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Patient disease knowledge, attitudes and behaviours related to non-alcoholic fatty liver disease: a qualitative study

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ABSTRACT

Objective Despite clear evidence that weight loss via nutritional and physical activity changes improves histological outcomes in non-alcoholic fatty liver disease (NAFLD), many patients struggle to implement and maintain these health behaviour changes. The aim of this study was to characterise disease knowledge, attitudes and behaviours among persons with NAFLD and to identify the factors driving these health behaviours and perceptions.

Design We conducted semistructured interviews among patients with NAFLD. We used purposeful sampling to enroll equivalent percentages based on age and sex, and enrolled approximately one-third of patients with cirrhosis to capture those perspectives. Interviews were conducted until thematic saturation was achieved. Transcripts were coded using NVivo software to identify themes and subthemes.

Results A total of 29 patient interviews were completed. Ambiguity about the diagnosis and aetiology of their liver disease was a key theme, though the vast majority of patients were aware that weight loss via nutrition and exercise was the primary therapy. Most patients were asymptomatic, diagnosed incidentally, and reported low level of concern regarding their diagnosis. The primary barriers and facilitators to health behaviour change were the presence of social support, competing medical comorbidities and low motivation to change behaviours. **Conclusions** Although patients are aware that lifestyle interventions are the primary therapy for NAFLD, there is a gap in knowledge about the condition. The presence of social support and competing medical comorbidities were the most consistent facilitators and barriers to lifestyle change. Tailoring treatment recommendations to provide relevant disease education, specific nutrition and exercise regimens, and personalised approaches based on specific individual barriers and facilitators will likely aid in uptake and maintenance of first-line therapy for NAFLD.

INTRODUCTION

Worldwide it is estimated that approximately 13% of all adults are obese and 29% are overweight. This increasing prevalence is a reflection of dramatic increases in sedentary behaviour and changes in composition of standard diets comprised of energy dense foods that are high in sugar and fat content.

Summary box

What is already known about this subject?

Many patients with non-alcoholic fatty liver disease (NAFLD) and non-alcoholic steatohepatitis (NASH) struggle with implementing and maintaining lifestyle changes. While there has been extensive evaluation of barriers to uptake of lifestyle interventions among patients with obesity in general, investigations of specific patient-related factors impacting treatment for NAFLD have been limited.

What are the new findings?

▶ Although persons with NAFLD are aware that lifestyle interventions are the primary therapy for NAFLD, there is a gap in knowledge about the natural history of condition. The presence of social support and competing medical comorbidities were the most consistent facilitators and barriers to lifestyle change.

How might it impact on clinical practice in the foreseeable future?

➤ Tailoring treatment recommendations to provide relevant disease education, specific nutrition and exercise regimens, and personalised approaches based on specific individual barriers and facilitators will likely aid in uptake and maintenance of first-line therapy for NAFLD.

In the setting of this pattern of lifestyle changes, metabolic syndrome and associated conditions are on the rise.³ As a direct result, within hepatology non-alcoholic fatty liver disease (NAFLD) has become one of the leading causes of chronic liver disease.⁴ Although research is ongoing to develop direct pharmacotherapy to treat nonalcoholic steatohepatitis (NASH), presently the cornerstone of therapy remains lifestyle interventions targeted towards weight loss as this has been associated with improvement in degree of hepatic steatosis, inflammation and fibrosis.^{5 6} In clinical practice, many patients with NAFLD and NASH struggle with implementing and maintaining these lifestyle changes.⁷ While there has been extensive evaluation of barriers to uptake of lifestyle

interventions among patients with obesity in general, there have been comparatively limited investigations of specific patient-related factors impacting treatment for NAFLD. Prior investigations have shown that persons with NAFLD reported a lack of information about their diagnosis, a perception that NAFLD was a relatively benign condition, and a gap in knowledge related to lifestyle modification being the primary treatment for NAFLD. 8-11 Cited barriers to exercise include a perceived lack of resources and education, physical discomfort and time constraints. Peported barriers to healthy eating patterns among individuals with NAFLD have also included time constraints in addition to life stressors and a demand for convenience. 11

Although there have been prior studies investigating barriers to and facilitators of dietary or exercise habits among individuals with NAFLD in isolation, there remain important knowledge gaps that can be addressed by additional comprehensive qualitative studies in this patient population. A qualitative evaluation among a diverse group of patients with NAFLD (accounting for age, sex and cirrhosis status) that investigates persons with NAFLD's perception of their disease and its treatment, their attitudes and behaviours related to both diet and physical activity, and the impact of their disease on health-related quality of life (HRQOL) would add to our existing knowledge base. These data would provide the groundwork for larger quantitative studies that can then further detail specific educational needs and inform potential interventions that can address gaps in care delivery and management. Improved healthcare models can ultimately improve outcomes for this patient population. The aim of this study was to assess disease perspectives and reported barriers and facilitators to management of their disease using semistructured qualitative interviews among persons with NAFLD.

METHODS

Patient population

Adult patients with a diagnosis of NAFLD or NASH (based on liver biopsy results, imaging with documentation of hepatic steatosis, or International Classification of Diseases Ninth/Tenth Revision codes with agreement by one of our managing hepatologists) were eligible for inclusion. Exclusion criteria included significant alcohol use (>14 drinks/week in men and >7 drinks/week in females) and other coexisting liver disease (ie, viral, alcoholic, autoimmune, genetic, cholestatic, etc). Patients with cirrhosis were eligible for inclusion, but those with decompensated cirrhosis (past or present including: variceal bleeding, ascites, hepatic encephalopathy or hepatocellular carcinoma) were excluded. This was a convenience sample, with all patients recruited from our general hepatology clinics during their routinely scheduled clinic appointments as a substudy to our larger survey-based study of 250 patients with NAFLD focused on quantitative analysis of disease knowledge, dietary habits, exercise patterns and HRQOL. We performed purposeful sampling with the aim of recruiting equal percentages of males and females, age (greater than/less than age 50), and one-third of patients with cirrhosis. It is estimated that 30 interviews will be needed in order to reach thematic saturation (as determined by investigator consensus as gold standard in qualitative studies). ¹³ All patients provided written informed consent. Enrollment occurred over 6 months in 2018.

Semistructured interviews

Semistructured interview guides were designed in consultation with the qualitative and mixed methods research core at University of Michigan. Grounded theory was applied in the design of this study. The interview guide and question prompts were designed using existing behavioural science literature on nutrition and exercise and based on a priori hypotheses. Interview guides were pilot tested and edited through an iterative process until the final version was achieved. The interview guide was aimed at characterising several domains: (1) patient's understanding of their disease and the related prognosis; (2) patient treatment knowledge and perceptions; and (3) patient-reported barriers to and preferences for different treatment options. All participants were informed about the goals of the interviews, namely to learn about their experience with NAFLD and their views on different treatments for NAFLD. Interviews occurred via telephone using the University of Michigan phone network. Interviews were conducted by trained study staff with extensive training and experience in conducting semistructured interviews for qualitative studies (JW). Participants had no prior knowledge or interaction with the interviewer. All interviews were audio recorded with the permission of the participant and subsequently transcribed using a professional transcription company to ensure data quality. Interviews were aimed to last approximately 30 min. In recognition of their time, modest compensation of a \$25 gift card was provided after completion of the interview.

Data collection and analysis

Two investigators (JW and MAT) with official training in qualitative research iteratively read transcripts and designed the qualitative codebook including code families and subcodes. This codebook was then applied to individual transcripts with coding iteratively compared between investigators to ensure a consensus on application of finalised codes. After all transcripts were coded, codes were organised into categories of emergent themes based on the data. NVivo software was used to support data management and analysis. The study design and reporting were in accordance with the 'Consolidated Criteria for Reporting Qualitative Research (COREQ)' checklist. 14

RESULTS

Patient characteristics

Overall, approximately 70% of eligible patients approached opted to enroll in the study. The primary reasons for declining enrolment were reported time constraints or lack of interest in participating in a qualitative interview on their chronic condition. The overall characteristics of individuals who opted to enroll compared with those who declined participation were similar. A total of 30 patients were enrolled. After completing the interview, one patient was excluded from the analysis as they did not agree with their diagnosis and thus were not able to provide meaningful responses to the question prompts. No repeat or follow-up interviews needed to be conducted. Fourteen patients were <50 years of age and 15 were ≥50. A total of 14 males and 15 females were enrolled. Ten out of the 29 patients had cirrhosis. Among this cohort, the majority met criteria for metabolic syndrome and approximately 40% had a history of diabetes and depression. Other common comorbidities reported included cardiovascular disease and osteoarthritis. Among the larger study cohort (n=250), the median BMI of the larger study cohort was 33.9 (IQR 30.3–37.9) and 48% had a history of NASH. The median duration of follow-up in our clinic at time of enrollment was 1.25 years (IQR 0.5–3). Table 1 shows between-group differences in major themes and codes across sex and based on presence of cirrhosis.

Emergent themes and codes

NAFLD disease knowledge and perspectives

Interviewees had varying levels of understanding regarding the cause and natural history of their liver disease. The majority of participants reported ambiguity regarding the cause or contributing factors of their liver disease, with men reporting this issue more frequently than women and patients with cirrhosis consistently reporting a high level of ambiguity about their diagnosis and disease (tables 1 and 2). Participants demonstrated frustration with lack of information and the approach of explaining their diagnosis as one of exclusion. Only 30% of patients identified that obesity or metabolic conditions

	Code	Female (n=15)		Male (n=14)	
Theme		No cirrhosis (n=10)	Cirrhosis (n=5)	No cirrhosis (n=9)	Cirrhosis (n=5)
Understanding of diagnosis	Ambiguity	3	4	6	4
	Related to obesity/metabolic syndrome	1	3	4	1
	Incidental testing				
	Liver enzymes	2	0	6	4
	Imaging	3	1	2	1
Behaviour change/disease management	Diet	9	5	7	5
	Exercise	5	4	5	2
	Weight loss	5	4	5	2
	Alcohol use	3	4	6	3
Barriers* or aids to treatment	Social support†, social norms*	10	3	4	1
	Other medical conditions*	5	5	3	3
	Motivation to change				
	High	5	2	3	1
	Low*	3	1	4	2
	Enjoyment/HRQOL	4	3	3	2
	Time constraints*	4	4	2	0
	Competing responsibilities*	1	4	2	0
Impact of disease	Worry/concern				
	High	3	2	2	1
	Low	4	3	4	2
	Symptoms				
	Causes symptoms	5	2	1	2
	No symptoms	4	2	7	3

^{*}Indicates a barrier.

[†]Presence indicates an aid, absence indicates a barrier.

HRQOL, health-related quality of life.

Theme	Illustrative quote				
Code	Male	Female			
Understanding of dia	gnosis				
Ambiguity	'It's like, "You don't have anything else so it must be this" versus "You have all these other symptoms, you have these labs and diagnosis". I would rather have a diagnosis that comes about by examining evidence that I do have saying "OK based on this data you have this disease" not "Based on the absence of all this other data you must have this disease".' (p 112)	'I wasn't sure whether it was two different things I had or the fatty liver turned into cirrhosis. I always thought that I probably had fatty liver but didn't know about it. Then whe I did find out something was wrong, it was like "Oh, it's cirrhosis." It's like I missed the whole fatty liver treatment.' (p 118)			
Related to obesity/ metabolic syndrome	'Well, as I understand it, I have a fatty liver that has been determined to not be from excessive alcohol consumption but from I guess a metabolic condition that is in my genes.' (p 112)	'I know that, for me, I believe it was hereditary and—a combination between being hereditary and my life choices—diet and stuff.' (p 127)			
Incidental testing					
Liver enzymes	'They found out that I had high liver enzymes, and they sent me to see a liver specialist, and that's when I found out I had fatty liver disease.' (p 28)	'Didn't really have any symptoms of anything, just had some punky bloodwork that a doctor wanted checked out and did some further testing and this is what they came up with.' (p 142)			
Imaging	'I found out by—I have also a disease diverticulosis and pain in my intestine. I had pain and I went to my doctor and he sent me for a test—a what's it called? A CT scan. They found my liver was enlarged.' (p 129)	'I started having some pain in my left-lower rib area, the front. I went to the doctor and they said it was a little enlarged. They did an ultrasound and discovered it was fatty liver.' (p 130)			
Behaviour change/di	sease management				
Diet	'I'm trying to change my diet and try to get my pop cut down as much as I can, and basically trying to get everything done to where I can reverse the damage, so I don't need to go in for a liver transplant and stuff.' (p 28)	'I try eating more fruits and veggies. It's better than what it used to be. A lot less eating out 'cause it was at least twic a day, every day. Now it's two times a week.' (p 54)			
Exercise	'I make sure I got to the gym at least three times a week. Before I'd be much more lax about that.' (p 26)	'I generally spend two hours a day engaged in some sort o exercise. Elliptical, stationary bicycle and walking. Strength training I do three times a week, but I do cardio daily.' (p 135)			
Weight loss	'Since I started, I've dropped seven percent of my body weight. I'm doing training to take more off. Overall I've seen a difference in myself, but I haven't hit my own personal goals yet.' (p 108)	'Like I said, I've lost all that weight. Not a lot of weight, but I'm fitting into clothes I couldn't fit into before. Ten pounds is only ten pounds, but it's enough to get me motivated, I guess.' (p 130)			
Alcohol use	'Well I guess I've made one major change. I've curtailed my alcohol consumption, which was at a reasonable level, at least a socially reasonable level. I went from about a drink a day to about a drink or two a week.' (p 112)	'Well, I'm aware that it's—if someone offers wine or beer or something, no, I don't do that. I wasn't a heavy drinker or anything like that, but an occasional beer or glass of wine was nice, but I don't do it at all now.' (p 114)			
Barriers or aids to tre	eatment				
Social support, social norms	'Anything outside my immediate family. There's really not much support there. In fact, if anything, there might be a little bit of an obstruction from my extended family because most of them are very overweight as well. Maybe they don't like seeing that you can change if you want.' (p 108)	'[My family] is more concerned on what they can do to be meMy family members are now doing research to see what they can do to help me. Making me more cognizant how and what I'm eating.' (p 143)			
	'HonestlySociety doesn't make it easy sometimes. To eat the proper foods. They have all the different fast food restaurants, TV commercials and things like that. I've been getting more of the bigger things. The food we eat is probably not the greatest for us.' (p 56)				
Other medical conditions	'It doesn't feel like a major deal to me. Like I said, I have Ulcerative Colitis. I'm probably more worried about that than about [my] liver.' (p 26)	'I have severe arrhythmia and my doctors are aware of this Exercise is not an option for me, at least at this point in time.' (p 111)			
Motivation to change					
High	'You know, I want to be around for a while, so why not adhere to the advice? You know, it's like anything. You gotta decide if it's important enough to you. If it is, you'll change. If it's not, then you won't.' (p 137)	'I have to say that I gave this my 100% shot with all my literature I'm reading, foods, changing my lifestyle, dieticia You name it, I've tried itCause it is important for me to get this weight off, to get this weight off my liver.' (p 143)			

Continued

Table 2 Continued						
Theme	Illustrative quote					
Code	Male	Female				
Low	'How hard am I gonna try to prolong the rest of my life? It's more of a philosophical thing. If I was 20 and diagnosed with this disease, I might have a whole lot more incentive to make lifestyle changes to live the rest of my lifeI'm gonna do things in more moderation but other than that I'm gonna ride this out however long. When it's time for me to get off the train, I'm getting off.' (p 112)	'I'm not sure. I need motivation somehow, and I'm not sure how I'm gonna get myself to stay motivated. I mean, I can be motivated at the beginning, but then things will decline.' (p 191)				
Enjoyment/HRQOL	'I'm not gonna make lifestyle changes that make me not enjoy my life at the expense of living longer.' (p 112)	'I've tried all those diets where you have to count [calories]I can do it for a little bit, and then it's just I can't stand it anymore. Shoot me in the head. Get it over with.' (p 118)				
Time	'I have attempted to increase my activity level, exercise. I am far from a fanatic and I don't exercise every day. It's a function of time and it's a function of I hate it.' (p 112)	'Time is a factor. I get off work late. I'm tired. I have a teenage daughter. I have dogs. I have the house to take care of. It's a timing factor.' (p 119)				
Other responsibilities	'After working a full time job, I'm the one that usually does the grocery shopping for the family. I'm the one that does the cooking for the family. I'm the one that does the cleanup for the kitchen and some of the laundry.' (p 108)	'I know this sounds like an excuse, but I graduated with my master's a year ago. My father just died, and this is—we're going on just over a year. It's been a year of very difficult adjustments.' (p 119)				
Impact of disease						
Worry/concern						
High	'Actually it was scary. They're telling ya there's something wrong with your liver and you need it to live.' (p 56)	'I wanna be here long enough for my kids. Pretty upset about it Everything about it is sad.' (p 54)				
Low	'Well, like I said, I would only be worried if it got worse 'cause at its current level, it doesn't seem like it's that big of a deal.' (p 26)	'The fatty liver is more like, "Oh, that's cute." You know what I mean? It's just the way it's—I know they try not to present it that way, but that's how it sounds to me.' (p 118)				
Symptoms						
Causes symptoms	'I mean I'm very fatigued most of the time, but I don't know. I think that's from the liver disease.' (p 159)	'I've had excessive fatigue and swellingI've had a lot of just faint pain in my liver area.' (p 127)				
No symptoms	'I didn't know I had it. I have no feeling involved with it. It doesn't hurt anywhere. No pain, no nothing. No symptoms that I'm aware of.' (p 116)	'I wasn't aware that I had it untilI was going in for that gastric bypass. I wasn't aware of it at all.' (p 114)				

Highlighted quotes represent responses from patients with cirrhosis; italicised quotes indicate respondents >50 years old. HRQOL, health-related quality of life.

were related to their NAFLD and a significant proportion expressing that NAFLD had a strong underlying genetic/inherited component. For the vast majority of respondents, the diagnosis of NAFLD was incidentally made based on results of imaging or laboratory work, particularly as a result of having had elevated liver enzymes.

Lifestyle behaviour change and disease management

Overall the majority of respondents expressed clear understanding that weight loss through changes in diet and increased physical activity were key components of the treatment for NAFLD. Of note, several respondents focused on the need to provide more specific recommendations on exactly how to achieve weight loss in terms of specific diets, exercise routines and alternatives like weight loss medications or procedures. Participants focused more on changes they had made in their diet rather than exercise, with many reporting time or physical limitations to changing their level of physical activity.

The primary focus on change in diet included removing sugary beverages and increasing the amount of fruits and vegetables in their meals. Approximately half of the respondents noted that they also changed their alcohol intake as part of their treatment plan.

Barriers and aids to treatment

The presence of social support was the primary aid or barrier to implementing lifestyle changes among women, whereas the presence of other medical conditions and low motivation to change behaviours were the primary factors among men. Medical comorbidities were also the predominant factor influencing health behaviours among patients with cirrhosis. Common comorbidities cited that impacted lifestyle behaviours included osteoarthritis or other physical injuries. The remainder of other comorbidities cited to impact behaviour change were heterogeneous across participants. Despite having a good knowledge of primary treatment for NAFLD, only

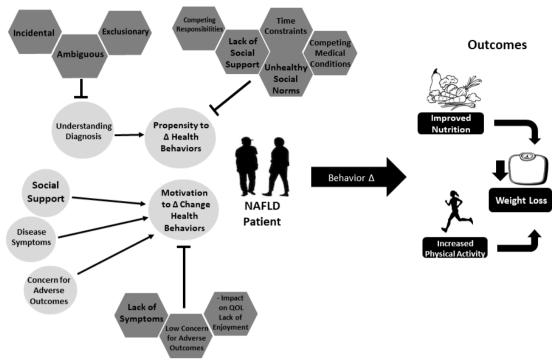


Figure 1 Theoretical model of barriers and aids to lifestyle behaviour change in patients with non-alcoholic fatty liver disease (NAFLD). QOL, quality of life.

37% of respondents reported that they were highly motivated to change their health behaviours. In terms of the other main reasons identified as barriers to changing nutrition and physical activity, the impact on HRQOL, time constraints, and competing responsibilities were the key subthemes.

Impact of disease

The reported impact of having a diagnosis of NAFLD was variable among respondents, with a minority reporting a high level of concern including potential future need for liver transplant and/or higher risk of mortality. Just under half of participants reported minimal concern about the diagnosis, even among individuals with cirrhosis. Reasons cited for having a low level of concern included other significant health conditions and the perception that the risk for significant morbidity and mortality related to NAFLD was low. Over half of the patients reported they had no symptoms. Females tended to report associated symptoms, primarily fatigue and abdominal pain.

A conceptual model encompassing the barriers and aids to lifestyle behaviour change is shown in figure 1.

DISCUSSION

Management of obesity-related conditions is challenging across disciplines and subspecialties given the requirement for long-term lifestyle behaviour change. Although these metabolic conditions share a common pathway of disease pathogenesis, each condition has distinct features in terms of symptomatology and associated morbidity and mortality that likely impact the propensity for lifestyle

behaviour change. Identifying the unique aspects of patient disease knowledge, attitudes and behaviours for a specific obesity-related condition can help shape care delivery targeted to the personalised patient needs in that disease. In this study we identified that patients with NAFLD reported a high degree of frustration regarding ambiguity about the nature of their diagnosis, though the majority were aware that weight loss via nutrition and exercise was the primary therapy. Social support was the primary reported barrier or facilitator in health behaviour change, though overall motivation to change and worry about disease progression or impact was low.

A key theme that emerged in our study was frustration and confusion regarding their diagnosis in terms of the aetiology/pathogenesis and the patient education provided about their condition. Participants found the exclusionary nature of their diagnosis unsatisfying. Only a small subset of patients reported a clear connection between presence of metabolic risk factors as contributing factors to NAFLD. This gap in knowledge may be related to the lack of symptoms and incidental nature of the diagnosis reported by the majority of patients. Respondents outlined that elevated liver enzymes and findings on imaging done for other reasons were the primary way they received their diagnosis. Among those with cirrhosis, they reported that their diagnosis was quite surprising given that they were largely asymptomatic and did not have the risk factors that they classically associated with developing cirrhosis. Interestingly, the reported level of concern about their diagnosis was low for most patients, even among those with cirrhosis. This risk perception may be related to reported gap in education provided for

their condition, and the sense that other comorbidities were comparatively more important.

In terms of disease management, respondents were aware that weight loss was the primary therapy for NAFLD. Importantly, they reported that provision of more specific recommendations for how to change their diet or increase their physical activity would be very helpful and was in general lacking as part of their care. This is consistent with findings by Stine et al where persons with NAFLD reported a lack of education from their treating provider about physical activity recommendations. Overall, patients were more focused on making dietary changes than changes in physical activity, in large part due to reported time constraints and physical limitations that precluded more exercise. Time constraint and physical discomfort were also primary barriers reported among persons with NAFLD who completed an exercise motivation questionnaire. 12 Of note, respondents characterised their nutritional changes largely based on removal of unhealthy items (ie, sugar-sweetened beverages, red meat) or addition of healthy foods (vegetables and fruits), rather than following a specific dietary regimen such as a Mediterranean diet. The key facilitator to making healthier food choices was the presence of social support, primarily coming from persons living with the patient. The importance of social support in motivating and sustaining health behaviour change has been highlighted in other studies and represents a key area to incorporate in disease management counseling. 9 11 A challenging aspect to tackle is low motivation to change health behaviours in this patient population. Several components appeared to impact the level of motivation, including presence of symptoms, competing comorbidities, and impact of lifestyle changes on HRQOL. A tailored approach to disease management with a focus on the key motivators or barriers to changing lifestyle habits for an individual patient may improve uptake of lifestyle recommendations, though this approach is often not feasible within the context of standard clinic visits.

There are several limitations to note for this study. First, the demographics of the patients seen at our tertiary care academic hospital are fairly homogenous. The majority of our patients are white (approximately 85%), and the average level of formal education is higher than the general population. These characteristics could have impacted the reported level of disease knowledge, as other studies have highlighted a significant gap in disease knowledge in this patient population.^{8 10} The sociodemographic characteristics of our participants may have also impacted the specific barriers and facilitators to health behaviour change. 15 A strength of our study was the purposeful sampling with regard to sex, age and cirrhosis status, which allowed us to capture a broad patient perspective with respect to those factors. As one of the few qualitative studies focused on evaluating patient-reported factors impacting care of NAFLD, our data build on the existing literature that can then help

inform larger quantitative studies of the facilitators and barriers of interest.

In conclusion, through this qualitative analysis of patient's disease knowledge, attitudes and health behaviours related to NAFLD, we have identified several gaps in care that are amenable to targeted interventions. These include provision of concise yet informative patient educational materials as part of standard of care to address ambiguity of diagnosis and inconsistent perceived risk of disease progression reported by our participants. Incorporating more detailed recommendations for specific nutritional changes and exercise regimens may also help facilitate behaviour change. Lastly, attempting to identify specific barriers and facilitators of health behaviour change for an individual patient would likely facilitate incorporation of first-line therapy for NAFLD. Focusing on the patient's social support and impact of competing comorbidities appear to be key specific factors driving diet and exercise patterns in NAFLD. Through this combination of efforts, we will be better able to align our care delivery with the needs and goals of persons with NAFLD, which in turn can help improve clinical outcomes.

Contributors MAT: study design, data collection, data analysis and manuscript preparation. JW: data collection and data analysis. MF: data analysis and manuscript review. ASL: study design and manuscript review.

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