommendations for future research.

### Disease Symptoms and Medication Side Effects

*Symptoms and Medication Side Effects.* Participants described a variety of symptoms and medication side effects that affected their quality of life. The symptoms included fatigue, sleep disturbances, neurological symptoms, pain, anxiety, and depression. The medication side effects included weight gain, mood disturbance, osteoporosis, myopathy, edema, and cataracts.

*Fatigue.* Most participants identified fatigue as a major symptom associated with AIH or its treatment. Some were extremely tired most of the time, while others noticed that their energy levels tended to wax and wane with “good days and bad days.” One participant stated, “Some days I have real tired spells where I feel like I could just kind of melt into a puddle.” A few participants reported drinking more caffeinated beverages since diagnosis to make it through the day. Several participants indicated that fatigue interferes with their ability to perform “easy” everyday tasks. One participant stated, “The fatigue controls my life.” Many participants were unsure what caused their fatigue, but all hoped for improvement in this symptom.

*Sleep disturbances.* Participants identified sleep disturbances as a highly problematic symptom of AIH. Some experienced interrupted sleep, and a few woke up frequently in the middle of the night to urinate. Others had insomnia and changing or variable sleep patterns. One participant stated, “I’m either up for two days and can’t sleep or I need to sleep 20 h a day.” Some participants attributed their sleep problems to treatment with prednisone.

*Neurological symptoms.* Participants described neurological symptoms that they associated with AIH. Some experienced “brain fog,” and others noticed that their memory had significantly deteriorated since diagnosis. Others had difficulty retrieving simple words. Many attributed these symptoms to their steroid regimen. One participant stated, “Because I’m still on a pretty high dose of prednisone, my biggest thing I think is brain fog. I forget things. I have trouble getting my words, finding my words.”

*Anxiety and Depression.* Participants reported experiencing anxiety that they attributed to their AIH. For many participants, the anxiety was related to issues related to disease burden and uncertainty. For example, several were anxious because they needed laboratory work done every few months and felt like a “nervous wreck” in the days leading up to their laboratories. One participant stated, “My labs are great, and I still feel nervous every time it’s lab time or every time it’s imaging time.” Others were anxious because reliable information about their disease was not available and the progression of their disease was uncertain. Participants also reported depression that they attributed to their AIH. Some reported feeling hopeless, pessimistic, and lonely. One participant stated, “I feel kind of like a loner in it sometimes with not having someone to talk to or relate to in regard to what I’m going through.” Some participants had no hope that their quality of life would improve.

*Medication side effects.* Several participants indicated that the side effects from medications used to treat AIH, especially steroids, were highly problematic. One participant stated, “I don’t understand how these medications are just taking every little bit of quality of life that I may have had.” Many complained about weight gain due to prednisone. Some participants attributed “moodiness,” osteoporosis, myopathy, edema, and cataracts to their steroid regimen. One participant explained, “Once when I was on prednisone, I was sent home [from work]. I was a little argumentative during one of our meetings.”

## **AIH and Quality of Life**

*Work life.* Participants indicated that AIH affected their work life in several ways. Several who were employed felt completely drained at the end of a full workday. One participant stated, “If it’s a particularly stressful day, that night I can’t do anything.” To deal with fatigue, many took frequent breaks

but felt guilty for doing so. Due to the SARS-CoV-2 pandemic, most were working from home at the time of the interview, and several felt anxious about eventually returning to work in-person. A few participants emphasized the importance of advocating for themselves in the workplace so they could continue to work despite their fatigue.

Many participants decided to work less or retire since being diagnosed with AIH, primarily because their extreme fatigue made it difficult to manage their responsibilities. Several switched to less demanding positions in their workplace. One participant stated, “A 12-h shift as a nurse is not something I can do strictly as my sole income, so I’ve had to diversify my work, my job, and find other jobs that are just an 8-h office job to supplement.” A few who were unable to work but too young to retire had to rely on disability income. Others who had retired before being diagnosed with AIH had to cut back on their volunteer activities.

*Relationships with family and friends.* Participants reported that AIH affected their relationships with family and friends. Most felt their friends and family did not understand the disease or what it was like to live with it, especially because AIH has no overt physical manifestations. For example, many believed their friends and family were unaware of the disease-related fatigue the participants experienced. One participant stated, “We don’t have a broken leg or a finger like that they can visually see. So, I think sometimes family tends to forget that we are sick and that I do need time to rest and take a breather.” A few felt “guilty” or “annoying” when they had to ask friends and family for help because the participants were too tired to do routine tasks. Some participants minimized their AIH symptoms so that family members would not worry about them. One participant downplayed her condition to avoid questions from others. A few pushed through symptoms to complete daily responsibilities as not to burden others. One participant stated, “I tend to push and just keep going and put my head down and just keep going, doing what I have to do, work, take care of family, whatever.”

Several participants worried about contracting an illness from family members, especially COVID-19, because the participants were immunocompromised. Many struggled to balance their safety and their need to spend time with their family. One participant stated, “I had a situation recently where I really wanted one of my grandsons to be able to come and stay with me, but I know that he’s not isolating himself and he’s out with his friends. I just didn’t feel safe about doing that. At the same time, I felt bad, and I felt guilty about not being able to do it.”

Most participants also described positive support they had received from family and friends. Some reported that family members would attend appointments with them to help advocate for their health. Other participants who struggled with severe fatigue had friends or family members that

would help out with everyday chores like going to the grocery store. One participant explained that her son now makes dinner every night, so she can rest when she gets home from work.

*Social life.* Participants indicated that AIH affected their social life and experiences being with others in a variety of ways. Many had to frequently miss out on social events and cancel plans because they were exhausted. A few had difficulty explaining why they could not drink alcohol in social situations and felt others were uncomfortable drinking around them. One participant stated, “My friends have been pretty accommodating, but they think because I can't drink, they have to put all the alcohol away. Then I feel like I'm holding back that they're having fun.” One participant who was diagnosed at a young age had a hard time refusing alcohol when everyone around her was drinking. One participant stated, “Social gathering is centered around alcohol and everybody's drinking and wondering why you're not drinking.” Some participants felt living with AIH made them generally uneasy around others and were self-conscious when their illness was brought up in social settings. Others experienced social anxiety, lack of self-confidence, and self-image problems that they attributed to their AIH and that decreased the overall quality of their social life.

*Leisure activities.* Most participants could not participate in leisure activities they previously enjoyed. The participants mentioned having to give up activities such as hiking, gardening, golfing, and line dancing. Most could no longer do these hobbies because of pain and fatigue, and a few had to spend all their energy on daily tasks and thus had no energy left for leisure activities. Some could continue their hobbies in moderation or by taking breaks when needed. One participant stated, “I miss being able to walk in nature and enjoy the peace and the beauty that's all around us. And as time and age has gone I've gotten older, and the disease has progressed, unfortunately, that's not something that I can enjoy anymore. So, I drive, I do a lot of driving in parks or wooded areas to get my fall fix.”

Participants indicated that one activity that was affected by AIH was traveling. While they once enjoyed traveling, some found managing things such as daylight-saving time changes and staying on schedule with their medications made traveling a “nuisance.” Others felt they were no longer able to travel at all. Several participants had to limit outdoor leisure activities because they had to avoid too much sun exposure. Many took extra precautions to protect their skin when under the sun, and a few were unable to tolerate the heat even with precautions. One participant stated, “If it's hot at all, I get red the face and I feel like I'm going to pass out.”

*Diet and exercise.* Many participants reported that they were following a specific or modified diet since being diagnosed with AIH. A couple of participants avoided

certain foods to reduce medication side effects, while others changed their diets to be healthier overall. Several chose to see a nutritionist on their own, and others did so because of a hepatologist's recommendation. Almost all were interested in understanding the relationship between diet and AIH, but several were frustrated because limited information was available to them about the dietary effects on disease onset and AIH management.

Several participants indicated that they either increased their exercise regimen or became more consistent in their workout routines. One participant stated, “My diagnosis made me more active. But I'm able to tolerate the activity too because I know how important it is.” Several were motivated to exercise due to weight gain after starting prednisone. Conversely, many switched to less intense, low-impact exercises to avoid pain, and many were unable to exercise at all due to pain or fatigue. Many who could exercise needed extended recovery periods following physical activity. Several participants experienced aches and pains the day after exercising. One participant had “bad flare-ups,” and another stated, “I tried walking more, but then I would find that the next day I felt I was run over by a truck.” Many were careful how they allocated their energy and were cautious of how their physical activity would affect them later.

## Healthcare and Research

Some participants had overwhelming positive interactions with their healthcare providers. These participants reported easy access to care for their AIH and had good communication with their providers. This made them feel they were provided high quality care.

*Interactions with healthcare providers.* However, participants had multiple negative experiences with their providers. These participants described poor communication in the office and in follow-up messaging. They also felt that their provider showed no interest in their symptoms. Some participants felt “abandoned” by providers who did not provide timely or directed follow-up care. One participant stated, “I feel like I've been diagnosed and then dumped out into my home.” Participants indicated that providers often did not have expertise in AIH, failed to provide adequate explanations of disease management, gave conflicting information about disease, and dismissed participants' symptoms. One patient stated, “There's so much conflicting information even from one doctor to another. You don't know who to trust. You don't know what to believe.” Another participant complained, “I've had these symptoms and the exhaustion and this pain that no doctor will address.” Several participants were dismayed that treating physicians did not take a holistic approach to their care, failed to treat them as a “entire person,” or never addressed their quality of life. Few participants also perceived stigma, often associated with liver

disease, even when at a provider's office by the provider or their staff. Such stigma is grounded in the erroneous beliefs that AIH is contagious or caused by alcohol consumption or risky behaviors. Many participants felt judged, embarrassed, and ashamed to report their disease to primary care doctors and clinic staff. One participant stated, "I'm so sick and tired of being treated like a drug addict."

*Recommendations for research.* Participants suggested that AIH research should center not only on finding a cure but on management of symptoms that dramatically reduce the quality of their lives. Many recommended that researching the mental health aspects of AIH should be a priority in order to reduce the stigma associated with these symptoms. Some called for research on diet regimens that could combat liver inflammation and symptoms associated with AIH. Most subscribed to an integrated model of hepatology and nutrition as they believed food choice or dietary alterations may be able to alter disease course or reduce troubling symptoms. A few participants mentioned interest in the study of alternative strategies such as acupuncture, massage, and supplements as approaches to manage AIH symptoms.

## Discussion

A variety of adverse AIH symptoms and troublesome medication side effects can have negative effects on patients' work lives, relationships with family and friends, social lives, leisure activities, and diet and exercise (Table 3). The most impactful associated symptom was fatigue, which curtailed activities that had previously brought pleasure or satisfaction, as well as anxiety and depression, which were associated with feelings of uncertainty, pessimism, and hopelessness. Having others not understand the nature of disease and the stigma that can accompany it were also distressing to participants. Participant dissatisfaction with their healthcare, including poor communication with providers and lack of attention to symptoms, compounded the negative effects of the disease on their quality of life. Participants called on the AIH research community to study the management of symptoms rather than focusing exclusively on finding a cure to AIH because symptoms could so profoundly affect their day-to-day lives.

While it is well-known that AIH patients are often affected by fatigue [6], our findings suggest some contributors to fatigue might be modifiable but are often overlooked. For instance, many participants reported experiencing interrupted sleep due to nocturnal urination, insomnia, and changing sleep patterns and thus might benefit from sleep evaluation by their primary care physician, urologist, or sleep specialist. Given the impact fatigue had on most participants, integrating patient-reported fatigue assessment into routine AIH clinical care visits would help target

patients most needing detailed investigation for modifiable causes. Fatigue in AIH has been closely associated with other notable phenomenon such as depression, anxiety, cognitive impairment (brain fog), and social isolation, therefore clinical integration of a structured approach (such as the TRACE (Treatment, Amelioration, Coping, and Empathy) algorithm in primary biliary cholangitis [12]) should be a priority (Table 3).

Our study confirmed that depression and anxiety can have profound effects on quality of life among patients with AIH. This finding is consistent with prior research that reveals that elevated anxiety and depression often coexist in AIH patients as well as in patients with other chronic illnesses [1, 2, 13, 14]. Our findings also revealed that depression and anxiety were not often addressed by participants' treating hepatologists or gastroenterologists, and, in fact, some providers were dismissive of these symptoms and did not link them to AIH [15, 16]. This failure of treating physicians and ancillary teams left participants feeling judged and embarrassed about their mental health struggles. We suggest that AIH office visits are missed opportunities for care teams to screen, assess, and intervene upon mental health symptoms in patients with AIH. Surprisingly, active surveillance and treatment of underlying mental health disorders is absent from recent AIH guidelines [6] and positional statements on AIH research needs [17]. While little is yet known about AIH outcomes when mental health concerns are well treated, research with other populations suggest this is an important goal. For example, depression is prevalent in liver patients with cirrhosis (up to 30%), and optimal treatment can improve survival among those in the pre- and post-transplant setting [18]. Moreover, mindfulness meditation practices have shown to impact markers of inflammation and cell-mediated immunity [19]. Schramm et al. reported that appropriate counseling and disease education can mitigate psychological symptoms among AIH patients and improve quality of life [1], thus identifying at risk individuals in the clinical setting is a critical first step (Table 3).

Concerningly, one third of our cohort was utilizing systemic steroids despite an average duration of disease beyond 4 years (Table 1). Observed prevalence of prolonged steroids combined with the finding that side effects of steroids were particularly troubling. Prior study linked corticosteroid use with reduced quality of life in patients with AIH, more specifically within the worry domain of the Chronic Liver Disease Questionnaire [2]. A number of participants blamed their poor sleep on the use of prednisone. Because of the impact of prednisone on sleep as well as on psychosocial well-being [2, 20, 21], it is critical to develop treatment regimens for AIH that minimize or spare corticosteroid use. Investigation into other non-steroidal agents or biologic therapies to meet goal treatment endpoints should be prioritized as a means to provide improved quality of life.

**Table 3** Thematic summary of disease and medication related challenges and possible treatment and support approaches among stakeholders

AIH patient concerns	Specific challenges	Strategic approaches by patients, family, or healthcare
Disease-related symptoms	Fatigue and its interference with daily tasks  Brain fog, slowed cognition, or word finding issues  Sleep disturbances	Consider detailed clinical assessment for other contributions to fatigue (medication side effects, coexistent medical conditions) with special focus on mental health screening tools  Seek other contributing factors or coexistent medical conditions, and optimize or treat other symptoms such as fatigue, mental health issues, and sleep disturbance. Consider neurologic examination if symptoms are progressive or consistent  Promote sleep hygiene education, sleep medicine evaluation for sleep-related disorders, evaluation of nocturia, and seek steroid-free treatment regimens
Medication-related impact	Depression and anxiety  Weight gain  Emotionality Interruption of sleep, trouble falling asleep	Consider psychiatric assessment and treatment of mood disorders, talk therapy, support groups, mindfulness techniques, and disease education  Seek steroid-free treatment regimens, weight loss plans, and dietary modifications  Practice mindfulness techniques, and seek steroid-free treatment regimens  Consider sleep hygiene education, sleep medicine evaluation for sleep-related disorders, and steroid-free treatment regimens
Work life	Inability to hold a full-time position/possible early retirement or disability  Concern about revealing illness and symptoms to coworkers	Seek less demanding work roles or positions that allow flexible work hours and breaks  Pursue self-advocacy training on how to speak about the disease, related symptoms, and patient's needs
Relationships with family and friends	Limited understanding by family of AIH and its symptoms; downplay of disease-related symptoms to alleviate family worry  Lack of physical disease symptoms; family and friends do not understand the severity of the disease	Invite family to attend doctor visits and read educational materials  Pursue self-advocacy training on how to speak about the disease, related symptoms, and patient's needs
Social life	Frequently missed events and canceled plans Difficulty explaining abstinence of alcohol Poor self-image and lack of self-confidence	Carefully plan and prioritize most important activities Practice talking points for how to speak about this issue Seek referral to therapist/psychologist
Leisure activities	Giving up activities they previously enjoyed because of symptoms  Sun avoidance and heat intolerance	Modify activities, include frequent breaks, and seek other enjoyable activities fitting of tolerance  Use sunscreen and skin protecting clothing, and avoid outdoor activities between 10 a.m. and 2 p.m
Diet and exercise	Food avoidance to improve health or treat medication side effects  No uniform recommendations on diet to improve symptoms or optimize disease Variable tolerance of physical activity	Clinical investigation in dietary approaches to manage disease symptoms and progression Consult with a dietician, and start a food and symptom journal  Encourage activity but adapt exercise routine to fit new tolerance level
Experiences with healthcare teams	Poor communication from physicians and staff	Promote disease education to healthcare teams and encourage advocacy by patients or patient organizations such as the Autoimmune Hepatitis Association

**Table 3** (continued)

AIH patient concerns	Specific challenges	Quality of life concerns not addressed by providers; no holistic approach	Strategic approaches by patients, family, or healthcare
AIH research goals	<p data-bbox="225 1104 248 1545">Quality of life concerns not addressed by providers; no holistic approach</p> <p data-bbox="225 1104 248 1545">Conflicting disease information from physicians</p> <p data-bbox="225 1104 248 1545">Perceived stigma from healthcare teams</p> <p data-bbox="225 1104 248 1545">No management of symptoms that reduce quality of life</p> <p data-bbox="225 1104 248 1545">No evidence-based diet and nutrition recommendations</p> <p data-bbox="225 1104 248 1545">Alternative strategies not discussed</p> <p data-bbox="225 1104 248 1545">Mental health symptoms not a priority</p> <p data-bbox="225 1104 248 1545">No disease cure</p>	<p data-bbox="225 884 248 1041">Encourage patient advocacy of symptoms among hepatologists, gastroenterologists, and primary care physicians</p> <p data-bbox="225 884 248 1041">Highlight educational campaigns/materials from leading hepatologists and patient advocacy organizations</p> <p data-bbox="225 884 248 1041">Hold destigmatizing campaigns for health providers</p> <p data-bbox="225 884 248 1041">Establish large collaborative multicenter patient databases and patient-driven registries. Rapidly increase clinical studies examining etiology and management of factors associated with reduction in quality of life (fatigue, depression, anxiety, pain, poor sleep). Seek novel, existing, or variable treatment regimens to identify steroid-free regimens</p> <p data-bbox="225 884 248 1041">Develop dietary research programs seeking foods or products that improve symptoms or disease outcomes</p> <p data-bbox="225 884 248 1041">Consider alternative strategies to address symptoms with minimal risk profiles (massage, acupuncture, meditation, yoga)</p> <p data-bbox="225 884 248 1041">Include local psychiatry and psychology providers as a part of multidisciplinary care teams</p> <p data-bbox="225 884 248 1041">Pursue large collaborative multicenter studies capable of examining treatment and outcomes among variable patient demographics with paired genomic and environmental data</p>	

Our findings also indicated that perceived stigma plays an important role in the lives of patients with AIH. Our participants revealed that family, friends, and even healthcare providers often do not understand their disease, and some may attribute it to drug use and other risk behaviors associated with some chronic liver diseases [22]. As a result, patients may hide their disease or downplay their symptoms. Negative feelings towards participants' treating healthcare providers, due to their limited disease knowledge, poor communication, and dismissal of symptoms, should be addressed. In our study, participants revealed that hepatologists, gastroenterologists, and other providers often displayed stigmatizing attitudes. Systematic anti-stigma approaches should therefore be implemented by healthcare teams. These approaches could include disease education campaigns, written protests to stigmatizers, disease advocacy, and stigma self-management strategies [23].

This first ever qualitative methods study to characterize the impact of AIH on multiple facets of living should still be interpreted in the context of the study design and its limitations. Our sample does not represent all persons with AIH by virtue of participants' involvement in AIHA and their choice to volunteer for the study. However, we believe our participants have characteristics that reflect those of many patients with AIH in the USA. Our sample was largely Caucasian and female, represented 16 states, and had variable durations of disease and fibrosis levels. On average, participants had a disease duration of 4.2 years, yet concerningly almost 50% were still utilizing steroids (prednisone or budesonide) in conjunction to other traditional immunosuppressants. Another limitation is that the study was conducted during the SARs-CoV-2 pandemic, which could affect how participants viewed their quality of life. Research has revealed lower psychological well-being and higher levels of anxiety and depression in the general public during COVID-19 [24]. To counter this, we were careful to focus on participant remarks that most clearly connected their experiences with AIH specifically. Moreover, due to our qualitative design, we could not link specific demographic characteristics to factors affecting quality of life. However, because we used multiple strategies to maintain the integrity of our qualitative findings, we were able to provide a rich description of these factors as they relate to the participants' experiences with AIH.

In conclusion, this qualitative study provides a unique high-resolution view of the quality of life among AIH patients beyond previous studies utilizing patient reported outcome tools. We have summarized possible first step strategies to minimize these thematic challenges by patients, caregivers, and even providers (Table 3). Dramatic reduction in quality of life was linked to AIH symptoms and medication side effects as well as lack of a general understanding of the disease, the stigma that accompanies chronic liver disease,

and problematic interactions with providers. Multiple opportunities exist for families, friends, employers, and healthcare professionals to develop strategies that can improve the quality of life in persons suffering from AIH.

## Declarations

**Conflict of interest** No relevant conflicts of interest to declare among authors.

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