Master thesis

Understanding the illness perceptions, quality of life, behavioural lifestyle changes and information needs of NALFD patients. A Dutch survey study.

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Abstract

Background

Non-alcoholic fatty liver disease (NAFLD) has seen an increase in recent years. Currently 1 in 4 people have been affected by this disease. The disease starts with an asymptotic stage but progresses to life-threatening stage. There is no current medication available, and it must be treated to with lifestyle changes. Earlier qualitative research pointed out that patients have a knowledge deficit, there is slight change in quality of life, and the illness perceptions of patients are none threatening, but up until now quantitative studies are still lacking.

AIM

The aim of this study was to increase our understanding of the NAFLD patients by investigating several aspects; the informational needs and wished of patients, what lifestyle changes have been advised or tried and to what extend these were successful, the quality of life (QOL) of NAFLD patients, and the illness perceptions (ILLP) of NAFLD patients.

Methods

An online survey was spread through the social network of the Dutch Digestive Foundation (MLDS) and the Dutch liver patient association (NLV). The questionnaire measured information needs, QOL, behavioural change aspects and ILLP. Descriptive analyses were performed in combination with Pearson chi-square and one-way ANOVA to test examine the relationship between the different NAFLD stages and the different aspects of the informational needs, QOL, and ILLP.

Results

352 patients completed the questionnaire. Patients indicated in general to not receive enough information and more than 80% wanted more information. Behaviour lifestyle changes had a overall successfulness rate of 50%. The QOL was 52 on a scale from 0-100. QOL decreased as NAFLD advances. Most patients are quite concerned about NAFLD and think it will be a long-lasting disease. Patients also think their understanding of the disease is low as well. Even though patients are concerned, there is a lack of high expected consequences and emotional affect due to NAFLD. Patients with advanced NAFLD stages had a significant difference in ILLP. The patients became more concerned, had increased understanding and perceived control, and expected more physical and emotional consequences due to NAFLD

Conclusion

The significant differences between the NAFLD stages, and the QOL and ILLP, indicate the possible impact of the disease. The abundance of received information in combination with the high need of more information could be used to improve and tailor the Dutch healthcare. Further investigation into what NAFLD patients need to start and adhere to lifestyle changes should be performed.

Introduction

Non-alcoholic fatty liver disease (NAFLD) is an emerging public health issue. The disease is closely related to obesity and diabetes and the prevalence is increasing. Currently about 1 in 4 Dutch inhabitants have NAFLD (Younossi, 2019). NAFLD knows four stages. In the first stage there is only an increased accumulation of fat in the liver. The second stage is called non-alcoholic steatohepatitis (NASH) this is characterised with inflammation of the liver. The third stage is liver fibrosis and is characterised with the creation of scar tissue on the liver. The last stage is cirrhosis of the liver, and this is also the worst stage, due to additional effects of portal hypertension and liver failure. The symptoms of these stages differ. Research has shown that during the first stage patients report almost no symptoms or impairment of health (Mlynarsky et al., 2016). Symptoms increase with increased stages of the disease and includes symptoms like forgetfulness, itchy skin, abdominal pain, abdominal bloating, loss of appetite and difficulty to carry out daily activities occur (Doward et al., 2017).

The development of NAFLD is known to have several risk factors. NAFLD is closely related to obesity, diabetes type 2 (Younossi et al., 2016), (Macavei, Baban & Dumitrascu, 2016). Furthermore, there are also behavioural factors that increase the risk of attracting NAFLD. Low physical activity has been found to correlate with an increase in NAFLD (Gerber et al., 2012). Low physical activity increases the burden on the liver to burn away excess food intake. In addition, a correlation has been found between an increased intake of food high in fat, fructose, or sugar (Leslie et al., 2014,). These behavioural factors increase the incidence of NAFLD since the burden on the liver to process nutrients increases. Consequently, these behaviour factors can lead to a higher BMI and Diabetes Type 2 and thus increase the risk of NAFLD even further (Hallsworth & Adams, 2019). In addition, there may be a hereditary component as shown by twin studies (Loomba et al., 2015). Next to hereditary and comorbidity there are also psychological risk factors. Perceived stress has been shown to increase the chances to attract a first stage of NAFLD (Kang et al., 2020).

Once NAFLD is diagnosed it is still possible to reverse the first stage and stop the progression to later stages. In addition, it has been shown that inflammation and fibrosis reduce with >10% weight loss, while 7% weight loss resulted into less steatosis and inflammation (Promrat et al., 2009). Currently there is no known medicine that can cure NAFLD. Therefore, multidisciplinary solutions have been researched that focus on the behavioural risk factors. Decreasing the risk factors seemed to be most successful by implementing a Mediterranean diet and increasing the physical activity (Perumpail, Cholankeril, Yoo, Kim & Ahmed, 2017). The Mediterranean diet consists out of mono-unsaturated fatty acids and high intakes of nuts,

vegetables, whole grain, fish, and fruits. The nutrients that come from these types of foods are better processed by the liver and therefore decrease NAFLD and NASH by 30% (Hallsworth & Adams, 2019). Qualitative studies regarding the facilitators and barriers of implementing these lifestyle changes have revealed several insights. Mentioned facilitators are, having close social support, dietary enjoyment, positive nutrition beliefs, enhanced nutrition knowledge and skills, and good self-regulation skills (Cardel et al., 2020; Haigh et al., 2019; Mlynarsky et al., 2016; Tincopa et al., 2021). Barriers that were found were, a poor understanding of the disease, it's progression and its management, the effectiveness of the behaviour lifestyle interventions, lack of practical knowledge, obesogenic environment, stress, time constraints, other medical conditions that inhibit physical activity, low concern of the fatality of the disease, and low impact of the disease on the quality of life. (Cardel et al., 2020; Haigh et al., 2019; Mlynarsky et al., 2016; Tincopa et al., 2021). Even though some qualitative studies have been performed, no quantitative study has yet been performed regarding the facilitators and barriers of performing different behavioural lifestyles, aong patients with NAFLD.

A recent systematic review showed that the impact of NAFLD is low on the QOL (Assimakopoulos et al., 2018). The asymptomatic nature of the disease causes low impact of the disease on the quality of life (Assimakopoulos et al., 2018). Only one study within this review made a distinction between the first and second stage of NAFLD. This single American based study showed that there was a significant distinction in the quality of life between patients in the first and second stage (David et al., 2009). The study indicated furthermore that the physical health aspect of the quality of life was more affected than the mental health aspect. Further research should be conducted to replicate these findings as well to understand the implication of the decreased quality of life on the behaviour.

Illness perceptions are influential in understanding the (emotional) impact of a disease and the uptake of behavioural lifestyle changes (Mlynarsky et al., 2016). Illness perceptions are defined as, *"The cognitive appraisal and personal understanding of a medical condition and its potential consequences"* (Broadbent et al., 2015). These perceptions are divided in six categories that together make up the overall illness perception a patient has: consequences of the disease, emotional representations of the disease, beliefs about personal and treatment control of the health outcome, timeline of the disease, identity (symptoms), and coherence. About NAFLD patients is known that they have the perception that the disease is harmless and not that influential (Mlynarsky et al., 2016). Furthermore, patients indicated that they do not foresee any consequences of the disease in upcoming years, had a low awareness of the disease and did not utilize healthcare enough (Mlynarsky et al., 2016). The low impact on

quality of life leads to a health belief with low perceived risk, severity, and threat of the disease (Zelber-Sagi et al., 2017). The reason for this might be that the symptoms in early stages of NAFLD are only small, like fatigue, malaise, or slight discomfort in the upper abdominal quadrant (Gao & Fan, 2013). Recent qualitative research has found that there might be change in illness perceptions during the progression of the disease (Cook et al., 2018). Even though several qualitative studies were performed regarding the illness perceptions of NAFLD patients, no quantitative studies were yet performed on the difference in illness perceptions between patients in different stages, or other factors that could influence the Illness perceptions.

Knowledge about the disease can affect the illness perceptions, yet there seems to be a knowledge deficit within the NAFLD population. A large deficit was found regarding the understanding, progression, and management of the disease (Cook et al., 2018). Furthermore, was found that there was a knowledge deficit regarding the diagnosis and effectiveness of treatment (Haigh et al., 2019) Regarding the cause of NAFLD indicated research that most patients think that genetics are the root of the disease (Tincopa et al., 2021). The cause of this deficit is according to the patients because of lack of education during diagnosis (Cook et al., 2018) A recent study found that clinicians felt they lacked the skills to educate in behavioural change styles (Hallsworth & Adams, 2019). Perhaps changing these deficits could also change the illness perceptions patients currently have and ultimately increase the uptake of behaviour lifestyle changes. However, too little is currently known about the information satisfaction grade of patients as well as their needs and wishes of the health care system.

To sum up, NAFLD starts as an asymptomatic disease that can progress into a life-threatening disease. The current treatments are behaviour lifestyle changes, but these are largely influenced by several factors like quality of life, illness perceptions and knowledge of the patient about several aspects of the disease. Previous studies have been mostly qualitative and singled out only one of these aspects. The quantitative more comprehensive approach of the study tries to fill the current knowledge gaps that are present. The current research will extend the already existing research on the aspects of behaviour lifestyle changes and its barriers, the quality of life and illness perceptions during different stages, the amount of information that patients receive from the current healthcare and its needs and wishes thereof. This could increase the understanding of NAFLD to improve the healthcare that NAFLD patients receive.

The following research questions will be answered.

1. What are the informational needs of NAFLD patients?
    a. How much information was received regarding different aspects of the disease (Nature, causes, consequences, self-management, medical treatment and further care)?
    b. Is additional information wanted regarding the aforementioned aspects of the disease?
2. Which lifestyle changes have patients undertaken since the diagnoses?
    a. Which lifestyle changes were advised?
    b. Which lifestyle changes were tried?
    c. Which lifestyle changes were successful?
    d. What barriers did patients encounter while performing the lifestyle changes?
3. What is the quality of life of patients with NAFLD?
    a. What dimensions (physical functioning, role physical, bodily pain, general health, vitality, social functioning, role emotional, and mental health) are most impacted by the disease, and to what extent is QoL different for people of different stages of NAFLD?
4. What are the illness perceptions of patients with NAFLD?
    a. Which beliefs and idea's (illness perceptions) do the patients with NAFLD hold, and to what extent are Illness perceptions different for people of different stages of NAFLD?

Methods

Design

The study is a cross sectional survey study. The data has been collected by using an online Qualtrics questionnaire between June and September 2021.

Participants & procedures

The study was approved by the ethical board of het Medisch Spectrum Twente (MST). The inclusion criteria for patients were that they should have self-reported NAFLD or any progressed stages of self-reported NAFLD and the ability to complete an online questionnaire. Exclusion criteria were patients with a fatty liver disease because of alcohol. The participants were recruited through the Dutch Digestive Foundation (MLDS) and the Dutch liver patient association (NLV), based on convenience sampling. The MLDS posted a short introduction letter to recruit participants. The invited redirected participants to a questionnaire made with Qualtrics.com. The first page of the questionnaire was a general explanation of the research. The second stated the rights of the participants and contained information about the anonymity of the participants. Active informed consent was required to be able to proceed to the questions (appendix A). Participants were informed that their address would be kept separate from their answers. A total of 741 participants consented and started with the questionnaire, 354 finished the questionnaire. The 387 participants that had not finished were excluded. Of the remaining 354 participants 26 had to be excluded because of self-reported alcoholic causes of NAFLD. The remaining sample consisted of 328 participants. When finished the participants were asked if they were willing to cooperate with further research and an email address could be filled in, 200 participants gave their email address. The duration of the questionnaire was on average around 20 minutes.

Measures

Personal characteristics

The sociodemographic variables, gender and education were asked through multiple choice questions and age was asked in years. Educational level was categorised in primary (i.e. no education and elementary) secondary (i.e. high school and vocational training), and tertiary (i.e. higher professional education and university degrees). Weight and length were asked to calculate the body mass index (BMI). This was done by: Weight/(length x length). A score below 18.00 indicated underweight, between 18.00 and 25.00 indicated a healthy weight, above 25.00 until 30.00 indicated obesity and above 30.00 extreme obesity. Second, their current NAFLD stages was inquired by asking participants to self-classify in one of the four stages or

indicate that they were unaware of the stages. If unaware of the stage it could be indicated that this was either, never told, forgotten or not examined. Third, the Dutch norm of healthy exercise (NNGB) had to be indicated. The Dutch norm for satisfactory physical activity per week was split up in performing moderate physical activity and performing bone and muscle strengthening exercises. The physical activity norm was achieved when physical activity was performed for 150 minutes or more. The norm for bone and muscle strengthening was achieved when muscle and bone strengthening exercises were performed 3 times or more. Fourth, inquiries were made regarding the comorbidity of NAFLD patients with other physical or mental diseases. The comorbidities that could be chosen from were, high cholesterol, high blood pressure, diabetes, cardiovascular diseases, joint problems like arthrosis or rheumatism, and other.

Informational needs

The informational needs were investigated through three variables, amount of received information, wanted information, and searched information. These three variables were measured with a questionnaire created by the research team. The specific subtopics for each variable were, what is NAFLD, Causes of NAFLD, Consequences of NAFLD, Self-improvement of NAFLD, Diet, Exercise, Treatment, Healthcare, Apps/websites, and fellow sufferers. An example question for the satisfaction topic would be: *"How much information did you receive about what entails fatty liver disease?".* Patients could respond with; *"No information" (0), "a bit of information" (1),* or *"Enough information" (2).* An example question for the wanted topic would be: *"Would you have liked more information about what entails fatty liver disease?"* Patients could respond with *yes (1) or no (0).*

Behaviour lifestyle

To investigate the behaviour lifestyles of patients an inquiry was made about possible lifestyles to self-manage NAFLD. Questions investigated what lifestyle changes were advised and tried ("*losing weight"* (1)*, "increase physical activity*" (2), "*low carb diet"* (3)*, "Mediterranean diet"* (4)*, "referral dietician"* (5)*, "referral physiotherapist"* (6) and *"other"* (7)) , and to what extend respondents were successful ("*No, that wasn't necessary"* (1), "*No, I have not been successful"* (2), *"Yes, in the beginning but only temporarily"* (3), *"Yes, I have been able to change permanently"* (4)). Furthermore, an inquiry was made regarding the barriers that were experienced while trying the lifestyle changes. The answer options for every category were "*yes*" (1) or "*no*" (0). An example question would be: *"What advice or treatments have been given to you…. ….Losing weight".* The self-reported successfulness was requested regarding three topics, changing the diet, increasing the physical activity, and losing weight. An example

question would be: *"were you successful in changing your eating pattern?"* the answer options would be, *"No that wasn't needed" (1), "No I wasn't successful" (2), "Yes for a while, but I relapsed into my old eating pattern" (3),* or *"Yes I have been permanently successful in changing my eating pattern" (4).* The barriers were asked regarding the behavioral lifestyle changes of diet change, increase in physical activity, or weight loss. An example question would be, *"what made it difficult for you to increase your physical activity?".* The answer options that could be given were, *"inefficient knowledge about NAFLD"* (1)*, "Insufficient knowledge about physical activity"* (2)*, "Insufficient practical advice"* (3)*, "Lack of motivation"* (4)*, "Lack of time"* (5)*, "Too much stress"* (6)*,* or *"other"* (7).

Quality of life

The quality of life was investigated with the Dutch version of the RAND 12 and partially (the mental health and vitality part) with the Dutch version of the RAND 36. The 12 items of the RAND12 can be categorised into eight separate health domains: general health (GH), physical functioning (PF), physical role (PR), vitality (VT), social functioning (SF), bodily pain (BP), mental health (MH), and emotional role (ER). To increase the understanding of the mental health and vitality of the patients the MH and VT we used the more elaborate RAND36 to measure these dimensions. All questions can be answered on a 3, 4, 5 or 6-point Likert scale. The different domains were scored according to the RAND12 and RAND36 manual (Hays et al., 1993). The norm score of 50 with std of 10 indicates a below or above score compared to the general population. The total QOL questionnaire in our study had a high level of internal consistency, as determined by a Cronbach's alpha of 0.89.

Illness perceptions

The illness perceptions were studied using the Dutch translated version of the brief illness perception questionnaire (De Raaij, et al., 2007). The scale consists of eight Likert scale items between 0 and 10, and one open item, investigates the causal factors. Five items' asses cognitive illness representations; consequences, timeline, personal control, treatment control, and identity. Two items assess emotional representations: concern and emotions. One item assesses illness comprehensibility. The scores on the scales have been scored based on the manual (Broadbent et al., 2006) The total ILLP questionnaire had a low level of internal consistency, as determined by a Cronbach's alpha of 0.527. Since, there was a low Cronbach's alpha a total score was not computed, and instead, the domains were examined separately.

Analyses

The data was transferred from Qualtrics.com to SPSS version 28.0 for Windows SPSS Inc., Chicago, IL, United States to execute all the statistical tests.

To examine what the information needs of the participants were descriptive analyses were performed on the informational need's variables. Furthermore, the group difference between different self-reported NAFLD stages, gender, and education were examined by correlation analyses.

The advice and tried lifestyle changes were examined through descriptive analyses. The barriers were examined separately per investigated lifestyle change.

To examine the QOL the different domain and overall score were analyzed through descriptive analyses and expressed through mean and ± standard deviation. To examine the group difference between different self-reported NAFLD stages a One-way ANOVA was used. Additionally, a post-hoc test was performed using the welch test.

To examine the illness perceptions the different domains were analyzed through descriptive analyses and expressed through mean and ± standard deviation. To examine the group difference between different self-reported NAFLD stages a One-way ANOVA was used. Additionally, a post-hoc test was performed using the welch test. All tests with a significant P value of <0.05 were deemed as significant.

Results

In table 1 the descriptive statistics of the demographic characteristics of the participants are given. There were 277 females and 51 males with a mean age of 56. There was a large difference in number of women compared to men that took part in the study. Regarding education, 60 percent finished secondary education and 29 percent finished tertiary education. Of the total population 45% was currently employed. Of the employed respondents 46% had a sedentary occupation, 34% had a mixed occupation, and 21% had a physical occupation.

Table1

Demographic characteristics of the participants (N=328)

Demographic Characteristics	*n*	*%*	*M (SD)*
Gender			
Female	277	85	
Male	51	16	
Age			56 (11)
Education			
Primary (None/Elementary)	5	2	
Secondary (High school/Vocational)	206	63	
Tertiary (Higher Vocational/University)	95	29	
Employment			
Employed	149	45	
Mostly sedentary	68	46	
Physical/sedentary	50	34	
Mostly physical	31	21	
Not employed	179	55	

The largest part, 43 percent, of the participants self-reported stage 1 NAFLD diagnosis (simple steatosis) and 41 percent indicated to have no idea. (Table 2). More than half of the patients indicated that the diagnosis was made by the gastroenterologist. One out of five patients have been diagnosed by the general practitioner. Of the patients that had or currently have comorbidities, 48% indicated joint problems, 41% indicated high blood pressure, and 36% indicated high cholesterol. Of all the patients 10% had no comorbidities. The vast majority (87%) had a BMI of >25; 35% was overweight (BMI between 25 and 30) 52% was obese (BMI>30). Only one third indicated to fulfil the Dutch norm for exercise (to be moderately active for at least 150 minutes per week) and almost half of the population indicated that a workout to increase bone or muscle strength was performed at least thrice a week.

Table 2

Self-reported medical characteristics of the participants (N=328)

Medical characteristics	*M(SD)*	*n*	*%*
Diagnosis			
Fatty		140	43
Inflammation		20	6
Cirrhosis/Fibrosis		30	9
Liver cancer		5	2
No Idea		133	41
Diagnosed by			
GP		64	20
Hepatologist		187	57
Radiologist		30	9
Internist		15	5
Nurse		9	3
Other		23	7
Comorbidity[1]			
Joint problems		157	48
High blood pressure		134	41
Cholesterol		117	36
Diabetes		79	25
Heart and vascular disease		58	18
Other		89	27
No comorbidities		33	11
BMI	30 (5)		
Underweight		4	1
Normal weight		40	12
Overweight		115	35
Obese		169	52
Sufficient NNGB			
Activity		99	30
Muscle/bone exercises		163	50

[1] Comorbidity includes past and present self-reported comorbidities

The informational needs and wishes of NAFLD patients

In general, participants received information less than little information (Table 3). Overall, the patients scored low on all different aspects, indicating that no information about NAFLD was provided, 37% of the patients and not enough information in another 46%. Only 17% replied that they received enough information about NAFLD. Even less information was received concerning causes of NAFLD, consequences of NAFLD, self-improvement, and which diet, exercise of treatment to perform.

Patients received the least information about fellow sufferers, however, there was also a low number of patients that wanted additional information about this topic. Last the self-management topic receives a low score as well and more information about this topic is most wanted. Furthermore, patients received little information about where to seek help or further information to gain access to information that was apparently wanted. Furthermore, out of the 328 patients, 70 percent tried to gain more information through the internet of which 72 percent used specific NAFLD related websites. 20 percent of the patients indicated that no further inquiries were made towards additional information. The remaining patients sought additional information through their social circle.

Table 3

Information that was received by patients and the request for more information per topic (N=328)

Satisfactory information received about…	No information (1) (n, (%))	Little information (2) (n, (%))	Enough information (3) (n, (%))	*M (SD)*	More information wanted on… (n, (%))
What is NAFLD	120 (37%)	152 (46%)	56 (17%)	1.80 (.71)	279 (85%)
Causes of NAFLD	128 (39%)	143 (44%)	57 (17%)	1.78 (.73)	289 (88%)
Consequences of NAFLD	154 (47%)	114 (35%)	60 (18%)	1.71 (.76)	287 (88%)
Self-improvement NAFLD	152 (46%)	132 (40%)	49 (13%)	1.68 (.71)	298 (91%)
Diet NAFLD	157 (48%)	120 (37%)	51 (16%)	1.65 (.73)	282 (86%)
Exercise NAFLD	164 (50%)	116 (35%)	48 (15%)	1.65 (.73)	239 (73%)
Treatment NAFLD	158 (48%)	133 (41%)	37 (11%)	1.63 (.69)	295 (90%)
Healthcare	224 (68%)	80 (24%)	24 (7%)	1.39 (.62)	239 (73%)
Apps/websites	251 (77%)	62 (19%)	15 (5%)	1.28 (.55)	250 (76%)
Fellow Sufferer NAFLD	272 (83%)	47 (14%)	9 (3%)	1.20 (.48)	130 (40%)

Analyses on the relationship between information needs and the NAFLD stage indicated that in general the patients that had no idea what stages they were in wanted more information (Table 4). Stages 1 participants and participants that had no idea, reported significant more interest in information, regarding what is NAFLD. Females reported to receive significant more information regarding what is NAFLD. Females also reported significant need of more information, regarding what is NAFLD, compared to males. Stages 2,3 or 4 patients reported a significantly higher need for information regarding fellow sufferers than stages 1 or participants that had no idea. Males also reported a significantly higher need of information regarding fellow sufferers than females. No differences were found between the educational groups.

Table 4

Information needs by NAFLD stage, gender, and education level (N=328)

Wants more information on…	NALD stages			Gender		Education	
	Stages 1 (*n*=140) (n, (%))	Stages 2,3,4 (*n*=55) (n, (%))	No idea (*n*=133) (n, (%))	Female (*n*=277) (n, (%))	Male (*n*=51) (n, (%))	Primary/Secondary (*n*=233) (n, (%))	Tertiary (*n*=95) (n, (%))
What is NAFLD [a]	115 (82%)*	42 (76%)*	122 (92%)*	241 (87%)*	38 (75%)*	192 (86%)	83 (82%)
Causes of NAFLD	124 (87%)	44 (80%)	121 (91%)	246 (89%)	43 (84%)	198 (89%)	87 (86%)
Consequences of NAFLD	122 (87%)	44 (80%)	121 (91%)	246 (89%)	41 (80%)	196 (88%)	87 (86%)
Self-improvement NAFLD	129 (92%)	47 (86%)	122 (92%)	252 (91%)	46 (90%)	205 (92%)	98 (88%)
Diet NAFLD	122 (87%)	42 (76%)	118(89%)	241 (87%)	41 (80%)	193 (87%)	85 (84%)
Exercise NAFLD	100 (71%)	39 (71%)	100 (73%)	203 (73%)	36 (70%)	165 (74%)	71 (70%)
Treatment NAFLD	127 (91%)	48 (87%)	120 (90%)	250 (90%)	45 (88%)	202 (91%)	89 (88%)
Healthcare	102 (73%)	37 (67%)	100 (75%)	199 (72%)	40 (78%)	162 (73%)	74 (73%)
Apps/websites	105 (75%)	44 (80%)	101 (76%)	212 (77%)	38 (75%)	168 (75%)	79 (78%)
Fellow Sufferer NAFLD [a]	47 (34%)*	30 (55%)*	53 (40%)*	103 (37%)*	27 (53%)*	86 (38%)	41 (41%)

[a] Post hoc test were performed when p<0.05

* p<0.05 differences between groups tested with chi-square tests

Obtained lifestyle advice and lifestyle modification

About 21% of the patients received no information about lifestyle changes. Of the 80% of patients who received information, these advice about lifestyle changes mainly referred to losing weight (61%) and increase physical activity (52%) (Table 5). About 31% of patients were referred to a dietician and 7% to a physical therapist. When asked about lifestyle changes that were tried a total of 7% of patients reported that they did not attempt any lifestyle change. The majority of patients attempted lifestyle changes including weight loss (80%, increase physical activity (81%). All the lifestyle changes were tried more often than advised.

Table 5

Lifestyle changes advised and tried

Lifestyle changes	Advised *(N=326)* n (%)	Tried *(N=324)* n (%)
Lose weight	200 (61%)	263 (80%)
Increase physical activity	172 (52%)	267 (81%)
Mediterranean diet	14 (4%)	31 (9%)
Low carb diet	67 (20%)	141 (43%)
Referral dietician	101 (31%)	135 (41%)
Referral Physiotherapy	24 (7%)	38 (12%)
No lifestyle advised/tried	67 (21%)	23 (7%)

The patients were asked whether their lifestyle changes had lasting effects. Of the patients that tried weight loss, 28% of patients reported that they were successful, 46% of patients reported that this was not successful and 19% of patients reported that this was temporary successful but that they returned to their old eating habits. Of the patients that increased physical activity, 45% of patients reported that they were successful, 24% of patients reported that this was not successful and 24% of patients reported that this was temporary successful but that they returned to their old mobility habits. Of the patients that changes their eating habits, 49% of patients reported that they were successful, 19% of patients reported that this was not successful and 23% of patients reported that this was temporary successful but that they returned to their old eating habits. The change of diet and increase in physical activity seemed to be the most successful compared to losing weight (Table 6). Besides the lack of general knowledge and many difficulties in practical advises, these findings are in line with the low information score as mentioned in table 3. Other reasons have been mentioned almost a third in every lifestyle change, pain was mentioned most frequent among these other reasons.

Table 6

Self-reported successfulness of three attempts to lifestyle changes (weight loss, increased PA and diet change) and the corresponding difficulties encountered (N=328)

Behaviour lifestyles	Los of weight n (%)	Increased physical activity n (%)	Changed diet n (%)
Not successful	152 (46%)	79 (24%)	62 (19%)
Successful	81 (25%)	127 (39%)	132 (40%)
Temporary successful	55 (17%)	79 (24%)	74 (23%)
Not necessary	40 (12%)	43 (13%)	60 (18%)
Difficulty due to: [1]			
Too much stress	90 (27%)	54 (17%)	124 (38%)
Lack of motivation	86 (26%)	75 (23%)	63 (19%)
Lack of knowledge NAFLD	81 (25%)	71 (22%)	148 (45%)
Lack of practical advises	70 (21%)	48 (15%)	119 (36%)
Lack of knowledge lifestyle	34 (10%)	22 (7%)	59 (18%)
Lack of time	27 (8%)	48 (15%)	29 (9%)
Other	100 (31%)	125 (38%)	77 (24%)

[1] Includes the successful/not necessary population as well.

The Quality of life of patients with NAFLD

The scores on the RAND12 have a norm for the overall score of 50 with a standard deviation of 10. The minimum score is 0 and the maximum score 100. The norm is the given cut off score for all the different domains, below 50 indicates an impairment in that domain. The total group score is higher than 50 in every category expect for role physical, vitality and general health. The first stages group scores higher in every domain compared to the second, third and fourth stages. Furthermore, A one-way ANOVA with post-hoc Tukey tests were conducted to determine if the overall quality of life and its subdomains were statistically different between the NAFLD stages. There were no outliers, as assessed by boxplot and data was normally distributed. There was no homogeneity of variances, as assessed by Levene's test of homogeneity of variances. There was significant difference in the subdomains Vitality, Overall QOL and Role emotional when comparing NAFLD stages.

Table 7

General descriptive of aspects of QOL (N=328)

QOL aspect	Total sample (n-328) *M (SD)*	Stages 1 (n-140) *M (SD)*	Stages (2,3,4) (n-55) *M (SD)*	No Idea (n-133) *M (SD)*
Mental Health (RAND36)	65.69 (18.32)	67.57 (17.62)	52.84 (21.16)	64.90 (17.69)
Bodily pain (RAND12)	59.92 (31.42)	62.14 (33.73)	58.64 (31.26)	58.08 (28.96)
Role Emotional (RAND12) [a]	59.91 (26.23)	61.79 (24.94)	50.90 (26.45) *	61.65 (26.88)
Physical functioning (RAND12)	56.02 (34.59)	60.89 (35.13)	55.18 (35.37)	52.07 (33.29)
Social functioning (RAND12)	52.36 (29.13)	55.18 (47.27)	47.27 (27.50)	51.50 (29.16)
Role Physical (RAND12)	46.49 (30.34)	50.18 (33.05)	40.00 (29.11)	45.3 (27.38)
Vitality (RAND36) [a]	43.08 (19.83)	46.39 (20.36)	38.64 (18.96) *	41.43 (19.18)
General Health (RAND36)	33.92 (20.47)	36.96 (19.99)	32.73 (20.34)	31.20 (20.74)
Overall QOL [a]	52.30 (20.74)	55.14 (20.65) *	48.03 (19.86) *	49.18 (20.06) *

[a] post hoc test were performed when $p<0.05$

* $p<0.05$ difference tested with one-way ANOVA and post-hoc Tukey

NAFLD patients and the view of their disease

Table 7 represents the various illness perceptions that the patients have about NAFLD. The mean score given can range from 0-10. A higher score indicates that patients consider their illness as more severe or threatening. A score of zero would be equal to having no disease. The high score on Timeline indicates that participants expect their disease to last long. Participants also seem to be concerned about their disease but do think their disease can be treated. Consequences, emotion, and control score lower compared to timeline, treatment control or concern. These scores would indicate that participants think they have low understanding regarding their own disease and think the disease does not affect them significantly. To further investigate the association between NAFLD stages and the different illness perception domains, a one-way ANOVA was conducted with a post-hoc Tukey test. There were no outliers, as assessed by boxplot and data was normally distributed. There was no homogeneity of variances, as assessed by Levene's test of homogeneity of variances. all the different subdomains showed significant differences between the groups except for treatment control.

Table 8

Mean scores and SD on Illness perceptions by self-reported stage of disease (N=328)

ILLP Aspect[1]	Total sample (n-328) *M (SD)*	Stages 1 (n-140) *M (SD)*	Stages (2,3,4) (n-55) *M (SD)*	No Idea (n-133) *M (SD)*
"How long do you think your illness will continue?" (Timeline) [a]	7.6 (2.3)	7.1 (2.4)*	8.5 (1.82)*	7.7 (2.3)*
"How much control do you feel you have over your illness?" (Control) [2] [a]	3.8 (2.4)	4.0 (2.4)*	4.1 (2.4)*	3.4 (2.4)*
"How concerned are you about your illness?" (Concern) [a]	6.2 (2.7)	5.7 (2.5)	7.9 (1.9)*	6.0 (2.8)*
"How much do you experience symptoms from your illness?" (Consequences) [a]	4.8 (2.8)	3.5 (2.8)	5.9 (2.8)*	4.2 (2.8)*
"How much does your illness affect you emotionally? (e.g. does it make you angry, scared, upset or depressed?" (Emotion) [a]	4.3 (2.9)	3.7 (2.7)	5.7 (2.8)*	4.3 (3.0)*
"How well do you feel you understand your illness?" (Illness comprehensibility) [2] [a]	4.2 (2.9)	4.5 (2.6)	4.8 (2.6)*	3.6 (2.5)*
"How much does your illness affect your life?" (Identity) [a]	4.2 (2.9)	4.2 (2.7)*	6.4 (2.2)*	4.7 (2.9)*
"How much do you think your treatment can help your illness?" (Treatment control) [2]	6.0 (2.4)	6.2 (2.4)	5.9 (2.2)	5.8 (2.5)

1 All items could be scored on a scale from 0-10

[2] A higher score indicates more control/understanding

[a] post hoc test were performed when $p<0.05$

* $p<0.05$ difference tested with one-way ANOVA and post-hoc Tukey

Discussion

The aim of this study was to gain more insight into the informational needs, behaviour regarding lifestyle changes, quality of life, and illness perceptions of the current NAFLD population of the Netherlands. The gathered information about demographic, medical, informational, lifestyle behaviour, illness perceptions and Quality of life will give multiple insights that will be further explained per topic.

Informational needs and wishes

The most significant finding was the general dissatisfaction about the received information from the healthcare practitioners. More information was wanted by almost 80 percent on every domain except the fellow sufferer's domain. More males were interested in fellow sufferers than females. These findings are to some extent in line with previous qualitative studies on informational needs. For example, Haigh and colleagues (2019) found that there was a general knowledge deficit among NAFLD patients towards their own disease and the effectiveness of behavioural interventions on the positive outcome on the disease. Also Cook and colleagues (2018) found that, NAFLD patients were unsatisfied by the education that was given by their physicians. The single quantitative inquiry regarding general informational needs (to out knowledge) was performed by the British Liver Trust (Britishlivertrust.org, 2020) on general liver disease patients. A survey of over 700 patients was conducted and 60 percent stated dissatisfaction with the information received. Our study adds to these studies in that it targets NAFLD specifically and in a quantitative manner. Also, the informational needs are investigated in more detailed domains and compared between NAFLD stages, gender, and education. Our results indicate a clear need for more information on every specific domain. Especially most patients (92%) requested more information on the topic of how to self-improve NAFLD. These findings suggest that emphasis should be placed on information provision in the healthcare system while diagnosing and treating these patients. This study showed more males than females were interested in fellow sufferers. Consequently, further research could investigate group differences regarding specific informational need's topics.

Behavioural lifestyle changes

Most of the patients got advised by their healthcare professional to change their behaviour lifestyles through interventions based on diet changes, increased physical activity and weight loss in general. It is remarkable that, more participants performed behavioural lifestyle changes than were advised. A reason for this could be that the patients were only asked what had been advised by health care workers, the 70 percent of participants that searched more information

through the internet could be the cause of this difference. 80 percent of the respondents are overweight, only 61 percent were advised by their healthcare professional to lose weight.

Looking further into the specific behavioural diet lifestyle changes, only 4 percent of the patients were advised to try a Mediterranean diet. However, this is one of the most effective diet changes for NAFLD (Hallsworth & Adams, 2019). A low carb diet was more often prescribed than a Mediterranean diet to patients, this could be due to the increased effectiveness on weight loss compared to other diets (Tricò et al., 2021). It should also be noted that the name and content of the Mediterranean diet may not be familiar for the patients, or not used by the health care professional. Regarding the self-reported effectiveness of the advice of a diet change, 42 percent indicated to not be successful in implementing this lifestyle change. The low self-reported successfulness in lifestyle change is in line with previous findings Stewart and colleagues (2014) who investigated, in a qualitative study, readiness to change in NAFLD patients. Steward and colleagues discovered that the readiness to change is low due to the asymptotic nature of the disease. Most mentioned barriers in the current study were lack of general knowledge about NAFLD, lack of practical advises and stress. These findings are partly in line with previous qualitative research from Haigh and colleagues (2019) who examined barriers in Mediterranean uptake. In that study life stressors and poor understanding of NAFLD were main (reported?) barriers. The barrier of lack of practical advises, found in our study, is in line with research from Hallsworth & Adams who examined behaviour advice from healthcare workers and found that clinicians indicated to be unable to properly explain behaviour lifestyle changes. Our study clearly supports the previously, low uptake rate and barriers toward dietary lifestyle changes. Also, further confirmation towards the low knowledge and importance thereof for behaviour change has been established. Further research must be conducted to investigate how to overcome these barriers that are currently present.

Looking further into the the results regarding physical activity it seems that an increase in physical activity within the target population seems necessary, since only 30 percent self-reported that their weekly activity suffices. There is a discrepancy between the 30%, of which the weekly activity suffices according to the Dutch activity norm, and the 39% that indicated the increase in physical activity was successful. A cause for this might be that the self-reported successfulness of the respondents is based on different criteria than the Dutch activity norm. From the total group of respondents 24% indicated to not be successful, and 24% indicated only temporary successfulness. Reported barriers were lack of motivation in combination with lack of NAFLD knowledge in general. These results are to some extent in line with a study by Stine and colleagues (2020) who pointed out that an increase in physical activity is needed for these

patients. Furthermore, lack of motivation and education were similar barriers. These barriers and its roots must be further investigated to find a solution towards the current physical activity problem.

Quality of life of NAFLD patients

Interpreting the results of the overall target group indicates an average QOL when compared to the general population. The only domain that is lacking is the 'general health'- domain. When comparing the different NAFLD stages, there is a negative decline in QOL as the stages advance. The reason for this could be the increase in severity of symptoms in more advanced stages compared to the first stage. The significant difference, between the first stage and advanced stages, on the subdomain vitality can be explained by the increased physical symptoms from the advanced stages. Furthermore, an increase of burden on daily activities due to the emotional effect of the disease was found in advanced NAFLD stages. These findings are in line with previous studies. For example, David et al (2009) found that there is no difference in QOL in NAFLD compared to the general population. However, a significant difference in the subdomain emotional role when the NAFLD stages progress was not found in previous research and could implicate that the emotional burden of NAFLD might be higher than expected. These findings confirm that the Dutch NAFLD population have a similar QOL compared to other western societies. But perhaps more research is needed towards the emotional burden of NAFLD.

Illness perceptions of NAFLD patients.

From the results regarding the several domains of the illness perceptions can be indicated that patients are concerned about NAFLD and think it will be a long-lasting disease that can be treated. Patients also think their understanding of the disease is low as well. Even though patients are concerned, there is a lack of high expected consequences and emotional affect due to NAFLD. Patients scored higher on the treatment control domain compared to the personal control domain. Besides, illness perceptions become higher when the stages are further advanced. Participants seem to become more concerned and expect more physical and emotional consequences from NAFLD. There is also an increase in understanding of the disease and identification with it. The higher scores regarding the duration of the disease, the possible medical treatment, and concern about NAFLD are in line with previous findings from Zelber-Sagi and colleagues (2017) who performed quantitative study in Israel. The low score on the perceived understanding of the disease in the current study, is contradicting previous findings of the study by Dhaliwal and colleagues (2021). The study examined illness perceptions

in newly diagnosed NAFLD patients in India and found that the perceived illness understanding domain scored highest. These two studies are the only previous studies towards NAFLD; however, these are in non-western countries and do not distinguish between different NAFLD stages. to create greater understanding of the position of NAFLD, regarding the illness perception, it is possible to compare the Illness perception scores with a disease similar in characteristic, Diabetes mellitus type 2. In previous research from Petriček and colleagues (2009) the subdomains of illness perceptions were investigated among diabetes mellitus type 2. The participants scored at least one whole point higher except on consequences, concern, and identification with the disease, which scored equal. Consequently, NAFLD has less threatening illness perceptions when compared to Diabetes mellitus type 2. Since the illness perceptions are influential in the uptake of behaviour lifestyle changes (Zelber-Sagi et al., 2017; Dhaliwal et al., 2021), more research should be done towards the origin and alteration of the illness perceptions in general as well as its subdomains. The information that resulted from the current study could help in the understanding of NAFLD patients. The understanding can be harnessed to create more effective and efficient treatment for NAFLD patients.

Medical demographics

Next to the investigated topics was found that there is comorbidity within the Dutch NAFLD population with other medical diseases besides NAFLD but also with obesity. In total 87 percent had overweight of which 60 percent obese. Besides overweight, there was a high number of patients with Joint problems, Cholesterol, and high blood pressure. Joint problems have a general onset of the age 40 to 60. The average age of 55 could therefore be an explanation. Only 22 percent of the patients indicated to have diabetes. Regarding the stages of their disease, the first stage was most prevalent. Remarkable was the high number of patients that had no idea what stage they were in. This result is not found in previous research but could be dangerous. The patient could wrongly evaluate their own health situation and perhaps not search healthcare. This could result in lower QOL of NAFLD patients. A reason for the large no idea group could be the low received information score. The large percentage of joint problems could explain the low number of patients that performed sufficient physical activity. Findings in the study of Younossi and colleagues (2016) are in line with the high number of overweight patients, which are not remarkable since overweight is a risk factor for NAFLD. The low percentage of Diabetes in the current study was remarkable since NAFLD is often comorbid with Diabetes (Younossi et al., 2016). The large percentage of respondents that have joint problems is in line with findings from previous research of Oliver & Silman (2006). Their study investigated obesity and found a large comorbidity with joint problems and specifically arthrosis.

Similarly, as with arthrosis is a high blood pressure is also often found in patients with obesity, but especially diets consisting of fats and sugars (Bays et al., 2005). In general, these findings indicate that the NAFLD group is a highly comorbid and difficult group to understand. These factors decrease the effectiveness of current healthcare. Further research should investigate the large number of patients that are unaware of the NAFLD stages, furthermore, should the implications of the high comorbidity be investigated to increase the understanding of the NAFLD patients.

Strengths and limitations

This is the first study that investigated the informational needs of NAFLD patients through a quantitative approach. Previous studies only investigated qualitatively the knowledge of NAFLD patients regarding their disease. Whereas other studies only investigate a single segment like QOL or ILLP, this study tried to incorporate the informational needs as well as the behavioural change aspects of the treatment of the disease. Many self-reported NAFLD patients participated which leads to greater generalizability.

Yet, the study has some limitations that should be considered when interpreting the results. First, an already existing social network (that of the MLDS) was used to recruit participants. This could lead to a more biased result since these patients are already more involved and active with their disease compared to other NAFLD patients. Second, the NAFLD and lifestyle changes were self-reported. This could mean that there were patients that had no NAFLD at all. Since, the NAFLD was self-reported the different group stages also become less reliable. Finally, there is a high response rate of women and a low response rate of males within the target population. According to the prevalence rate there is no difference between males and females. Future studies could overcome these limitations by including medically diagnosed patients and control gender variety.

Scientific implications

There are several scientific implications that stem from the current research. First, has the research indicated that there is a large knowledge provision deficit within the Dutch healthcare system regarding NAFLD patients. Not only a general deficit has been found but also domain specific deficits, which can be used in the increase effectivity of Dutch healthcare. Also has literature about advised, tried and self-reported successfulness expanded to increase the knowledge on which behavioural lifestyle change is performed and what the barriers are regarding these lifestyle changes. Lastly were domain specific changes found of illness

perceptions between different groups of NAFLD stages. This leads to a greater understanding of the different patient types with the NAFLD domain.

Conclusion

Summing up can be stated that the NAFLD patients are a group with a high number of comorbidities and overweight/obese patients. These patients are unsatisfied about the information that is received by the Dutch healthcare system. Only half of the patients is successful in performing behaviour lifestyle changes. The QOL of NAFLD patients seems to be unchanged in general in their first stage but decreases when their disease advances. Patients indicated that they are concerned about NAFLD, and think will be a long-lasting disease that can be treated. Patients also think their understanding of the disease is low. Even though patients are concerned, there is a lack of high expected consequences and emotional affect due to NAFLD. Illness perceptions and QOL could be influential in the low successfulness in behavioural lifestyle changes. Further research needs to be done to increase the understanding of what patients might need to be successful in their behavioural lifestyle change.

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Appendix A
Active informed consent

Beste belangstellende/deelnemer,

Hartelijk dank voor uw interesse in deze enquête! Hieronder vindt u meer informatie over het onderzoek.

Niet-alcoholische leververvetting (NAFLD) komt steeds vaker voor en kan ernstige gevolgen hebben voor uw gezondheid. Om de informatievoorziening en zorg rondom deze aandoening (en het vergevorderde stadium NASH) te verbeteren is deze enquête opgezet. U kunt hier een belangrijke bijdrage aan leveren door de vragenlijst in te vullen.

Middels de vragenlijst hopen wij meer te weten te komen over hoe u aankijkt tegen de leververvetting en in hoeverre deze aandoening van invloed is op uw dagelijks leven. Ook zijn wij benieuwd hoe u de informatievoorziening vanuit zorgverleners heeft ervaren, waar u graag meer over had willen weten en wat u heeft geprobeerd om de aandoening terug te draaien. Tot slot zijn wij geïnteresseerd of u gebruik maakt van apps of spellen en welke elementen u daarbinnen aanspreken.

De antwoorden op de vragenlijst worden anoniem verwerkt. Uw antwoorden worden gebruikt om een hulpmiddel te ontwikkelen om u en andere patiënten met NAFLD (of NASH) te ondersteunen bij het begrijpen en terugdraaien van leververvetting. Hoe meer mensen de vragenlijst invullen, des te beter de uitkomsten weergeven wat de ervaringen en behoeften van mensen met leververvetting zijn.

De uitkomsten van dit onderzoek worden naar verwachting eind 2021 gedeeld via de Maag Lever Darm Stichting en de Nederlandse Leverpatiënten Vereniging. U kunt aan het eind van de vragenlijst ook aangegeven dat u de uitkomst rechtstreeks per e-mail wilt ontvangen. Uw e-mailadres wordt in dat geval gescheiden van uw antwoorden bewaard.

Het invullen van de vragenlijst duurt ongeveer 20 minuten. Het is mogelijk om tussentijds te stoppen en op een later moment verder te gaan. Uw eerdere antwoorden blijven dan behouden. Het vervolgen van de enquête kan tot uiterlijk één week vanaf het moment dat u aan de vragenlijst begonnen bent.

Deelname aan deze enquête is geheel vrijwillig. Als u besluit mee te doen, kunt u op elk moment stoppen met de vragenlijst, zonder hiervoor een reden op te geven.

Het onderzoek wordt uitgevoerd door onderzoekers van het Medisch Spectrum Twente (dr. M. Guichelaar), de Universiteit Twente (prof. dr. J. Van Gemert-Pijnen, dr. C. Drossaert en H. ten Berge) en hogeschool Saxion (dr. M. den Ouden en drs. S. Oude Veldhuis).

Alle informatie die wij tijdens dit onderzoek verzamelen wordt gedurende 10 jaar beveiligd opgeslagen bij de Universiteit Twente. Alleen de betrokken onderzoekers hebben inzage in deze anonieme gegevens.

Mocht u vragen hebben over de vragenlijst of over juridische aspecten ten aanzien van het invullen van de vragenlijst, dan kunt u contact opnemen via: h.j.tenberge@student.utwente.nl

Klik op ‘verder’ voor informatie over uw rechten als deelnemer.