


BMJ Open Exploration of Latina/Hispanic women's experiences living with non-alcoholic fatty liver disease: a qualitative study with patients in Houston

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To cite: Heredia NI, Mendoza Duque E, Ayieko S, *et al.* Exploration of Latina/Hispanic women's experiences living with non-alcoholic fatty liver disease: a qualitative study with patients in Houston. *BMJ Open* 2024;**14**:e084411. doi:10.1136/bmjopen-2024-084411

► Prepublication history and additional supplemental material for this paper are available online. To view these files, please visit the journal online (<https://doi.org/10.1136/bmjopen-2024-084411>).

Received 18 January 2024
Accepted 05 March 2024



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ABSTRACT

Objectives A deeper understanding of the lived experiences of Hispanic patients with non-alcoholic fatty liver disease (NAFLD) can help guide the development of behavioural programmes that facilitate NAFLD management. This paper explores Hispanic women's experiences living with NAFLD.

Design, setting, participants We collected brief sociodemographic questionnaires and conducted in-depth interviews with 12 low-income (all had household income ≤USD\$55 000 per year) Hispanic women with NAFLD from the Houston area. Transcripts were audio-recorded and transcribed. We developed a coding scheme and used thematic analysis to identify emergent themes, supported by Atlas.ti.

Results Participants identified physicians as their main information source on NAFLD but also consulted the internet, family, friends and peers. Many were still left wanting more information. Participants identified family history, sedentary lifestyles, poor diet and comorbid conditions as causes for their NAFLD. Participants also reported emotional distress after diagnosis. Participants experienced both successes and challenges in making lifestyle changes in nutrition and physical activity. Some participants received desired social support in managing NAFLD, although there were conflicting feelings about spousal support.

Conclusion Multifaceted programming that improves patient-provider communication, conveys accurate information and enhances social support is needed to support Hispanic women in managing NAFLD.

INTRODUCTION

Worldwide, non-alcoholic fatty liver disease (NAFLD), also known as metabolic dysfunction-associated steatotic liver disease,¹ is the leading cause of chronic liver disease.² By 2030, it is estimated that there will be 100.9 million Americans with NAFLD, with a general prevalence of 28.4%.³ The prevalence of NAFLD is higher in the Hispanic/Latino (hereafter Hispanic) population (56.6%) than among non-Hispanic whites.⁴ NAFLD is the second leading and most rapidly

STRENGTHS AND LIMITATIONS OF THIS STUDY

- ⇒ This study focuses on a sample—Hispanic/Latina patients—that are at high risk for steatotic (fatty) liver disease.
- ⇒ This study was limited to individuals who self-identified as having been diagnosed with non-alcoholic fatty liver disease (NAFLD)—and there is no specific information on the severity of disease for these participants.
- ⇒ The perceptions and experiences of our study participants may not be generalisable to patients with NAFLD at large.

increasing indication for liver transplantation, behind hepatitis C.^{5 6} NAFLD can also lead to non-liver-specific adverse outcomes like adverse cardiovascular issues,⁷ colorectal cancer,⁸ cancer recurrence and a threefold increased risk of cancer-specific mortality among cancer survivors.⁹

Weight loss through behavioural changes is the main therapeutic approach for managing NAFLD and preventing progression to the adverse outcomes, as there are currently no drugs approved by the United States Food and Drug Administration for the specific treatment of NAFLD. The ability of individuals to consistently incorporate lifestyle improvements depends on societal, psychological, physical, genetic and epigenetic factors.¹⁰ Clinically significant weight loss (≥5%) is associated with meaningful reductions in important liver-related outcomes, including steatosis, steatohepatitis and fibrosis.^{11 12} Even in the absence of clinically significant weight loss, dietary modifications and increased aerobic physical activity are each associated with reductions in liver fat and improvements in insulin resistance.^{13–15} Thus, the focus for patients with NAFLD should be on achievable and sustainable behaviours (physical activity

and healthy diet), with the longer-term goals of weight loss and improved liver outcomes.

An in-depth understanding of patients' experiences with NAFLD and managing their condition through lifestyle behaviours and weight loss is needed to design effective interventions. Prior qualitative studies found that limited knowledge, psychological stress postdiagnosis, need for social support for behavioural changes and cultural and gender norms influenced disease management.^{16 17} Additionally, patients with NAFLD want a team of healthcare practitioners who display a caring attitude for them.¹⁸ Of the three qualitative studies with Hispanic patients with NAFLD,^{19–21} none has addressed patient experiences with being diagnosed and living with the diagnosis, and the emotional and social challenges of making lifestyle behaviour changes specifically for Hispanic women. Thus, the purpose of this study was to gain an in-depth understanding of Hispanic women's experiences living with NAFLD.

METHODS

Patient and public involvement

We engaged with the Community Scientist Programme available to researchers at the University of Texas MD Anderson Cancer Center and the University of Texas Health Science Center at Houston to develop this study.²² The Community Scientists provided input on the overall research question, recruitment for the study and the interview guide.

Participants

Our clinical partner, a Federally Qualified Health Center in a predominately Hispanic neighbourhood, helped recruit participants using convenience sampling.²³ Physicians provided information about the study to potential participants and solicited their permission to share their contact information with the research team. The clinic also posted study flyers so interested individuals could contact the study team directly. We also contacted women from a previous study who had consented to being contacted for future studies. The study team contacted potential participants via phone to explain the study and gauge interest in participating. Potential participants provided oral informed consent to be screened. Those meeting eligibility criteria (identifying as Hispanic, being 18 years of age or older and having been diagnosed with NAFLD) were scheduled for an interview. All individuals who were able to connect with the study team via phone were eligible and agreed to participate.

Data collection

We conducted in-depth interviews with Hispanic women with NAFLD to explore their experiences living with this condition. Interviews were conducted by a female bilingual, masters-trained research coordinator with extensive experience conducting in-depth interviews and focus groups specifically with Latinas and in Spanish. Prior

to the start of the study, NIH provided the interviewer with a booster training on interviewing techniques, especially on using neutral comments and avoiding evaluative phrasing.²⁴

For the interviews, we used a semistructured interview guide developed by NIH, with consultation and edits from LHM, JH and MEF, and input from the Community Scientists. NIH was guided by a review of the existing NAFLD literature at the time, as well as extensive background training in behavioural sciences; however, no conceptual models were explicitly used. Review of the guide from coauthors helped ensure there were no leading questions. We asked patients about their thoughts and feelings regarding all aspects of NAFLD, including what information their doctor shared, what they understand about the development and progression of liver disease, and what lifestyle changes they may have made, among other questions related to NAFLD and management with lifestyle behaviours (see online supplemental table 1). We also included probes and prompts, as these are important to achieve saturation.²⁵

The process of verbal informed consent initiated the relationship between interviewer and interviewee. The interviewer study personnel provided a detailed description of the study and answered any questions, and then participants provided verbal consent after the interviewer read through a verbal script explaining the study, length and voluntary nature of participation, benefits and risks of the study and provided appropriate contact numbers should participants have questions or concerns. After verbal consent, participants completed a brief questionnaire that measured basic demographic and other characteristics, such as age, gender, income, education, marital status, year of NAFLD diagnosis and self-reported height and weight. Prior to starting, the interviewer reminded participants of the purpose of the study, that participation is voluntary, that they can stop at any time, and that there are no right or wrong answers to the questions. The interviewer asked participants what name they preferred to be used—including the option of a pseudonym—and the interviewer used this name during the interview. The interviewer told participants that she would be taking notes throughout the interview.

Interviews lasted a mean duration of 43 min, were conducted over the phone or through a virtual platform (ie, Zoom), depending on the participant's preference and technical abilities, and were audio-recorded via this platform. Participants were mailed a USD\$25 gift card following completion of the interview. At the end of the interview, participants received informational brochures about NAFLD, either mailed or provided electronically (their preference). We conducted sufficient interviews to reach data saturation (ie, the point at which data obtained from participants begins to be repetitive), which resulted in 12 interviews. Audio recordings of the interviews

were transcribed verbatim and translated to English (if conducted in Spanish) by a professional outside vendor. Transcripts were not returned to participants as the study design aimed to preserve anonymity.

Data analysis

Transcripts were imported into a qualitative software analysis programme, Atlas.ti, which facilitated the identification of phrases, patterns, relationships, and commonalities or differences to create themes.²⁶ We coded and analysed the data using thematic analysis.²⁷ After reading all transcripts, SA developed a first set of codes and codebook, in conjunction with NIH. After rereading all transcripts, NIH and EMD met to modify and expand the initial coding scheme. After this process, all interviews were recoded and analysed according to this procedure. EMD and NIH met to come to agreement on the codebook and the major ideas represented in the interviews. We used basic descriptive statistics (means and proportions) to characterise the demographic characteristics of the sample.

RESULTS

Our sample consisted of Hispanic women with NAFLD. The average participant age was 47 years old. Most were either married or living with their partners (83%). Half of the women had completed only grades 1–5, 17% were high school graduates, and 33% had some college or were college graduates. Two-thirds (67%) earned less than USD\$40 000 per year. Three-quarters were diagnosed ≤ 4 years, 67% were diagnosed by primary care physicians and 33% were diagnosed by subspecialists like endocrinologists, gastroenterologists or hepatologists (see table 1). We identified the following themes, which are discussed below: understanding NAFLD; sources of information on NAFLD; causes of NAFLD; diagnosis experience; emotional distress postdiagnosis; behavioural lifestyle changes; and social support for lifestyle behaviour change.

Understanding of NAFLD

Women used the expression ‘fatty liver’ to refer to their disease. Participants also used other terminology like ‘liver disease’ or ‘problems with the liver’. One participant said she omitted the word ‘disease’ because “I have it pretty much under control, so I don’t feel sick. I don’t consider it a disease now” (participant 1). Participants related NAFLD to high intake of unhealthy foods and being obese and mentioned potential complications from NAFLD like cirrhosis and cancer. One participant said, “As time passes and if you don’t take care of yourself at least a little bit, it turns into cirrhosis. That’s what I’ve heard—and well, you die, obviously. It is something serious” (participant 1). Participants mentioned concerns such as muscle deterioration, complications related to type 2 diabetes, like leg amputations and transplantation, and death. One woman mentioned “I don’t want to get to

Table 1 Demographic and health characteristics (n=12)

Age (years)		
30–39	3	25.0%
40–49	3	25.0%
50–59	6	50.0%
Education		
Grades 1–5	6	50.0%
High school graduate	2	16.7%
Some college or college graduate	4	33.3%
Marital status		
Divorced	1	8.3%
Living with partner	1	8.3%
Married	9	75.0%
Never married	1	8.3%
Income (USD\$)		
<15 000	3	25.0%
15 000–25 000	2	16.7%
25 000–40 000	3	25.0%
40 000–55 000	2	16.7%
Don't know	2	16.7%
Employment		
Employed for salary	3	25.0%
Housewife or unemployed	7	58.3%
Independent or self-employed	2	16.6%
Health status		
Poor	1	8.3%
Fair	9	75.0%
Good	1	8.3%
Very good	1	8.3%
Years since diagnosis		
<3	4	33.3%
3–4	5	41.7%
>5	3	25.0%
Who diagnosed?		
Endocrinologist	1	8.3%
Gastroenterologist	2	16.7%
Hepatologist	1	8.3%
Primary care	8	66.7%
BMI category		
Overweight	4	33.3%
Obesity	8	66.7%
Total	12	100.0%

BMI, Body Mass Index.

the point where they will have to amputate something. I mean, that scares me a lot” (participant 7).

Source of information on NAFLD

Participants identified their physician as the primary source of information on NAFLD but most of them complained about the deficiency of content and clarity of information, mainly regarding behavioural changes, pharmacotherapy and prognosis. For instance, one participant said, “I would have liked to hear what caused this... I mean, I would have loved to get more information from them” (participant 12).

Women used the internet as an important source of information and some of them commented on how the lack of information from physicians led them to seek clarification from the internet, including social media. For example, one participant said, “That is how I found out about that and all the symptoms I have had. Every time I get on some website, I read about that, but no, my doctor doesn’t explain a lot of things to me regarding—no... So, everything else I know is because I have heard about it, I have seen it, or from the websites” (participant 12). One participant complained about the quality of the information found on social media, commenting: “On the Internet, they talk about the long-term fatalities caused by fatty liver, but they don’t say—they don’t give you too much hope for the present. And that is exhausting” (participant 7). Participants mentioned other sources of information on their condition, such as other patients, relatives or friends who are healthcare professionals.

Causes of NAFLD

Women mentioned family histories of NAFLD, obesity, metabolic diseases (eg, diabetes, hypertension or dyslipidaemia) and other hereditary factors as potential causes of their condition. Participants identified their own metabolic-related conditions (diabetes or pre-diabetes, obesity, hypertension, etc) as being contributing factors to their NAFLD diagnosis. One participant said, “I am aware that this is caused by obesity. Because I was obese—that was the cause of my liver damage. Obesity causes the liver to fill up with fat” (participant 3).

Participants recognised they had not been physically active before receiving their NAFLD diagnosis and saw this as a contributing factor. Women identified several factors contributing to their physical inactivity, including having a job where they sit most of the day, having children and lack of neighbourhood safety. One participant, who held two jobs, said, “In my job, I’m almost all the time sitting down, so yes, I think I have a very sedentary lifestyle” (participant 2). Regarding safety, one participant said, “It is not very safe here because there are dangerous people where I live, so I don’t want to be walking around” (participant 9). They also talked about other competing factors including being a parent, saying “Before I used to be more active because I worked and took care of things. And then I had my children, and I started to stay at home more. And I feel like I was a little less active; I did not

exercise as much. And it took me like 3 years to start again and focus on my health—it was like I let myself go” (participant 11).

Participants also saw their diet as potentially causing NAFLD. One participant said:

It doesn’t help you at all if you mistreat yourself. With time, it has consequences. I mistreated myself a lot. I came home and ate a meal. I left early for work, as I said before, and I drank a Red Bull in the morning, my coffee, my bread, and I didn’t eat again until six, seven in the afternoon. And those things never help with anything, they just cause problems over time (participant 1).

Women highlighted their diet was framed by their culture and recognised it was rich in fats and carbohydrates. They mentioned typical plates like fried food, tortillas, *carne asada* and chocolate. One participant commented: “The food that Hispanic people eat is like very—we are very predisposed to developing these types of diseases like diabetes, hypertension, fatty liver, bad digestions, gastritis and all that. I feel that it is related to like my race, the fact that we are more predisposed because of our diet” (participant 6). Only one participant mentioned eating vegetables while two others emphasised never eating them. One participant attributed her lack of consumption to family influences growing up, saying, “They did not force us to eat vegetables” (participant 8). One participant attributed her disease to inappropriate weight-loss diets, saying “I used to follow diets that—some of them were all about including fats and that. And I feel that I got the fatty liver disease because of all those diets” (participant 7).

Diagnosis experience

Women mentioned being diagnosed through ultrasound and a few of them referred to the use of a biopsy. A few added that were diagnosed by someone other than their primary care physician, like a gastroenterologist or endocrinologist. Participants reported feeling dissatisfaction regarding the information received from their physician during the diagnosis. Very few participants mentioned receiving explanations regarding the causes, symptoms and complications of their disease. There were disparate descriptions of how NAFLD was characterised by their physician. One participant said, “They told me that this was a disease that could be controlled, meaning that it wasn’t very serious, that a lot of people had it” (participant 6). Also, regarding the prognosis, one participant added “Another doctor told me that yes—that I had to take care of myself because otherwise, with the passage of time, I was going to get worse, and they wouldn’t be able to do anything” (participant 10).

Participants mentioned receiving recommendations to make nutritional changes, mainly increasing water intake and reducing consumption of high-fat foods and sodas. They also mentioned they were given recommendations to reduce their consumption of pasta and bread and to

increase fruit and vegetable intake. Women reported being referred to a nutritionist/dietician. Some participants reported that they also received recommendations about physical activity and alcohol consumption. Participants also reported that their physicians explained the link between alcohol use and the liver and gave recommendations to limit or eliminate alcoholic beverages, despite that not being the cause of their current condition. Two participants mentioned being referred to a psychologist. One participant described their decision not to see one, saying: “I didn’t go to a nutritionist, I didn’t go to anything, I just did it by myself. And, well, you can’t do it alone. So, I had to take care of myself because liver problems get more serious over time” (participant 1).

Emotional distress postdiagnosis

Participants described emotional changes since receiving their diagnosis, including stress, mood swings and depression. One participant said:

Of course I got scared because when they told me that, I thought I was going to die. I’m going to die. That is it. That is why I started dieting like crazy because I got scared. It is traumatizing. I got traumatized. I got scared. I mean, I thought I was going to die. When they tell you that you have fatty liver, you know that the liver cannot be repaired and you think the worst (participant 1).

Women had specific concerns that they indicated worried them, including the absence of pharmacological treatment to treat or cure NAFLD. One participant added: “It worries me that you cannot take any prescription medication. The only treatment has to do with your food—your diet, and well, sometimes it is difficult to stay 100 percent healthy when it comes to food” (participant 7). Participants also recognised that there was a misunderstanding in their social network of their condition and were upset and stressed by dealing with these interactions postdiagnosis. For example, one participant highlighted her feelings when asked about the origins of her condition, saying “They tell you, ‘And did you drink a lot of alcohol?’ And, well, I do not drink alcohol. I mean, once or twice a year. And people are like, ‘And that is because of the alcohol,’ and I’m like, ‘No, you can get fatty liver disease without drinking alcohol.’ And so all that—mentally—it—oh, it drains you. It stresses you” (participant 7).

A few participants mentioned mechanisms for coping with these emotions, including physical activity and walking more specifically: “So, I have that from time to time, the panic attacks. So, what I do in order to control them is go for walks outdoors” (participant 1). Another coping mechanism mentioned was listening to music.

Behavioural lifestyle changes

Participants discussed changes that they made after their diagnosis to help manage their condition, including both nutrition and physical activity.

Women mentioned that they made nutritional changes, expressing that they understood the importance of doing so for their condition. One participant said, “Having a healthy diet is the best medicine for this type of disease” (participant 6). Aligning with their physicians’ recommendations, most said their main nutritional changes were reduced consumption of high-fat foods and sodas and an increase in water and vegetables. Other adjustments that the participants made were limiting chocolates, fast food and bread and increasing fruits, olive oil, oatmeal, chicken and tea. Participants also identified things that they found the most difficult to change, which included reducing or eliminating chocolate, sodas and sweets, as well as adding vegetables and water.

Beyond adding or eliminating certain foods, participants referred to changes such as eating a vegan or vegetarian diet, using air fryers, reducing their portion size and eating early dinners. Participants also mentioned barriers to maintaining healthy dietary changes. They discussed their emotional state getting in the way, with one participant saying “It’s like an emotional rollercoaster. Sometimes, when I feel scared, I do everything right. And then I feel good, and the months pass, and I go back to not doing anything” (participant 7). Others mentioned how holidays, social events or going on trips could throw them off their new nutritional behaviours, with one participant saying “And then if there are times like Christmas, like Easter—well, I would eat then, right? Vacations, for example—I wasn’t able to stick to my plan during vacations. And then I would start eating badly again” (participant 11). Participants had plans for being able to cope with these types of barriers, with one participant expressing how she tried to counterbalance the unhealthy foods served during social events, saying “I try not to buy so much food outside the house because during the weekend—a little party and all that, and they normally bring pizza, hamburgers, so I try to have healthier food at home” (participant 2).

Women mentioned various forms of physical activity, with walking as their main form of physical activity, in addition to biking, dancing at home, domestic chores and exercises at home. They reported doing these activities about 30–60 minutes a day. Participants stated that walking with someone, such as their children or parents, helps motivate them. Two participants highlighted improvements in health after becoming more physically active. Participants mentioned doing physical activity in their neighbourhood or local parks. Additionally, three participants stated that they did not do any physical activity. Barriers mentioned included the weather, being tired, lack of time and living in an unsafe neighbourhood.

A minority of women mentioned using natural remedies to manage and treat their NAFLD. One participant shared “I went to see a naturist and they gave me a medicine that helps you clean your liver...It is like a flower that—he prepares the capsules, but they are natural herbs. Yes, there are several natural herbs that they mix. The man prepares them, grinds them, and he puts them in

capsules which you take. And I can tell you that is the only thing that has helped me because I slept” (participant 1). Another took ‘Jocote’, a small tropical fruit also known as purple mombin, which she said helped her lose weight after her diagnosis. One participant mentioned she was currently researching natural remedies for NAFLD.

Social support for lifestyle behaviour change

While family, partners, friends and peers were mostly seen as a positive influence, there were several exceptions. Three participants did not describe support from any of these groups and stated that they do not talk about their disease with anyone because they “don’t really feel comfortable telling people about it” (participant 3).

Participants highlighted the important role their families play, by motivating and supporting them as they make physical activity and nutritional changes. One participant talked about support from her mother, who also has NAFLD, while many others found their children and grandchildren the main source of motivation. For example, one participant said, “My motivation is my family...to look better, to feel better, and live a little more with them” (participant 4).

Just a few participants discussed their husbands. One participant explained that her husband also has NAFLD, so they support one another in managing the disease. By contrast, another participant described a lack of support from her husband, saying “He does not understand me.... I have told him that I’m sick, but he doesn’t believe me” (participant 2). Other participants described how the unhealthy eating habits of their husbands were negative influences on their own diets and attempts to make dietary changes.

There were mixed reports about the support that friends provided. A few participants mentioned feeling supported by friends, with one woman finding support from a friend who is a dietician and several others mentioning support from other friends who have the same disease. Other participants indicated that other patients with NAFLD could be a good source of information about their condition. Conversely, some participants detailed neutral or negative experiences involving their friends. One neutral experience led a participant to recount: “Talking to my friends, ‘Oh, yes, I have that’ or ‘Oh, yes, my husband has that.’ I hear that a lot. Friends who also have it—but they do not worry about it too much” (participant 11). Two women had more negative experiences, one due to her friends’ assumption that her condition was caused by high alcohol consumption, and another who mentioned feeling uncomfortable due to negative comments about her diet, saying “It bothers me when they say, ‘You have diabetes, you cannot eat sugar or that cake. I’m going to give you a small piece’” (participant 2).

DISCUSSION

This study explored the experiences of Hispanic women diagnosed with NAFLD. Perceived disease severity varied

among the participants, with some not perceiving NAFLD as a severe condition and others reporting strong negative feelings following their diagnosis. Patients with a low perceived threat of NAFLD may not be motivated to change their behaviours.^{28 29} Participants in this study who perceived their condition as severe made conscious changes to lifestyle behaviours. Previous studies have reported that among individuals with NAFLD, a low perceived threat of liver diseases was associated with lower participation rates in NAFLD management programmes.^{30 31} Interventions seeking to improve lifestyle behaviours among patients with NAFLD should tailor programme components to address severity perceptions.

Some conditions that are comorbid with NAFLD (eg, diabetes and hypertension) are treated using pharmaceutical products.¹⁷ Our study found that some patients with NAFLD expected similar treatment options and were concerned that NAFLD treatment primarily involved behaviour modifications. Weight loss through physical activity and nutrition is considered the primary treatment for NAFLD,³² though weight loss medications are now available on the market.³³ However, lifestyle behaviour change will continue to be a main pillar for management, especially in populations where the costs of these medications (even with insurance) are untenable. Patients in this study, like in others,¹⁷ were hopeful about pharmacological therapy, but these treatments can be expensive and burdensome to low-income households or those without insurance. A study assessing cost-related medication non-adherence among patients with diabetes estimated that non-adherence to medication was higher among women, Hispanic, non-elderly and those with lower socioeconomic status.³⁴ Our study population with similar demographic characteristics (middle-aged, female, Hispanic individuals with an average annual household income of <USD\$40 000) are likely to experience cost-related barriers to treating NAFLD.

The current study’s findings indicate that while participants had a good understanding of the causes of their disease, others in their social circles had misconceptions. An Arizona study with a similar population showed that respondents ascribed alcohol consumption as a risk factor for NAFLD.^{19–21} One study in the general population showed a limited understanding of NAFLD, with only 5% believing that a non-alcoholic person could be diagnosed with NAFLD and the majority (84%) unaware of NAFLD risk factors.³⁵ Similar findings in national studies in the USA and South Korea indicated that most respondents had poor knowledge of NAFLD-related risk factors.^{36 37} Hopefully, the change in terminology to include ‘metabolic dysfunction-associated’¹ will help clarify this and other confusions. Regardless, education efforts will be needed at the community-level to improve general understanding of the condition and aid prevention efforts.

Research among Hispanic adults highlights the critical role of social support for lifestyle and behavioural changes.³⁸ Most participants in the present study considered their family and loved ones to be the primary

motivation for making lifestyle changes postdiagnosis. However, a few participants in this study described negative experiences with partners and friends, such as dismissive attitudes, incorrect assumptions or partners' unhealthy eating habits. It is important to note that our participants were all women, and thus may have a different experience than Hispanic men in this regard. Gender norms in the Hispanic community as well as sociocultural determinants may shape the responses towards NAFLD in the female Hispanic community. One other study that explored social support in Hispanic patients with NAFLD found mixed perceptions of spousal or familial support for dietary changes postdiagnosis,²¹ though this study was with Hispanic men. Ultimately, family-centred NAFLD interventions may still be useful in this population given the critical role of a support system.²¹

In our study, we found that while physicians were the primary source of information for patients about NAFLD, patients often felt their physicians failed to adequately communicate NAFLD risk factors, management and treatment options. This finding aligns with existing research. For example, one study showed that 80% of the participants with NAFLD had never heard about fatty liver from their physicians.^{19–21} Additionally, a systematic review also showed a communication gap between providers and patients with NAFLD regarding the management of the condition postdiagnosis.¹⁷ Our study participants' inclination to seek clarification on their condition from friends, family or the internet to supplement information from their healthcare provider aligns with other work²¹ and suggests a gap in the dissemination of NAFLD information among medical professionals.^{19–21} However, it should be noted that our population had very low levels of formal education, which is correlated to reduced healthy literacy,³⁹ and may contribute to our participants reporting that they did not receive enough information from their physicians on NAFLD. Since patients generally desire effective patient–provider communication, quantification of needed changes and tailored treatment plans,¹⁷ providers should receive additional training to make this a reality—especially for populations with low health literacy. Providers can also leverage their role by connecting patients and their families with other reliable sources to increase NAFLD awareness.

Limitations and strengths

There are a few limitations to this study. First, the study participants were a small sample of Hispanic women with NAFLD recruited from one city in Texas; therefore, their perceptions and experiences may not be generalisable to other Hispanic women in other parts of the country, Hispanic men or patients from other racial/ethnic groups. Future studies could consider exploring how experiences are similar or different across heterogeneous samples. Given the rapidly changing landscape related to NAFLD, some of the concepts presented here may be slightly outdated. However, with the high rates of NAFLD among Hispanic populations,⁴ this study contributes to

the literature by highlighting some gaps in healthcare provision within this population. This study was also limited to women who self-identified as having been diagnosed with NAFLD—and there is no specific information on the severity of disease for these participants. With most study participants receiving an NAFLD diagnosis in the past 4 years, the period between diagnosis and the interviews was appropriate to understand the experiences with diagnosis, treatment and lifestyle changes. Subsequent studies should consider comparing the experiences of those recently diagnosed patients and those who have had NAFLD for a longer period.

CONCLUSION

Even when Hispanic women with NAFLD receive care from similar clinic settings, many have different experiences with the diagnosis and management of their condition. Effective patient–provider communication and accurate information are essential for NAFLD treatment and management. The misconceptions about NAFLD among women's networks suggest the need to expand NAFLD awareness by facilitating community-level engagement and education. Given the role of social support in promoting lifestyle behaviour changes among Hispanic women with NAFLD, public health programmers should design social support-centred interventions.

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Acknowledgements We'd like to thank Larkin Strong for her support in helping recruit participants.

Contributors NIH conceptualised, designed, acquired the data, analysed and interpreted the work, drafted the manuscript, and is responsible for the overall content as guarantor. EMD and SA analysed and interpreted the data and helped draft the manuscript. AA, LHM, JH and MEF assisted with the conception and design of the work and reviewed the work critically for important intellectual content. All authors gave final approval of the version to be published and agreed to be accountable for all aspects of the work.

Funding This study was funded by the Prevent Cancer Foundation.

Competing interests None declared.

Patient and public involvement Patients and/or the public were involved in the design, or conduct, or reporting, or dissemination plans of this research. Refer to the Methods section for further details.

Patient consent for publication Not applicable.

Ethics approval This study involves human participants and was approved by the University of Texas Health Science Center at Houston (HSC-SPH-20-1388). Participants gave informed consent to participate in the study before taking part.

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available upon reasonable request.

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