

**Dietary Treatment of
Heterozygous Familial
Hypercholesterolemia
and Quality of Life:**

*A qualitative interview study on the
perspectives of adolescents and
young adults*

Master Thesis by

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Silje I. Søybye

Abstract

Background: Heterozygous Familial Hypercholesterolemia (FH) is an autosomal dominant disease, caused by mutations in LDLR, APOB or PCSK9, which results in high levels of LDL-cholesterol. Inheriting this mutation involves increased risk of premature coronary heart disease and a need for lifelong treatment. Early initiation of treatment is recommended. The treatment consists of drug therapy and dietary modifications for a cholesterol-lowering diet. Adolescence could represent a vulnerable period, where living with dietary restrictions due to a genetic predisposition could be challenging in an age-specific way. Little is known about how adolescents and young adults experience the dietary treatment of FH.

Aims: The purpose of this study was to contribute to knowledge about how adolescents and young adults with FH experience living with dietary restrictions; to what degree and in which way this affects their quality of life (QOL). This study focused on the participants' perspectives on FH, dietary treatment and impact on QOL.

Subjects and methods: 13 young participants aged 16-25 with FH were recruited from the outpatient Lipid Clinic at the Oslo University hospital. In-depth interviews were transcribed verbatim and analyzed qualitatively using the principles of grounded theory.

Result/Implications: The findings of this study revealed that the adolescents and young adults did not consider the FH diagnosis and dietary treatment to have an overall impact on QOL, they did however describe some challenges. Using grounded theory and through open, focused and thematic coding, the analysis of interviews identified certain aspects as important to the experience of dietary treatment. The aspects FH readiness, Social consideration, Food enjoyment, Practicalities and Consequences are presented in an integrated figure. The findings suggest that health care professionals should take special care to consider the context when consulting adolescents with FH.

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Abbreviations

ApoA-1	Apolipoprotein A -1
ApoB-100	Apolipoprotein
CHD	Coronary heart disease
CVD	Cardiocascular heart disease
FH	Familial hypercholesterolemia, heterozygous
Ho-FH	Familial hypercholesterolemia, homozygous
HDL	High-density lipoprotein
HDL-C	High density lipoprotein cholesterol
LDL	Low-density lipoprotein
LDL-C	Low-density lipoprotein cholesterol
REK	Regional Etical Comitee
TC	Total cholesterol
TG	Triglyserides
VLDL	Very low-density cholesterol
QOL	Qulaity of life

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1 Introduction

1.1 Familial hypercholesterolemia

1.1.1 Genetics and prevalence

Familial Hypercholesterolemia is an autosomal dominant genetic disease caused by mutations affecting the plasma clearance of low density lipoprotein-cholesterol (LDL-C) (1, 2). The disease is caused by mutations in genes involved in coding for the LDL receptor protein, (LDLR), apolipoprotein (apoB) and proprotein convertase subtilisin/kexin type 9 (PCSK9) (3, 4). The mutations results in a reduced uptake of LDL-C from the bloodstream and reduced breakdown of cholesterol (**figure 1**) (5). Affected individuals have elevated plasma levels of LDL-C, which is a risk factor for premature coronary heart disease (2).

Homozygote Familial Hypercholesterolemia is rare with a frequency of 1 in 1 000 000 people (6). Heterozygous Familial Hypercholesterolemia (abbreviated FH in this thesis) on the other hand, is the most common autosomal dominant inherited disease, with a prevalence of 1/500 on world basis (7). The prevalence of FH differs between countries. The prevalence of heterozygous FH in Norway is estimated to be somewhat higher, with an estimate of 1/300 (8). Recent studies indicate that this is yet an underestimation and suggests an estimate of 1/200 (5, 9), which makes FH nearly as common as Diabetes type 1.

Although frequent, the condition remains underdiagnosed, and it is estimated that approximately 2/3 are not aware they have the diagnosis (10). Patients diagnosed with familial hypercholesterolemia are encouraged to contact their relatives, yet several studies have shown that this is not effective in practice (11). According to the National Advisory Unit for FH, there are currently 19 000 living with an unidentified FH in Norway (12). Every year around 60 000 children are born in Norway (13), given a prevalence of 1/300 that equals 200 children with FH born every year. Under-diagnosis is an even greater challenge among children and young adults, in whom clinical features are rarely present (6)

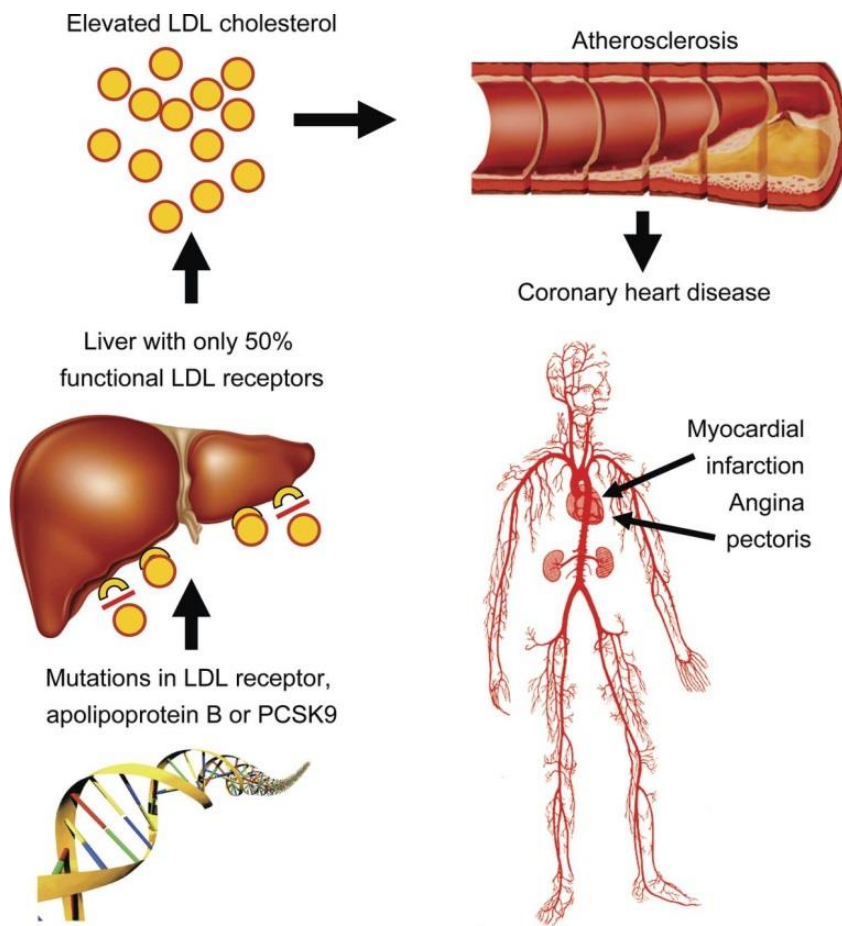


Figure 1 Pathophysiology of heterozygous familial hypercholesterolemia (FH). From Nordestgaard et al (5) Mutations in low-density lipoprotein receptor (LDL-R), apolipoprotein B (apoB) and proprotein convertase subtilisin/kexin type 9 (PCSK9) affect level of functional receptors in liver, resulting in elevated LDL cholesterol. The elevated LDL cholesterol is a risk for developing atherosclerosis and coronary heart disease (CHD) (5).

1.1.2 Clinical features

High cholesterol levels or heart attack in men under the age of 55 or women under 65 are good indicators of doing a genetic test to find out whether the patient have FH (14). The criteria used to identify individuals with FH include a combination of clinical characteristic, personal or familial history of early heart disease and biochemical markers (**figure 2**). DNA-based methods can be used to verify the diagnosis and identify the pathological mutations (15, 16). If FH is identified, there is reason to examine family members for high cholesterol before they potentially develop atherosclerosis. Children in families with known FH are recommended to do a gene test at an early age. Screening of cholesterol levels in children is recommended between the ages of 2-10 as children can have low levels until age two. Screening and initiation of treatment in early childhood is highly recommended (5).

Simon Broome Register Group definition of familial hypercholesterolaemia (1)

- Definite diagnosis of familial hypercholesterolaemia requires presence of (a) plus (b) below
- Possible familial hypercholesterolaemia requires presence of (a) plus one of (c) or (d)
 - (a) At least two confirmed measurements of total cholesterol >7.5 mmol/L and LDL cholesterol >4.9 mmol/L in adults (total >6.7 mmol/L and LDL >4.0 mmol/L in children aged <16 years)
 - (b) Tendon xanthoma in patient or DNA based diagnosis of familial hypercholesterolaemia in first or second degree relative
 - (c) Family history of myocardial infarction in second degree relative aged <50 years or in first degree relative aged <60 years
 - (d) Family history of high cholesterol in first degree relative or concentration >7.5 mmol/L in second degree relative

Figure 2 Simon Broome Register Group definition of familial hypercholesterolaemia (FH) (1).

The Clinical features of FH are cholesterol deposits in the form of xanthomata, xanthelasmata and corneal arcus (**figure 3**).

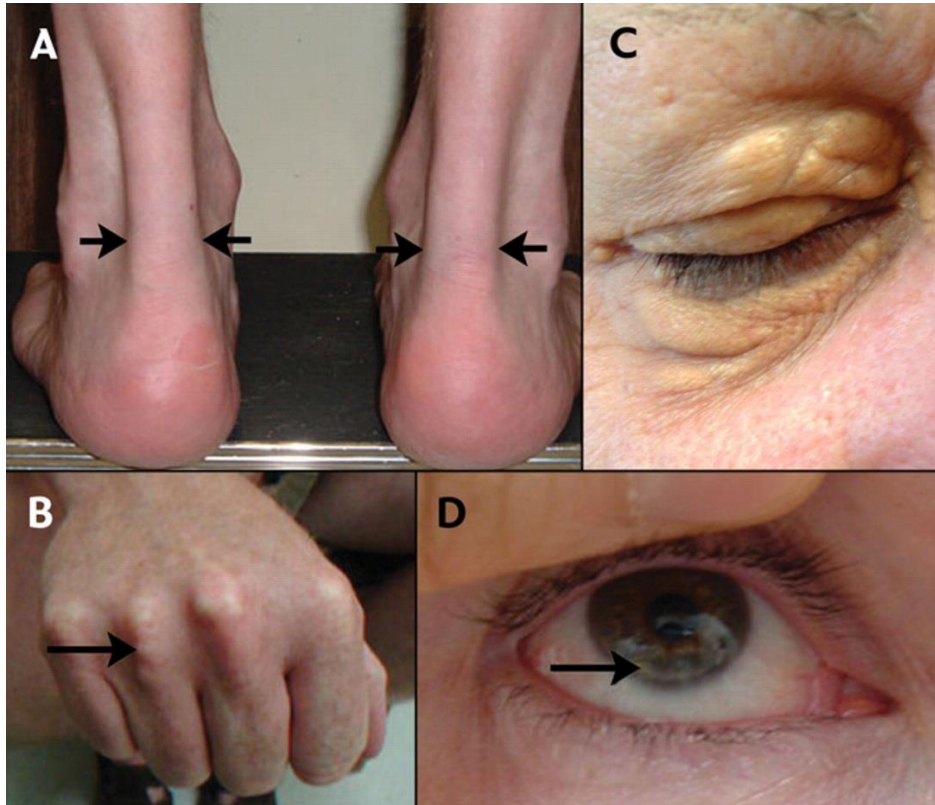


Figure 3 Clinical features of heterozygous familial hypercholesterolemia (FH). From Yuan et al. (17) A: Lateral borders of thickened Achilles' tendons are shown with arrows. B: Tendinous xanthomas in the extensor tendons of the hands (shown), this can also occur on feet, elbows and knees. C: Xanthelasma, cholesterol deposits in the eyelids. D: Arcus cornealis results from cholesterol infiltration around the corneal rim (arrow) (17).

These clinical features are due to cholesterol deposited within macrophages in specific sites. The tendinous xanthomas manifest first as thickening of, and later as deposits within, extensor tendons. Deposits in and around the eye tend to be more specific for FH in people younger than 45 years; in elderly people they may be related to other conditions like arcus senilis or others (17). Clinical features are often not yet present at time of diagnosis, especially in children who rarely have these clinical features, as this is only present in later stages (18).

1.1.3 Lifetime risk assessments

The elevated levels of LDL cholesterol with FH are a predisposition for early initiation of atherosclerosis (5). The atherosclerotic process starts early, as seen in study of soldiers killed in action in Korea, where 35% of the fallen soldiers had "fibrous" thickening or streaking causing insignificant luminal narrowing (19).

FH patients have elevated levels of total- and LDL-cholesterol from birth, and if untreated, develop coronary heart disease (CHD) by the age of 55 in 50% of men and 30% of women

(20). In the most severe cases even young people are at risk of heart attack (21). The cumulative LDL burden sufficient for CHD to develop is reached by age 35 if untreated, by age 48 if treated since age 18, and by age 53 if treated since age 10 (5) (**figure 4**).

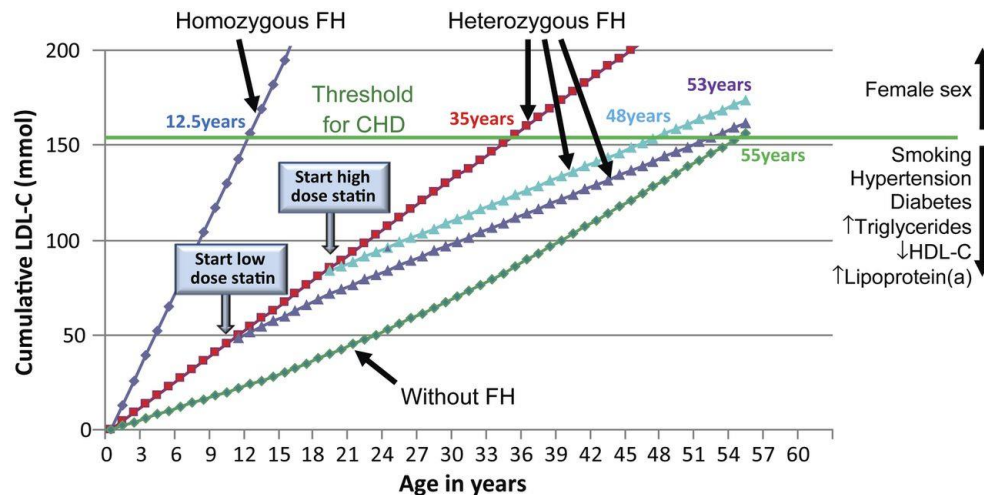


Figure 4 LDL cholesterol burden in individuals with or without familial hypercholesterolaemia as a function of the age of initiation of statin therapy. From Nordestgaard et al.(5).

The early onset of atherosclerotic processes is a reason for early initiation of cholesterol lowering treatment. Although the condition often stays asymptomatic it is possible to evaluate degree of coronary atherosclerosis using imaging techniques (22). When applying imaging techniques it is possible to see changes in the arterial wall related both to FH and to age as early as childhood and adolescence. These changes involve an increased thickening of intima-media in arteria carotis (23, 24). Children with FH have an endothelial dysfunction that is observable from around age 7 (25, 26). Atherosclerosis is difficult to treat, easier to prevent.

1.2 Treatment components

1.2.1 General and medication treatment

Patients with FH are to be followed closely and need lifelong treatment in order to lower their cholesterol levels. The recommendations from European Society of Cardiology function as the current guideline (27). Treatment of FH consists of dietary and lifestyle modifications in addition to medication. Lowering of LDL cholesterol is the primary target of the treatment. Reduction in cardiovascular and total mortality is proportional to the reduction in LDL, 1

mmol/L reduction in LDL is associated with a 22% reduction in CVD mortality and a 12% reduction in total mortality over 5 years(28).

Among patients with FH the total cholesterol values typically vary between 7 – 12 mmol/L. The lipid profile for children and adolescents diagnosed in cascade screening in Norway was on average 7.40 mmol/L total cholesterol and LDL cholesterol 5.60 mmol/L (29). It is recommended to consider drug treatment from age 10 if LDL-C is above 4.90 mmol/L or when LDL is above 4.10 mmol/L if there is premature CVD in their family. The target for treatment is cholesterol levels under 4.5 mmol/L, or even lower if the risk is particularly high. Treatment target for children and adolescents is LDL-C level under 3.35 mmol/L although LDL below 2.85 is preferred (30).

The medications used in FH are statins, ezetimib, resins and omega 3. Statin therapy has been proven highly effective in the treatment of FH patients (**figure 4**), and the importance of an early identification of FH patients for the statin treatment has been demonstrated (31) and recently highlighted (32). Early treatment has been associated with improved non-invasive measurement for early atherosclerosis in children; this may lead to fewer cardiovascular events throughout the lifespan (33). Studies indicate that early initiation of statin treatment delays the progression of carotid IMT in adolescents and young adults and might be beneficial in the prevention of atherosclerosis in adolescence (34-36). The LDL-reduction is similar as seen in adults, with about 40-50% reduction in LDL (37). The extent of treatment with statins of Norwegian children and adolescents is shown in **figure 5, 6 and 7**. It is likely that nearly all who receive statins as children or young adults in Norway have FH. We can therefore assume that the numbers from the prescription registry is a measure of how many children and adolescents with FH that use statins. It is likely that the vast majority of children and adolescents with FH received statins prescribed at the Lipid Clinic.

In addition to medication it is also necessary to take special care of lifestyle. Absence of smoking, combined with physical activity and a cholesterol lowering diet is absolutely necessary (38).

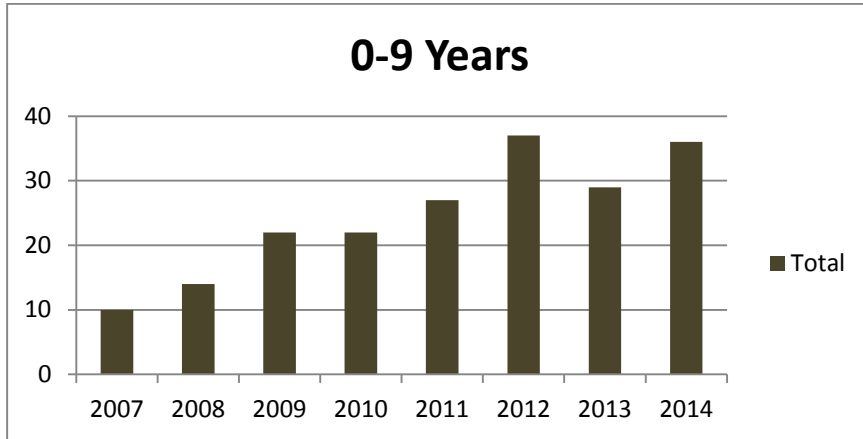


Figure 5 Norwegian children aged 0-9 on statin treatment (39, 40).

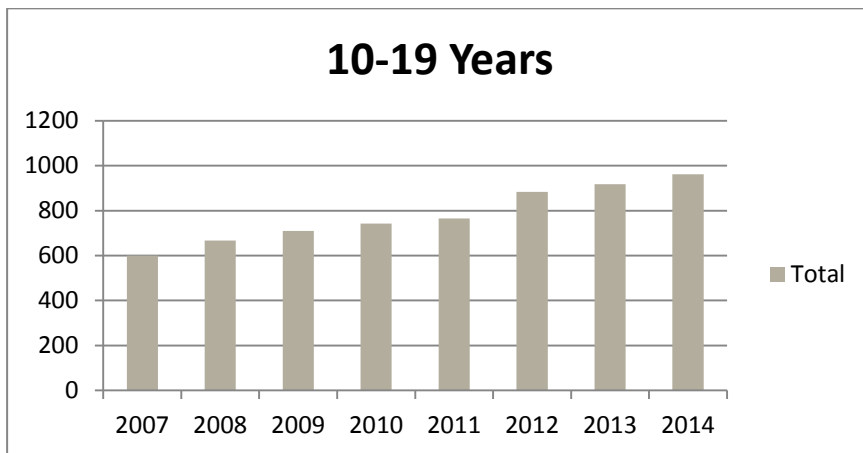


Figure 6 Norwegian adolescents aged 10-19 on statin treatment (39, 40).

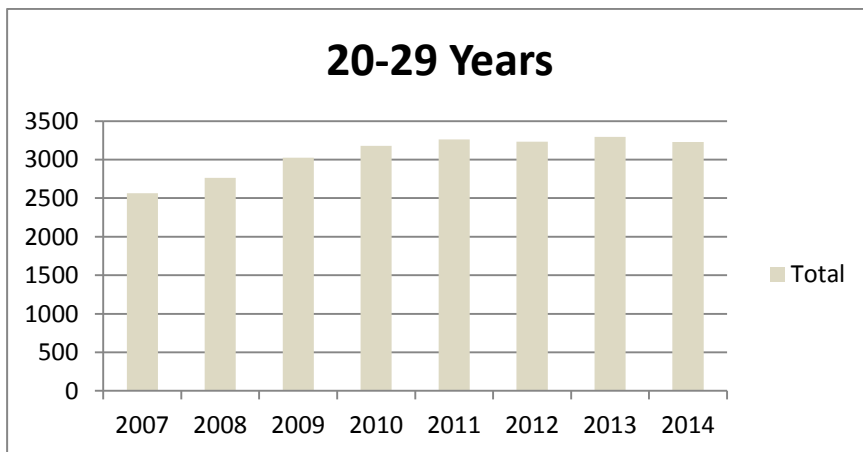


Figure 7 Norwegian adolescents aged 20-29 on statin treatment (39, 40).

1.2.2 Dietary treatment

From 2 years of age a dietary treatment of FH with main focus on reducing intake of saturated fat should be applied. When the child reaches age 6-8 they should get a referral to a Lipid Clinic for adjusted dietary counseling. At age 8-10 the child should see a Lipid Clinic for an evaluation of the need for starting up medicament treatment. New European guidelines are on the way (12).

The nutritional therapy aim is to gradually decrease fat and cholesterol intake, at the same time as focusing on the right type of fat, and a high intake of wholegrain, fruit, berries and vegetables. The American National Cholesterol Education Program recommends a lipid friendly diet where the total fat intake contributes with 25-30 E %, where less than 7 E % is saturated fat and less than 20E % from monounsaturated fat. The intake of cholesterol is recommended to be lower than 200 mg/d, while recommendations on fiber is 20-30 gram per day (38). Functional foods that lower LDL, such as plant sterols and stanols are also recommended. The dietary advice is in accordance with the national Norwegian dietary recommendations on diet, nutrition and physical activity (41), but focusing in particular on reducing the intake of saturated fat, trans fat and cholesterol. Dietary advice is the same for adult and children, but with caution to caloric restriction. Securing an adequate intake of unsaturated fats is essential in regards to growth and development (42).

Cholesterol-restricted diets for children have been shown to be safe in relation to growth and cognitive development in several studies (42-44). Dietary treatment may cause other side effects too. In an unpublished study on an adult population at the Lipid clinic, 51 % agreed or partly agreed that FH could lead to feeling guilt and 20 % agreed or partly agreed that FH decreased enjoyment of food. In the same study 53% agreed or partly agreed that it was a challenge at public restaurants and 36 % agreed or partly agreed that FH could create difficult situations.

With adherence to the dietary advice the expected reduction in cholesterol levels is approximately 10-30 % (18, 45). A study by Tonstad et. al showed that lipid levels (total and HDL cholesterol and triglycerides) in children with heterozygous FH was more affected by, body fat, diet and cholesterol levels in parents, than by the FH- mutation (46). The prescribed diet is for some seen as unvaried and this may lead to problems with adherence (18).

1.2.3 The Lipid Clinic

Norway established its Lipid Clinic in 1983/84, and the Lipid Clinic serves as the center for research on FH in Norway. The Norwegian Lipid Clinic has one of the world's largest patient populations on FH. The Lipid Clinic serves a role as a specialized outpatient clinic with a national responsibility for the treatment of patients with FH. The clinic receives patients from all over Norway that are referred by their general practitioner due to lipid disorder or failure in therapy; this includes both adult patients and children. The National Advisory Unit for Familial hypercholesterolemia and dyslipidemias was recently established and is also localized here. There is a national patient organization, "FH Norway", cooperating with the Lipid Clinic and offering internet pages and a magazine with information about FH to those who want information between consultations.

Children with known FH often have their first consultation at the age of 6-7 years and are at first treated with nutrition therapy before they start statin treatment at a later age. Dietary treatment is a central part of the treatment of FH. The first consultation at the lipid clinic is usually a 2 hour long consultation, consisting of 1 hour with a registered dietitian and 1 hour with a doctor. The consultations often involve the whole family. They receive material such as information brochures and lists for exchanging products with better alternatives.

Usually, a 2 year interval for control is used. The visits include a 30 min. control with a physician and 30 min. with a registered dietitian. All controls are individual. The Lipid Clinic has developed a simple questionnaire, Smart Diet, for assessing of diet and lifestyle prior to consultation. The questionnaire gives a quick introduction to the patient's situation in comparison to recommendations and is a useful entrance to an individual diet consultation. The goal of consultation is to achieve adherence and reach treatment target, yet avoid unnecessary stress.

1.3 Adolescence

Adolescence is the only period where the health worker does not relate to another adult (47). The adolescent is not yet an adult but since no longer a child the parent will not necessarily be involved. Adolescence involves physical, cognitive, emotional and social development as well as a formation of a new identity as an adult. The period is characterized by a transition from dependence to independence, when adolescents take on new social and emotional roles

as well as learn to cope with their bodies altering. This transition period is vital to maintain self-esteem and confidence (48).

The traditional organization of adolescence can be divided into three stages, early adolescence (10-13 years) middle (14-16 years) and a late period (17-21) years (49). A limit of 25 years for the period of adolescence has been suggested (47, 50) arguing that adolescence seems to be elongated in today's society. The demands of higher education combined with parent's ability to give financial support, moves ahead the time when young people are able to stand on their own two feet. The development of the brain is in fact still under development until the age of 25 (51). This period is also referred to as emerging adulthood (50). This thesis explored the perspectives of participants aged 16 -25.

Although physical development in adolescence can be described as the period beginning with the appearance of secondary sexual characteristics and terminating with the cessation of somatic growth, the behavioral aspects of this period have become equally important benchmarks(52). Conflicts are prevalent as adolescents become less interested in their parents and more devoted to their peers (50, 53). In a quest for independence the adolescent spend more time with his peers and adopts new values and standards (54-56).

Adolescents with chronic conditions that require dietary restrictions need to demonstrate even more refined social skills than do healthy peers since they have to be able to accommodate treatment requirements and social demands(57). Having conditions that require dietary restrictions calls for awareness and self-monitoring. Treatment requirements may be at odds with the newly developed lifestyle. The adolescent may value the liberating company and social acceptance of friends more than following restrictive treatment regimens (58, 59).

Dietary habits generally go through changes as children become adolescents and young adults, as seen when comparing with the childhood diet. Statistics from Ungkost 2000 compare boys and girls in the 8th grade with 4th grade and found a significant increase in pizza, chocolate and potato chips from the 4th grade to the 8th grade. In the 8.th grade 56% of the adolescents ate more then 30 E% fat, while 21% ate more than 35 E% of fat (60).

The Norwegian adolescents and young adults living with FH have a median Smart Diet Score of 32.5 of 41 points. This represents an median score on diet, indicating room for improvement, where a change in diet and lifestyle may give benefits (61).

1.4 Quality of life

Quality of life (QOL) is defined by WHO as ``a broad ranging concept affected in a complex way by the person`s physical health, psychological state, level of independence, social relationships and their relationship to the salient features in their environment``(62). There is some disagreement about how QOL is best defined, but there is agreement that QOL must be seen as a subjective experience, and as a consequence of that, the experience cannot be directly observed.

A study conducted in Sweden in 2004 assessed the question of what QOL means for patients with FH. An analysis of interviews with 12 adult patients showed that they see QOL as having harmony of life. To achieve harmony this involved a feeling of contentment as well as togetherness. Knowledge of coronary heart disease and mortality was balanced against the support of togetherness and satisfaction with life. The study concluded that it is important to meet each patient on their level and support the feeling of balance and the choices they do to maintain or regain harmony in life (63). Some studies conclude that the adults with FH have even higher QOL, even though they were at the same time worried about CVD (64, 65). A cohort study on the impact of screening further support this, but showed an initial effect on QOL in some of the participants(66).

In a Norwegian study from 1996 on FH and QOL, 11 % of parents with children aged 6-16 said that their QOL would have been better if they did not know they had the disease. None however said that they agreed completely in the statement that they would have wanted to not get diagnosed. Among the parents, 20 % reported that they had familial conflicts and 8 % that their children`s emotional or social life had been negatively affected. Some of the kids were interviewed themselves and worries about coronary heart disease were present among 22 % of the children(46).

In another study done at the Lipid clinic (67), patients said they experienced no guilt or shame for having FH, but that they did experience guilt and shame in regards to how well they coped with the condition (68). The study concluded that in order to tailor the clinical treatment of patients with FH, you need insight in how the patient understands the burden of heart disease in the family and how they perceive vulnerability of heart disease (69). Health personnel should therefore acknowledge the patients preferences and use conversational/communication strategies that reduce experiences of guilt and shame in patients (68).

If FH affects QOL for patients it is important for treatment to map how it affects QOL so that treatment can be targeted for the needs of the patient. In a previously unpublished questionnaire at the Lipid clinic in 2004 patients with FH considered the dietary part of the treatment to be more challenging than the medical part of the treatment. This was even though many were using the maximal medical dose of lipid lowering treatment. Some of the patients also said that they wish they would have been diagnosed later in life so that they did not need to stress with diet before becoming adults. This could indicate that adolescence and young adulthood is a particularly tough period to follow dietary advice and live on a diet.

What characterizes research on QOL among patients with FH is that it is mainly done on adult patients. There are few studies on what QOL means for young patients and whether challenges with this diagnosis affect QOL. It has not previously been investigated how patients with FH in Norway experience receiving dietary advice and living on a diet. In dietary therapy of FH the consideration is to find a balance between achieving compliance and not stressing the patient more than necessary.

Dietary treatment is the responsibility of the patient; it is of importance to see how this impact on psychological and social aspects related to QOL. To adapt treatment to this sub-group it is necessary with more knowledge on how they experience living with and managing FH. Previous studies on QOL in adolescents and young adults using qualitative methods have to the authors knowledge not been conducted in Norway.

2 Aim and objectives

Aim

The aim of this study was to contribute to knowledge about how adolescents and young adults experience the dietary treatment of FH. We wanted to investigate whether they experienced any challenges related to dietary treatment and to what degree, and in which way, this affects their QOL. This age group was chosen because adolescence represents a period between childhood and adulthood where age specific challenges could arise. The study focused on the participant's perspective experience and feelings when following dietary advice.

Objectives

- How do they experience living with dietary treatment, and how does this impact on QOL?
- Are there any situations or aspects of the dietary treatment in particular that are considered to be challenging?
- What is motivating in regards to adherence to dietary advice?
- How do they experience the dietary treatment compared to the drug treatment?

3 Methodology

3.1 Study design

3.1.1 Qualitative approach

A qualitative approach was chosen for this study. This approach is well suited for understanding the perspectives and experiences of individuals or groups. It is also particularly useful in areas with less prior knowledge. The aim of this study was to explore adolescents with FH perception of dietary treatment and impact of dietary advice. Semi – structured interviews were analyzed based on Grounded theory (GT).

GT was developed by researchers in medical sociology to study and theorize, localized social processes such as QOL (70). The epistemological orientation is a realist orientation and the method aims to produce knowledge that resides in the data. Through direct interaction with people in open-minded inductive analysis it is possible to understand the symbolic world of those studied. GT is based on symbolic interactionism: a way of understanding how people perceive, understand, and interprets the world.

GT involves the progressive identification and integration of categories of meaning from data (71). It is both the process of category identification and integration and its product (72). The basic principles are theoretical sampling, saturation, constant comparison and theoretical sensitivity. The constant-comparative method of classical grounded theory was applied for data collection and analysis (70). Considering limitation due to time frame, this study did not involve an attempt to develop a theory, but to examine the data in light of some previously proposed theories.

3.1.2 Recruitment and participants

Every year; the out – patient Lipid Clinic has around one hundred teenagers and young adults diagnosed with heterozygous FH coming in for consultation. For this study some of these patients were invited to participate. The participants were recruited from patients scheduled

for a follow-up consultation at the Lipid Clinic in the period between August and October 2014.

The inclusion criteria were that the participant had to be between 16 and 25 years of age, and have heterozygous FH verified by genetic testing. The selected bottom-end for the age range was 16 years old, due to an appreciation that younger participants might not be comfortable about being interviewed on their own. The exclusion criteria were homozygous FH or other known diseases and conditions in addition to FH. Participants who had a sibling already included in the study were also excluded.

The participants were recruited with consecutive sampling, inviting all accessible subjects qualifying the inclusion criteria to participate. This attempt was chosen due to the limited size of the study population pool. The invitation to participate was sent out by mail 4-6 weeks before the consultation (**appendix 1**). This was sent separately from the standard notice of appointment. For those registered by phone, an attempt to call was made 1 week before consultation, giving short standardized information. Only one phone call was made to each participant. They could agree to participate by phone, email or at the day of the consultation. The interview was scheduled for the day of their consultation.

The recruitment process is illustrated in **figure 8**. A total of 61 adolescents and young adults were initially invited to participate. Of those invited, 1/3 cancelled their consultation at the Lipid Clinic or did not show up and were therefore not included. Of the 2/3 that did come in for their scheduled consultation, 1/2 wanted to participate in the study. In cases where it was needed to choose between two participants due to logistics or due to siblings wanting to participate, the one bringing more variability to the study sample was chosen. The interviews were conducted with a total of 13 participants.

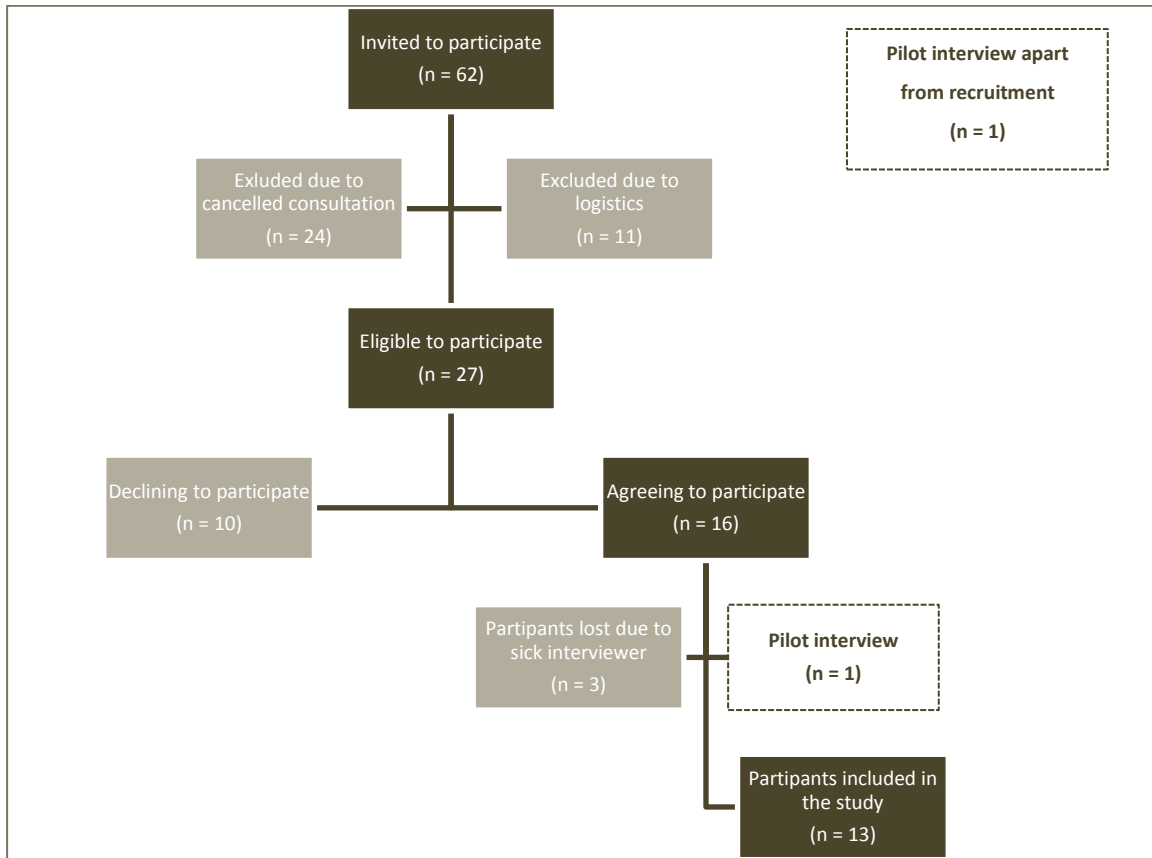


Figure 8 Recruitment process for participation in study.

3.1.3 Ethical considerations

The study was reviewed by the Regional Committee for Medical and Health Research Ethics (REC), South East. The participants were informed that participation was voluntary and that they could withdraw at any time. The written consent was explained and signed prior to conducting the interview (**appendix 2**).

The use of a semi-structured interview requires sensitive and ethical negotiation of rapport between the interviewer and the interviewee. Interviewers should not abuse the informal ambience of the interview to encourage the interviewee to reveal more than they may feel comfortable after the event (72). There needs to be a balance between creating a stage where the interviewee feels free to talk while not creating illusion of friendship. Equally there needs to be a balance between pursuing interesting knowledge and respecting the integrity of the interviewee. Another question raised is whether to go behind face value? This could be a conflict between scientific and ethical concern as it is a main concern to give a true representation of what they express (72).

It could be that it was a burden for participants to reflect on the questions asked in the interview, but it is also possible that it was rewarding. If the study is successful in contributing with knowledge to improve the nutritional therapy, other adolescents could benefit of this in later treatment. The project could contribute to better and more individualized nutritional therapy.

The anonymity of the participants was secured by de-identifying the audio files and transcriptions and using coded names. Data code was stored securely on the Lipid Clinic computers and signed consent forms were kept in a locked storage. In the presentation of data it is taken into consideration that this is a small population and therefore a detailed table of information about participants was not included. All quotations presented in the results are anonymized and represented by gender and age only.

3.2 Data collection

3.2.1 Interview guide

The master student developed an interview guide for the purpose of the study in collaboration with the supervisors (**appendix 3**). The background included a previous study, yet to be published, about FH and dietary treatment, and literature on the subject. The interview guide was further supported by input from dietitians and doctors at the Lipid Clinic, as well as professors at the Department of Psychology at the University of Oslo.

The interview guide for a semi-structured interview usually consists of a relatively small number of questions. As the researcher was new to interviewing a more elaborate interview guide was developed. The interview guide consisted of main themes, sub-themes and sample questions to each theme. The questions in the interview guide were open-ended and neutrally worded.

The initial part of the interview focused on obtaining background information such as age, occupation, living arrangements and lifestyle was obtained. The guide included questions about dietary habits, adherence and goals, environment and situations, challenges, diagnosis, impact on habits, medication treatment, QOL, motivation and social support. As the interviews progressed new questions were added and others disregarded. Themes were

approached neutrally and free speech was encouraged. The purpose was to investigate how the participants thought and felt about their experience using their own words.

3.2.2 Pilot interviews

Two pilot interviews were conducted in July 2014, prior to data collection. One of the pilot interviews was with a young woman that did not meet inclusion criteria. The other pilot interview was conducted with a boy who *did* meet the criteria, but who had less time available than required to do a full interview. The pilot interviews were conducted as interview practice and to review the interview guide.

3.2.3 In-depth interviews

The interviews were conducted in the period of August 2014 to October 2014. All interviews were conducted by the master student. The interviews took place at the Lipid Clinic at the same day as participants came in for a consultation. This was done in an office space other than the one used by the dietitian. The master student was not involved in the medical care.

In order to encourage the participant to speak freely, it was made clear that the interview was anonymous and separate from the medical journal. The role of the researcher and the aim of the study were explained before initiating the interview, and this explanation was standardized so all the participants would receive the same information. Only the interviewer and interviewee were present during the interviews. The tone of the interview was kept less formal due to the age of the participants in order to make them feel comfortable with the situation (72).

The interviews were conducted as semi – structured interviews; with the interview guide functioning as a checklist for themes, but with some alterations of the original set of questions as new themes emerged. The interviewer kept open to new themes and subjects emerging from the interviews. The interviews were conducted in Norwegian. All interviews were digitally recorded with the iTalk software. In total, the interviews lasted 655 min, with an average of 50 min and a range of 34 to 74 min. Field notes were written directly after interviewing to support data material.

3.3 Data analysis

3.3.1 Transcription

The audio files were transferred to a computer for transcription; they were initially listened through and subsequently transcribed verbatim. All interviews were transcribed by the master student. This was done using the software FTW Transcribe to create a written transcription in word –processor format with added timestamps. The interviews were transcribed in Norwegian Bokmål, with the dialect word in parenthesis were fit of corresponding word was unclear. The transcription resulted in 202 pages and a total of 114 843 words. The transcribed interviews are the data material in this thesis, supported by field notes.

3.3.2 Coding and analysis

The transcriptions were analyzed in the theoretical framework of GT (70). The data material was initially re-read to get an overview before uploading it to the qualitative data research software Nvivo10. The data was further explored within the research software to enhance the overview and get insights on what subjects the participants mentioned more frequently. The GT analysis consisted of coding the interview transcripts line-by-line, by adding descriptive codes, giving names to segments with a tag that categorized, summed up and accounted for each part of the data (73). All coding was then performed by the master student. An audit trail was activated to keep track on codes made and altered.

In the initial coding data was compared with data and given short, precise and active codes about what was happening in the material. This coding stayed close to the data and focused on processes and actions or behavior. In the focused coding, the most important or most frequent initial codes, which were most relevant for analysis, were discovered. This phase of coding was direct, selected and conceptual, choosing certain codes and merging with other codes. The process of GT coding involves going back and forth between initial and focused coding(71).

The codes were given descriptions in the Nvivo10 software to make coding coherent. The personal attributes of the participants were added in the program to be able to make comparisons between interviews.

Theoretical coding focused on relations between codes and code families. Constant comparative analysis consists of negative case analysis, theoretical sensitivity, theoretical sampling, and theoretical saturation.

The translation from Norwegian to English of key quotations presented in result was done in collaboration with the supervisors to ensure that the translation had the same meaning and language qualities as in the original language. Quotations with “...” indicate that quote has been shortened. Participants over the age of 18 are presented as woman/man and participants below 18 are presented as girl/boy in the quote source in addition to given age.

3.3.3 Categories and concepts

Using grounded theory and through open, focused and thematic coding, the analysis of the data material identified concepts and categories of importance to the experience of dietary treatment. The results section is presented according to the research question initiating the study, for ease of the reader. Each category is elucidated with quotes from the transcribed interviews in the results section. The categories and concepts are summarized, integrated and discussed in the discussion section.

4 Findings

4.1 Participant characteristics

There were 13 adolescent and young adults participants contributing to this study. The sample was heterogeneous in regard to age, gender, time of diagnosis, current occupation and geographical affiliation (**table 1**). There were 9 female and 4 male participants. Age of participants was evenly spread in the age range of 16 to 25 years of age, with 20 as the average age. The participants also represented a wide spread in geographical affiliation. Some of them came from west and some from east, a few from south, north and middle of Norway. The majority was studying in college or university, while others were working or between jobs.

The participants had different FH backgrounds when it came to time of diagnosis, living situation, having siblings with FH or no siblings with FH, separated parents or married parents, score on smart diet etcetera. Half were living at home with one or two parents, the remaining were living with friends in housing collectives or with a boyfriend or girlfriend. Half of the participants had parents who were not living together, and they grew up in two homes. The other half had parents living together or grew up in the home of one parent. The time of diagnosis varied from birth to young adulthood, the average age of diagnosis was 9 (median 10) years. Most of the participants were diagnosed before teen ages (n=9), or even before school age (n=6). The remaining participants were diagnosed in their teen ages or after (n=4). Half of the participants had a sibling who was also diagnosed with FH. One had a sibling refraining from testing.

Table 1 Demographic data of participants (n = 13)

Demographic data of participants	
Age	16 -25
Gender	9 female, 4 male
Occupation	5 student, 5 high school, 2 working, 1 unemployed
Siblings with verified FH	8 yes, 5 no
Age of diagnosis	3 birth, 3 childhood, 3 early–adolescence, 2 mid-adolescence, 2 late-adolescence

4.2 The view on the FH diagnosis

The views on what the diagnosis FH entails varied. Some referred to it as “the mutation”, some pointed out that they did not see it as a disease at all. For some, the view on FH had changed since the time of diagnosis. At first they had a feeling of being sick or being labeled as sick. Later on they changed opinion to no longer considering it as a disease.

«It’s nothing special; I don’t really look at it as a disease. It’s just there. It’s...taking some medication and eating a little healthier» (Interview 8, woman 18)

In evaluating the diagnosis they also compared themselves with others, including those having high cholesterol for other reasons than FH. They pointed out that high cholesterol was a common problem that people often are unaware of.

«Yeah, or like, what it actually means, having hyper cholesterol and that you also can get high cholesterol by having a really unhealthy diet, so yeah. I think there are just a few who know that» (Interview 13, woman 23)

Such reflections could also lead to the conclusion that their own situation was better than that of others.

«I’ve often thought about how it is with Americans and the people that eat at McDonalds, and how they get so fat and big. And they also have, they also get cholesterol

problems, even without those diseases, and mutations and all that. So it is, if they got what I got, and have a diet like a lot of those with less money have over there, they will have big problems when they get older. So if you look at it like that, I am pretty lucky that I, or we, have this here in Norway» (Interview 1, man 19)

Although age of the time of diagnosis varied, all participants had similar answers to the question about what they thought about the age of diagnosis. All but one said they were content with the age when they got their diagnosis, and would not want to get it later in life. However, after reflecting a little further, those diagnosed after school age said it could have been better to get to know the diagnosis even earlier.

Those diagnosed early elaborated that it was good for them to know early because of various reasons. Some talked about age as a factor in how serious they would take the message; at a younger age they would take it less seriously, and at an older age they would take it too seriously. Getting an diagnosis early meant that the parents would take responsibility, They also considered that being diagnosed later meant they would potentially have difficulties adjusting and having to go through big changes.

«...then you were old enough to kind of understand some of it, but at the same time you didn't do much yourself, the parents did it in a way, and it became a natural thing» (Interview 1, man 19)

«No, I thought it was fine to get to know it at that time, because then I got to know what I was gonna do, or so, yeah. My mom took over and had control over it. And she taught me about how I should do it. It is more like a lifestyle now compared to if I would find out now and would have to change my whole diet» (Interview 8, woman 18)

The participants diagnosed after early adolescence seemed to see this more as something they themselves needed to master. This was further supported in the descriptions of their reactions when getting the diagnosis at the time they actually did. The experience of getting a diagnosis seemed to be different for those diagnosed in their mid-adolescence or later compared to those who were told at an early age. The experience of getting diagnosed with FH was by some described as scary or as a sudden burden. This could also be related to the initiative to testing, whether this was related to a CVD incidence with close relatives or not. Late diagnosis was often due to FH not being known in the family, but being discovered in relation to a CVD event.

«Yes, in the beginning I got very scared, because it was a little dramatic. My dad just got a cardiac arrest, so that was in a way... clogged veins and stuff so I was really scared that

I would get heart disease or that it was serious illness. But then after a while it turned out to be like... I had such high levels so I had no chance to get through it with just the diet. So I had to start on medications anyway. For me it didn't take much time before I started thinking that as long as I'm on medications and live halfway healthy it will be fine» (Interview 3, woman 22)

«And then I started to cry, I did. Because it was, (name of mother), mum, said, mum said “yes, you know that I have it” and then my sister said like “I don't have it” and was happy about that, and then it went..., I almost felt a bit crushed to the ground» (Interview 4, woman 20)

One participant said it would be better to either know sooner *or* later, just not in that specific part of the teenage period. The participant expressed this in an explicit manner proposing there was a window in time where getting a diagnosis was particularly difficult;

«Between the ages of 16 – 18 years old I totally refused, I was immortal, and there was no one that could tell me what I should eat and drink. I was just doing my own thing. But I could see how that turned out through looking at what the numbers told us, and it turned out that no one is immortal. Then, when you finally get out of the thoughts that no one can tell you what to do, and like you can become a bit more grownup, you understand it yourself... But between the age of 14 -18 years old, it should rather be discovered before or after» (Interview7, man 22)

«So you think that there is sort of a window where it's a bit bad to get that message? » (Interviewer)

«Yes, you're already struggling a lot... you get a feeling of getting slapped in the face with all this at the same time. And then it becomes, it becomes too much. And then you act out like I did, and you act out like crazy» (Interview7, man 22)

The participants that got the diagnosis at birth or before adolescence did not seem to have any clear first time experience of the disease as they have “always had it”. They explained that this had made it a natural part of their life.

4.3 Overall impact on quality of life

The overall finding on experience of QOL was that participants did not think FH and the dietary treatment had any impact on quality of life. Having a good life was considered to be something FH would not influence.

«What a good life means to me. That is, that is a kind of different way than nutrition though. It's more like that, I can have a perfect life with the way I eat now, that has...I eat,

and I eat maybe a snickers bar in a week, which is my chocolate sin. And, and I still have very low cholesterol levels, and as long as I'm not going to get a heart attack when I'm 40, then there is something totally different that decides what a good life is for me. Then it is more like my job, girlfriend and kids when that time comes, and stuff like that instead of this disease» (Interview 2, man 21)

«No, it doesn't affect it at all, it is, and the life is what it is anyway. That, no matter if I have FH or not, I can live until I'm 80-90, but you never know. I can get hit by a car any time you know, that's just how it is. When it comes to just that, I like to think like that, I never know what's coming up next. It's just, that I have the disease, it's there. It's not going to go away. It's just something you take with you. Like, it's nothing that ruins your life, you know stuff that makes it better. It's just, it's something that's there. It's like the small spot you got on the wall. It's there, you can paint over it, but you know, you know it's there » (Interview 7, man 22)

Some participants even said having FH made QOL life better, and said that they were glad they had it.

«No, I actually don't think so. It does influence on, I get a lot healthier life style. If you look at it like that, the quality of life gets better» (Interview 6, girl 17)

Although the participants did not consider an overall effect of dietary treatment and QOL the majority had more or less challenges related to the treatment.

4.4 Challenges with dietary treatment

4.4.1 Challenges related to food enjoyment

Taste of food was important and sometimes taste and eating FH friendly seemed uncombineable. This was also relevant to foods usually preferred by the young crowd. Dishes like tacos, pizza, kebab and hamburgers were often mentioned as foods others ate that they needed to adjust or avoid. These kinds of food were eaten in a social setting and that could be challenging. The food could be tempting and it could be difficult to find alternatives and eat something else. Some see the products recommended for FH as strange and less tasty.

The experience of the first dietary consultations was remembered by those diagnosed after school age. Although they were overall pleased with the consultation, it was also mentioned that the first consultation was overwhelming and that they were given a lot of information about the diet recommended. The recommendations seemed difficult; like they couldn't eat

anything they liked because these foods were really bad. They came across as “forbidden” foods.

«Yes, I remember I thought it was a little like that, it sounded like it was so awful to eat like, regular cheese and to have regular butter and to eat one Grandiosa a week... But, I have not been thinking that much about it afterwards, to change that much. And the cholesterol had not gotten much higher, and some of the things I eat on an everyday basis is not, were not as bad as I thought they were. So maybe I have just been lucky with the natural choices I have done» (Interview 1, man 19)

Initially many felt like they needed to change a lot, later on it felt like they didn't really need to do that many changes after all. One participant said that it was sad sometimes to see recipes on blogs and not be able to make it; it helped when the mother gave suggestions as to how to make it with special products but it didn't really look the same. Another told that he didn't like it when he had guests and wanted to use certain products, but restrained from doing that due to FH, but at the same time feeling he compromised on taste. Several said that when they went out for dinner they would let taste decide because it was difficult to know what was in the food anyway. Some felt like some situations were more tempting than others, like cakes on the table at work or going home after a night out and stopping by a fast-food place.

There was a challenge in feeling like they had to choose between taste or dietary recommendation. Those feeling like they ate very restrictive felt like they lost something on enjoyment of food, others felt like enjoyment of food was something they didn't want to sacrifice and said this was a reason for not following recommendations.

«I'm still eating what I think is good and what I like, but now it is because I have to, but it tastes better now compared to what it did before, but that's because I'm eating more of it, right. Forced myself to eat it and stuff» (Interview 9, woman 25)

«But were there any problems with enjoying your meals in the beginning?» (Interviewer)

«It clearly was, when I forced myself to eat fish in the beginning, I didn't really like it. And I tried some cod too, but I couldn't deal with it at all, so I stuck with salmon and I could prepare it in different ways, so now it is two ways I... » (Interview 9, woman 25)

4.4.2 Avoiding attention and “special treatment”

Some were very open about FH and informed most people around them, whereas others did not mention FH unless the issue came up when they were seen taking medicine. The reasons

behind not talking about FH could be divided into three main categories. The first was the challenge of explaining the diagnosis to others. Most experienced that others did not fully understand what FH was about. They worried that the others would see them as sick, - like something was wrong with them, being faulty goods. Some said that the others perceived the diagnosis as more serious than they did themselves, or they did not take it seriously enough.

«Yes. That I, if I eat for example one wrong thing I won't, die the same second. So I have tried to explain it though, but they think it is a bit difficult to understand» (Interview 10, girl 16)

The other main challenge was that talking about the disease was seen as something that could lead to too much attention for some of the participants. The attention meant that others could bug into what they were eating, be worried, and have to make adaptations and so on.

«I have been talking about it. I have, there are some friends that know I got it, the ones that..., I know would care, or off course I know that everyone would care about it if I told them, but it's nothing I go around yelling out. It's not. Because of that fear that people will treat me different or that someone will ... even though it's not really a reason for special treatment, but just like...»

The third reason was that it didn't seem to them like it would interest others and that it didn't occupy their mind so it didn't seem natural to talk about it to others.

Several made a point of it not being shameful to have FH. Some also said that there was not a difference between having FH and not having FH. One did find it a little bit embarrassing to talk about FH.

«But now I think it is more embarrassing to talk about... people begin to ask and stuff, and think that there's something wrong with me or something, that, yeah, I don't know, that people in a way are going to have weird thoughts about it, that wouldn't be true.» “Yeah, yeah, yeah that's really what I think. Like it is, or, it is kinda hard to explain, but it's just that, I think that people could misunderstand a little. Thinking that it's some sort of disease, nasty stuff. Yes, I don't really know what people would think, but yeah. Yes. I'm trying to actually not talk too much about it» (Interview 11, man 18)

Some said they didn't want people to have to adjust to them due to FH. Instead they would eat whatever the others ate and did not see that as a problem. Some had experiences where other knew but still did not make the necessary adaptations, such as cooking classes in school, organized activities, or even partners. They experienced that some people did not understand how important it was.

«... When I had, when I was living with my boyfriend. And we were going to cook together, and he was very fond of, really, well, tasty, tasty food, but often unhealthy food though. At that time it was very difficult, and it ended up being a lot that I probably shouldn't eat, but that I was eating because it tasted good. And he made food too, so yeah» (Interview 13, woman 23)

They told that when people tried to adjust they did also sometimes get it wrong and excluded foods that they actually could eat and included foods that they couldn't eat. They said that while they appreciated the effort, it was difficult for others to keep track of what the diet was about. Sometimes it could be complicated to keep track even for them. One participant described how when her friends asked if a certain dish was ok, she would confirm, only to discover later when checking with her mum, that it was in fact not a good choice and ending up bringing something herself after all. Bringing foods to situations that involved cooking or eating together was a strategy several of the informants choose on occasion.

4.4.3 Access, time and money

The youngest participants talked about how getting their own money made them buy more food themselves. Accessibility of food was a factor and some would eat what they were served without giving it much thought, saying that at home they got healthy food served and therefore didn't think that much about food out of the home. This statement was somewhat modified by other information given throughout the interview about eating behavior. FH friendly food sometimes felt harder to access than non-FH friendly food. In some situations it could feel like there weren't really any good alternatives. So they would go for whatever the others did and then go for moderation of amount instead

«And, often it is like that, when we don't really have anything healthy at home or like, any healthy food at home, I normally just take what's in the cup-board and make something, and maybe I make unhealthier food. Just to eat something. I'm too lazy to walk to, or till now I haven't really bothered going up to the store to buy something, like I maybe ought to do. Because we don't have it at home» (Interview 11, man 18)

Time was another consideration. As they were growing up they felt like they became busier and sometimes there wasn't enough time to make the healthy food choices. The need for food to be quickly prepared became an element. This could for the student be represented by the ready-made pizza. The participants who were students also talked about how healthy food was more expensive. Special products like salami or bacon with less fat, Vita products and

similar products cost more than other products. Being cheap sometimes triumphed over being healthy on a tight student budget.

4.4.4 Age specific challenges

With growing age the participants started taking choices of their own. The participants could choose to make healthy choices, and justified this with FH or just a desire to be healthy in general. They meant that present emphasis on health in society gave them room for health behavior without having to explain about FH. For some this emphasis on health combined with dietary counselling made them overwhelmed with the focus on diet. And although they said they were not personally negatively impacted by the focus on diet, they expressed concerns for other young patients. This regards in particular those diagnosed at a late age.

Those with divorced parents often experienced different dietary habits in the two homes. One home could be very correct and strict whereas the other was without restraints.

«Yes. So it was kind of weird, really. Because to come from home, like, everything was so correct. And going over to dad's where there weren't any of those products exactly. But, it did take some time. And I understand that, because it is unusual for them too. And, especially when I came over just now and then. The products often became a little old and then we had to buy some new and then they had forgotten about that. So, it was a little like that, but it has been much better lately» (Interview 10, girl 16)

«Yes, they, but dad knew a lot about it. But mom wasn't that good because she didn't know that much about it. So it just turned out to be like, we were good at my dad's and really bad at mom's, it got very separated that way» (Interview 1, woman 20)

In young age this could be experienced as difficult as they had to take responsibility themselves.

«It was hard when I was younger, because I didn't understand that this was really serious, a heart attack, I mean, you have to eat right. I was like 10 – 11 years old, ... and when your dad doesn't tell you that you can't have certain food. Because you can't think about that all by yourself, you need some help. So it was a bit like. That he didn't» (Interview 5, girl 16)

One participant said they would take advantage of the situation and eat unhealthy snacks when they were with the unrestricted parent. Some said it was inconvenient because they got used to the normal products and flavors and that made the special products taste strange again.

Some said it made them feel like they were abnormal, idiotic. Because they suddenly were the one who needed special food that the others didn't understand the severity of the diagnosis or the need to stick to diet. This was especially difficult when the parent would encourage them to just eat what was served, saying the food was OK to eat. This sometimes led to a conflict because they wanted to eat what was served, but they knew it wasn't really good for them. They said that they didn't blame the parent for this, explaining that the parent did try. Some even said that maybe the lack of good habits in one of the homes was good, in order to see what not to eat.

They said that they needed to live a little, and maybe even more so because they were young. They said it was both more difficult to eat better now and less important now when they were young than when they got older. Some said they thought they would improve eating habits later in life, when they would be adults.

Student life was for some seen as a situation where lifestyle was a bit out of the ordinary.

«It, it is like, I am in the “studentersamfunnet”, where we organize meetings and stuff. And sometimes there is a lot of alcohol. People start to drink at 4 on a Monday, and with the food and stuff. It's not like people get drunk or anything, but I mean, it's a lot, like a lot in a week. So I have been thinking about that while I was sitting here, that I can get a little better at stopping myself» (Interview 13, woman 23)

4.5 Following or not following dietary advice

4.5.1 Compensating and balancing

Participants made a differentiation between every day and exceptions; emphasizing that every day is what matters. Cheat days was seen as a way to balance the restriction on other days. This was for some participants days were they would think “whatever” and just eat what they wanted.

«Yes, I make some changes all the time, to just make the situation better. And yeah, sometimes, I just don't care, I'm eating lots of chocolate and just enjoying it, and get good and round, and the day after I badly regret it, because I know, I realizes that, I know, you shouldn't have done this (her name), because you know you are going to live with this the rest of your life, and you are going to live a long time, as long as possible, and I actually really feel bad. But it takes two weeks and I'm doing it over again. But well, I regret it that day, and

then I am really healthy the other days. Extremely healthy the other days, but that's like everyone else, you just drop out sometimes and use other things» (Interview9, woman 25)

Others had their little treats on certain days. When it came to holidays and celebrations, the majority said they did like others as this was exceptions.

“What matters is not what you eat between Christmas and New Year but what you eat between New Year and Christmas is an expression I like a lot.” (Interview 9, woman 25)

A few were quite restrictive on holidays too, eating Christmas food on Christmas day only, sticking with the dietary recommendations the rest of the days. On birthdays some had more healthy choices if they celebrated with their own family. And when they were younger the parents of the one celebrating birthday would take FH into consideration. If it was a family dinner one could ask the parent what was ok to eat and not.

Eating unhealthy one week and healthy the other, and feeling like eating unhealthy sometimes was believed as necessary for the balance. Physical activity also acted as a balancing agent for some, if they had been good at working out they did not need to be that good with food and vice versa.

4.5.2 Degree of control

The feeling of having control or not was important for how they judged dieting. Some had high degree of control and high level of restricted eating and did not see this as a problem, having FH in mind in all meals and making exceptions only under selected circumstances. High level of control was for them seen as an obvious thing, not defied by taste or other obstacles. Others were more relaxed and joked about eating cholesterol increasing foods. Cravings for certain foods could challenge the control. And it could be difficult to resist temptations.

Setting the bar to high could be problematic as advice was then considered impossible to implement.

«... after a while I felt like it was impossible. Like, I can never do this anyway, because if I can't eat any candy or chocolate or anything like that, anything at all, and I can't like, have butter on the bread because I don't think Vita pro tastes good and the only thing I can eat is fish, you think that you will never make it anyway, and you just don't even want to bother trying. So there was absolutely a period when I just didn't bother, because I could not do it» (Interview 3, woman 22)

4.5.3 Confusion

When reciting dietary advice or knowledge gained on their own, advice was sometimes not in concordance with dietary advice normally given at the lipid clinic. This was often related to very specific products.

There was some confusion about applying advice in everyday life. For the youngest participants it could be difficult to choose foods in the store. Several said that when going out to eat it could be difficult to know the contents of the food in restaurants. When they were unsure they would ask the parents or siblings about what the best option would be.

When they mentioned advice from the Lipid Clinic, they sometimes mentioned advice they were unsure about or that didn't match with the dietary recommendations from the Lipid Clinic. Examples of this were for instance, "I think they said I can only eat 6 almonds." "I am eating shells instead of taco tortillas because of FH." "Dark chocolate is the best option for snack?"

4.5.4 Guilt

Some said they always felt guilty, whereas others didn't really feel guilt at any point. For some one episode of eating badly could trigger guilt, whereas for others this was more about bad periods leading to guilt. For some guilt led to an increased motivation to stick to the advice, for others it was soon forgotten.

«I do notice that, if I eat something I know I shouldn't, and I think about it sometimes, like no, and get a little ache in my stomach, this isn't really good. But I mean, I have that thought in my head all the time, that I should not have it, I should have it, I should not have it, so I mean yeah» (Interview 5, girl 16)

«... I do feel a bit bad when I eat like that, and sometimes when I eat that kind of unhealthy, really unhealthy food. Like greasy food, but I don't think I would feel that bad if I didn't have it (FH) » (Interview 11, man 18)

The majority experienced guilt when eating foods that were "bad" for FH. Some did not think about it, and a few said they didn't think much about FH at all. Some participants meant that they previously had difficulties finding a way to deal with FH, but now felt like they found a balance. The times they choose to eat something bad for FH were considered acceptable and

well-deserved enjoyment of food. The guilt could be triggered both from following advice and not following advice.

«... if I am sitting down by the table and get served something. Then it's a bit like, it is kind of weird to eat it, when I know that it doesn't really pay off to eat, so it is weird. But in a way I just have to, at least if there are more people around me, I'm trying to eat a little. So it doesn't look like I'm not eating at all, but I do feel bad for mom and the others, that I'm eating it» (Interview10, girl 16)

«You think about the others?» (Interviewer)

«The people that makes the food, if I don't eat everything. I feel bad for them, but most people know about it. So they understand. So they, they make adjustments» (Interview10, girl 16)

«But that you feel bad for your mom if you're eating too?» (Interviewer)

«Yes, and then I feel bad for the other people if I don't eat, so it is like a little dilemma» (Interview10, girl 16)

There was by many a difference between situations when they had a choice and situations where they felt like they did not. Some also got “permission” from parent to not think about FH in certain situations. If they were served "bad" food but were away they would see it as an exception.

«Yes, I actually do. But I mean, you can't really say no either. Often, when I'm eating with friends and stuff it is a lot like that, more unhealthy food than compared to if I am home. So yeah, I feel bad, or in a way I don't, since I kinda don't have any choice. Then it's a bit different» (Interview 11, man 18)

4.5.5 Thoughts about risk

Talking about risk of CVD or CVD incidents in their family was a subject that occurred in the majority of interviews although this was not included in the interview guide or asked about specifically. Some said avoiding CVD was part of why they ate the way they did. This was in some cases an explicit expression that they did not want to die of CVD, whereas for others it was implied in what they said.

One said that you could die from anything, and that it could be CVD. Some said they didn't care now (diet), that it would be better in the future and that it was not that important now, but would be more important when they got older. They also talked about the increased risk of

CVD and wanting to live long or to avoid disease. They mentioned it was important to understand the seriousness of the disease.

«Because even if I have low numbers now, I'm trying to not do it too much (let loose), but well, it's not like I think that I am going to die now if I don't watch it» (Interview 2, man 21)

4.6 Motivation and support

4.6.1 Knowing what to do

The descriptions of the experience of treatment at the Lipid Clinic were characterized by a positive attitude to the Lipid clinic. The majority of participants showed a lot of trust in advice given by the Lipid Clinic and rarely questioned the advice. The reason given for this was in general that personnel at the Lipid Clinic are the experts, they do research; they know the patient and the disease. They found comfort in advice and more so if they were able to apply them, because knowing what to do was calming.

«And I attended in a study... and I sort of got extended dietary advice and follow-up, so I got really familiarized with it. I think that was a good thing for me, because I got more knowledge about it and I got more sure about what this is all about and how it was» (Interview 3, woman 22)

Those who were initially frightened by the diagnosis talked about how they felt that it was less scary when they got to know that there were things they could do about the condition and that they could feel like they were in safe hands at the Lipid Clinic

«...as long as I take the medications and I'm in the systems of the Lipid Clinic, there's nothing to be scared of, and it doesn't bother me much at all actually. So it doesn't affect me that much, it doesn't» (Interview 3, woman 22)

They felt more or less certain when challenged by others, but they all felt quite certain that the Lipid Clinic advice was correct when compared to what they were exposed to in the media. This information was disregarded as either false or just not relevant for FH. One exception to this was a participant disagreeing about butter; this was something she discussed with a nutritional advisor in the family.

« I usually read what's important in the media and what they are trying to get through about nutrition and diet in social media, but yeah it is. I don't think that much about it. Like what media writes about, because I think it is a lot in media now that's not true about

nutrition and stuff, and I know a lot about it because of the disease. So I listen and follow most of what I hear here, and just don't care about what the others say, they are talking about nutrition in general, here they talk about my disease and they are specialists and I listen more to them really compared to what I hear on TV- programs» (Interview 5, girl 16)

Although they put a lot of faith in the Lipid Clinic, they highlighted the importance of feeling like they had a choice in the matter, and being told that dietary advice was advice and not demands. They appreciated when being presented with options and getting advice that was considered possible to implement.

«It's been a long time since I had counseling here, but I think they have to be good at telling the version that is recommendations, because my doctor said that to me now, that this, this is nothing he or they can force me to do, it is my choice. But it's recommendations. And that's what the doctor and this place would like us to do and want us to do, and they want to know that they gave me the best advice that they can give» (Interview 1, man 19)

Some said it was a motivational factor to be healthy in general terms. Healthy seemed to be considered something of a different concept than FH prevention. One said that the main motivator was eating healthy as her diet didn't affect cholesterol levels much. Healthy was also related to having a body that was functional, having an excess of energy and living longer and better. In this aspect having FH could be redefined as adding something positive to life.

«...I just look at it as something positive. I really do. It's, it's not really a challenge, that way. So yeah, I am actually happy I got it. It has helped me too» (Interview 6, girl 17)

«When it comes to?» (Interviewer)

«The diet and that we are more conscious about what we are choosing. So it's absolutely not a challenge, not at all» (Interview 6, girl 17)

«So you think that to have FH means that you eat healthier or?» (Interviewer)

«Yes, yeah, that's clear, it's not a, it's not something good to have it, but, but when it comes to nutrition and exercise and how much I know about it, it is very good» (Interview 6, girl 17).

They all had dietary habits that were more or less cholesterol lowering, focusing to some extent on fat and fat quality and including some products recommended from the Lipid Clinic in their diet. All said that they did some choices that were affected by FH, but the degree varied greatly. Some said that every meal was influenced by having FH, whereas others said that they didn't really think much about it.

For some the cholesterol lowering choices mentioned were not really choices but preferences developed since childhood, as parents had known of the diagnosis and been good at introducing the “correct” food. This had made the changes seem small.

If the recommendations had become more or less habits, this reduced the time they needed to be restrictive. They would initially say that they did not think about FH, but then reveal that they ate according to advice. Growing up with FH friendly food seemed to internalize advice to an extent they did no longer consciously think of it. Some had also developed habits on their own after becoming independent that were FH –friendly.

Others were eating better in a period after consultations and then falling back into previous patterns after a while. They ate better when reminded, but had to make this as a choice, requiring a more restrictive way of eating.

4.6.2 Measurable results

The measurable results of adhering to dietary advice and medicine regimen were of importance to all participants. This was in regards to the cholesterol measurements in particular, but also Smart Diet score and bodily changes. In fact, just filling out the Smart Diet questionnaire could be a motivator. Some said that they thought about this while eating, reasoning that if they had 2 eggs one day they needed to avoid it the next week to be able to fill out the right box on the Smart Diet. In this way, the Smart Diet motivated for a limited intake. Adjusted eating habits based on the score of the Smart Diet was also mentioned as a motivator for increasing beneficial choices for the recommendations, such as increasing fish intake. One said it was good to hear that they scored low on something even though this was expected, as it was a confirmation that something needed to be done.

The cholesterol levels were by one girl described as “judgment day” and she got really nervous. The feeling of the cholesterol levels being the ultimate indicator of how well they were doing and if they were on track, was common. This seemed to be related to the lack of other noticeable symptoms of the diagnosis.

«It’s hard to imagine everything that’s going on inside the body when you can’t feel anything or tell at all. So everything is just numbers on a paper» (Interview 1, man 19)

Some even wanted to impress the doctor, or family members. They told family members about levels and got positive feedback if it was good. It was also reassuring when it was good. Some wished they could get their cholesterol levels measured more frequently but didn't seem to have considered doing this at a general practitioners office. Others however, checked their levels regularly at their general practitioner already.

The majority of the participants mentioned thinking about their body, either in regards to physical appearance or health. They talked about having a healthy body and giving the body what it needed.

«Yes, I use the consequences to think about when I should drop things. So I eat, yeah, and it's also a lot of shows on TV now about eating healthy and the right food, and it is a lot of body pressure at the moment, right. So it is a lot that influences me to think about what I should and shouldn't eat. It's not only the disease, but it's also the thought about wanting, that I want to have, be strong on the inside and outside in a way, so I have to eat the right food» (Interview 6, girl 16)

Looking and feeling good was important to some. The male participants talked about being strong and working out. Some of the participants spoke explicitly about weight and mentioned losing weight after making dietary changes. Some had lost weight intentionally, whereas others had lost weight without keeping track of weight. Being weighed and measured at the Lipid Clinic without talking about body and weight was considered risky according to one. One spoke explicitly about pressure on body appearance and how this was at its worst during middle school, but improved in high school.

«Yes, I would say so. Like in the age of 13-14-15 years, the middle school years, I would say there is a lot of body pressure, and social media causes it too. There's a lot of people posting pictures of their food, right? What are you eating, healthy fitness type of thing. And pictures in bikini are also posted, right. And when you are scrolling down and you can see all these pictures, the super-babes at your school and you get a little like, ooh. But now, I feel like I'm finally beginning to be comfortable with myself and I eat whatever I want, yeah, I do whatever I want in a way» (Interview 5, girl 16)

4.6.3 Social support

Social support from family, friends, partner and the context of a society focused on health were factors that made the dietary part of treatment easier. Family support, was as mentioned earlier, a potential source of healthy eating habits from an early age. They expressed gratitude for their parents influence in developing these habits and not having to make drastic changes.

«Yes, but my mom has done a great job, always gotten it in to my mind, we have always known what's healthy or not. Stuff like that. So I have actually had that in the back of my mind the whole time» (Interview 2, man 21)

«Yeah, yes she has taught me what I should have and shouldn't have. Since she knows, since she has it too she knows a lot about it and she is very good at eating the right way and stuff» (Interview 5, girl 16)

«Yes, it was when we were here at the Lipid Clinic the first time. They gave us some advice about what you should eat and a little about those levels, blood tests and this and that. And then, I think after that I have been a little more aware of it in a way, or that when I was a kid or a little younger than 15 in a way, I didn't really care about it. Or my parents took care of all the food stuff. But now when I need to take care of it myself, when I have to buy food, and that's pretty often, it is more like, a bit different. I'm thinking a little more about it» (Interview 11, man 18)

Those who had a sibling with FH would also discuss the situation with the sibling if needed. Having a sibling with FH meant they were not alone in the situation of being young with FH.

«Yes, I thought it was pretty okay that she (sister) also got high cholesterol (laughing) in a way. It had been like, if I would be the only sibling that had it, I think I would, I might have thought differently about it. I would say that it would probably be a little harder from the beginning if there only were one that had to. Now we both have, have the same diet» (Interview 13, woman 23)

«...I think it was easier for me than for my older sister, because I lived at home and had my mom that was watching over me, but my sister didn't live at home. Since she's 8 years older than me, so it must be harder for her in a way since she was alone about it. She and her boyfriend, but for me it was different because me and mom had each other and were going through this together in a way» (Interview 4, woman 20)

Family members, especially mother and father, were of great support, for having someone to ask if any questions arose about specific food items. The mum or dad represented someone to aspire to and someone they wanted to please. Being clever (flink) was measured in the above described cholesterol levels and smart diet, but also in comparison with others eating behavior. They often compared themselves to their parents, with the parent representing a role model. This could be motivating, although some said that the requirements the parent put on themselves, could be higher than what the participants aspired to on their own behalf. Some also compared themselves to siblings or a group of friends and tried to do just as good or better.

«Yes, actually...it is like, I kind of become a bit like, it's a lot, or it's some of my friends that eat a bit unhealthy, a lot of unhealthy stuff, so that kind of makes me want to eat healthier than they do, like, maybe it is a kind of competitive instinct. But yeah» (Interview 11, man 18)

Having a group of friends or a partner who had dietary preferences that matched dietary recommendations made social settings easier. Having shared with others that they had FH gave friends and the partner an opportunity to adapt meals to the dietary treatment.

«... I talk a little with my boyfriend too. That he has to know that there are certain foods I can't have. And he is watching out a little when I'm not watching myself, so he is watching out for me in a way» (Interview 12, woman 20)

«Yes, we have those kinds of nights sometimes. But all my friends know about it so, because I have had it my whole life in a way. And like, my mom has been talking with most of their parents and told them, so it is like they take it into consideration. When other people buy food, they like, think about it a bit, like what product I actually can eat and stuff, so» (Interview 10, woman 16)

The general tendency in the Norwegian society to make an effort to eat healthier was seen as an advantage because it made more options available in stores. Having options made it easier to eat according to recommendations, but the focus on healthy eating also made it easier to do so without getting unwanted attention.

«It is like, it is a positive development in society in general now, with things being the way they are with us, it is good that we got this healthy focus going on right now, because that makes us not stand out that much in a way. It, it would be something else if it wasn't like that, maybe people would start asking questions» (Interview 4, woman 20)

4.7 Comparing dietary treatment to drug treatment

When comparing diet and medicine some said medicine is more challenging, because it was not yet a habit. It was also quite frequent to not like the idea of taking medication as they had a general attitude towards avoiding medication. They still took it because they had been convinced it was necessary. Some said it was uncool when others see them taking medication and may ask questions, which could be uncomfortable.

«To be 20 years old and get told that I have to use medications the rest of my life was not fun at all. It really wasn't. I had a harder time handling it then I thought I would have» (Interview 9, woman 25)

«Yes, I think I started when I was 14 maybe. Around 14 or 13. It was a big difference, because that I have to take every single day. But yeah, and I have to go to the doctor many times a year to check if it works. And then I get send here. Every second year. So it was a bigger difference» (Interview 8, woman 18)

When asked about the impact of diet vs. medicine on health some reflected that it must be diet that means the most because it changed most. Others said medicine because they had to take medicine because they could not reach the target with the diet alone. Some said medicine due to the fact that they got more stressed if they forgot one pill than they did if they ate food that wasn't good for them one day. The medication was also seen as a security.

«Yes, I should maybe be a little stricter later, but it's also that safety, that if it goes wrong, that there is nothing you can do, then you have the medications that can keep it low anyway. So you are, you're kind of safe if it goes wrong. But as said, you can work with it for a while. And if, if you do well, you get a smaller dose, that is cheaper. And if you do badly you get a much stronger dose that is a lot more expensive. So it is a little bit about that too. That you, when there is a plan B too that is also safe, so yeah» (Interview1, man 19)

This participant did also take into consideration the cost for the Norwegian society when it came to expenses related to the medication.

«...It is good to know that Norway won't have to spend a whole lot of money on medications for me as long as it's not necessary, if you just work out and eat a little healthier and are conscious about choices you make in a way. The money can be spent on some other things» (Interview 1, man 19)

4.8 Potential adjustments in future dietary treatment

4.8.1 Practical and adapted information

Several participants requested more practical information, with more focus on recipes and meals rather than product information alone. They wondered what they could make with the food they had available and how they could change products without losing flavor. They all talked about preferences for food that is typically considered food for young people. Some said that they wished this was also a focus in dietary treatment, to give examples and recipes of food young people like and eat.

«... the products are kinda weird, the ones that are recommended, or not weird, but things that almost no one buys. And yeah, it is, I think it's very hard to in a way have to follow

that... Yes, mostly because I don't think it's good. That's it, that's what I think most about. And that, yeah, you know. That I would rather eat stuff that I think, that I have always eaten, or like, bad habits, that I follow that a little more than the healthy stuff... To eat like, that really stone hard type of bread, in a way. With those lean spreads. I don't think that is, you can't buy it many places either. At least I don't find that, thing you can buy in the store in a way. Eat it for lunch. And in school and at the same time that is good, and I can eat» (Interview 11, man 18)

Some suggested a more pedagogic approach, such as an educative stage by stage approach, and adjusting to a realistic level for patient. Others mentioned that setting the bar to high could make it seem unachievable and make them wanting to give up. For others who were more on top of it, the dietary advice became repetitive.

«Yes, that's what I'm thinking actually, when I go here, or, I don't really know. I guess it was okay, the dietary advices in the beginning, but it was like, I kinda knew a little from before. But like, when we had it, I think it was for the 4th time we had it, we asked if we could skip it. It was a little too much about the same topics every single year» (Interview 13, woman 23)

The participants' needs changed, what occupied the participants at one age did not necessarily apply at a later age and vice versa. For instance alcohol advice became more relevant in student years, same goes for fast-food.

«Yes, there is a challenge in regards to that, about like, tips about, yeah, for example what you can be drinking instead of alcohol, or for example what the more healthier types of alcohol are that could be better to drink and that kind of stuff. There`s not that much information about it. Maybe it would be good to have. But I have seen, I do get, I get that magazine sent home, that FH magazine or something, and it tells you a little more about it and stuff. So yeah» (Interview 13, woman 23)

They also found it difficult to integrate consideration to taste, time and cost and would like to know more about ways to eat well on low cost. Availability of information between consultations was something they thought would be useful. There was a lack of information available online as well as option for asking questions in between consultations. Some read blogs, and others googled but did not feel like the information they found applied to FH. .

4.8.2 Holistic approach

Some said that they felt like there was a lack of focus on the diet as a whole. They wondered about the impact of carbohydrates and about the other good habits they had that were not

taken into account in the Smart Diet. One said that she felt the Smart Diet didn't see the total and that she didn't get positive feedback on other healthy choices and that it was confusing that eating brownies made with oil was good, when cakes and sugar for everyone else was bad.

«Yes, I think it was hard to know, because I was doing all the FH advices, I didn't eat that much egg in a week and low fat la la la. But I ate way too much cake, rolls and soda, but it wasn't that much fat in it and it had a lot of sugar and that's not healthy in general, no one else said it was healthy, but when I took the diet test here, I had very good scores. »
(Interview 3, woman 22)

Others felt that there was a difference between healthy for them as FH patients and what was healthy for others.

Several participants talked about the body and one said explicitly that the way dietary treatment of FH involved talking a lot about diet and weighing and measuring patients, the health care professional should also be aware of risks of triggering dieting behavior and extreme health behavior.

«Yes, absolutely, yes, it is like you are aware of that body and self-image are very connected and that diet and body is too. And that you, they have never told anyone here, ... that you need to lose weight... they have never said anything about that you have a unhealthy life style... but no one told me that what I did was good enough. They never followed closely up on that. Because for all they knew, I could be on my way to have eating disorders, without them caring about it here in a way. And in this case, I didn't have that, but if I had eating disorders or was really interested in losing weight at an age of 14 years old, and that they didn't know about that; I could sit here and be cross-examined about my eating habits and be told that; no, you're eating a little too much candy and too little fish, I heard that a lot, or it was like, eehm. To sit there and hear that what you should eat and not could be really dangerous because... Even my doctor said that I need to be healthy» (Interview 3, woman 22)

Others also mentioned a risk of becoming too obsessed with diet, and that it was important to not get too "healthy".

«Yes, that people don't, like, freak out. But you know, people freak out even if they've got high cholesterol or not. When it comes to exercise and diet now, I feel like it is so much that it is no longer healthy. Because it has effects on psychological aspects. So, I think that is important, to have that balance, so it doesn't turn in to something that affects the psyche. But I don't know how it is with the rest that comes here, but it hasn't affected me, not to that degree» (Interview 13, woman 23)

5 Discussion

5.1 Discussion of methodology

5.1.1 Data collection

Study sample

The participants were identified through the hospital register which makes it a less selected group than if recruited from for instance a patient organization. A problem in the recruiting process was that many did not show up for their consultation. Recruitment was however relatively good among those who came for a consultation. This could represent a bias in recruitment, with an imbalance in who showed up for consultation or not, and in who said yes and no to the study. It may be that the sample would have more of those FH patients who feel they are following the dietary advice and have less challenges with treatment. It cannot be eliminated that those not participating represent those who on the other hand think or care less about FH and dietary treatment. We know little about those not attending consultations, as they are difficult to recruit for studies.

Grounded theory requires a variety in the sample. The sample was heterogeneous in regards to attributes such as age, time of diagnosis and life situation. The study sample consisted of more boys than girls and this could have affected the results. The sample appears to otherwise be representative of adolescents and young adults with FH receiving dietary treatment at a Lipid Clinic. The non-participants were not contacted about their reasons for not participating.

A sample size of 13 is small, but this is comparable to other qualitative studies. The size was chosen to have enough data material to have a chance to be able to generalize, but not too many, so there would still be enough time to make penetrating analysis of the material.

Qualitative research is time consuming, and quality of analysis is preferred over quantity of data. The aim of the study was not to look at prevalence of certain attitudes but to explore the perspectives of the adolescents. This was possible to do in these interviews were they could speak freely.

Pilot interview

Pilot interviews were conducted to practice on the interview setting and adjust the interview guide. Including pilot interviews in the study design can improve the quality of later interviews. In addition to the pilot study, adolescents were asked to read through the interview guide and give notice of words or sentences that were perceived as too difficult. The pilot interviews were valuable experience prior to conducting the interviews. Minor changes were also made to the interview guide. This included making a keyword list to help structure interviews.

It would have been beneficial to have a second researcher present at the pilot interviews but this was not possible. There might also have been an additional improvement in including more pilot interviews. The recruiting process from a small population however, gave reason to focus on getting participants for the main study.

The use of in-depth interviews

Semi structured interviewing requires preparation and planning. Beforehand it was determined *who* would be interviewed, *how* the interview would be conducted, recorded and transcribed and *what* they would be asked. Nevertheless interviewing is a skill and the technique was most likely developing throughout the process. As a part of grounded theory methodology, the interviews were altered as the interviews progressed.

It is important to beware that the interview is a conversation between two people and that it is this interaction that generates data. It must be reflected upon, that in this context, the participant may think about new aspects of their experience so that new experience and understanding emerge as a result of the interview setting (74).

The hospital setting could have made the participants more reserved and disempowered. The presence of non-participants was avoided to prevent affecting the opinions expressed by the participants. One participant asked to have a partner present because of the partner's interest in FH, but was agreed to the option that the partner instead would see some brochures on FH while the interview took place. The interviewer had familiarized with the participants "cultural milieu" of adolescence and young adulthood, keeping the interview less formal.

The degree to which the adolescents shared information varied, some were less verbal than others resulting in less informative richness in interviews. Some were nervous but relaxed throughout the interview. Others were afraid they couldn't answer and hesitated to participate. Some said after the interview that it was not "scary" after all and that it was nice to talk about FH in a setting like this.

The information given beforehand encouraged the participants to openly speak about their viewpoints. If doubt was expressed during interview on whether they were giving the right kind of information or if excusing themselves for going off topic, they were reassured that there was no correct answer and that it was their thoughts in their own words that was of interest in this study. The neutral wording of the questions was developed to reduce response bias.

Semi structured interviewing is non – directive, yet, steering in keeping to subjects related to the research question. This requires a balance between control and letting the participant speak freely. The lack of experience as an interviewer may have led to topics getting lost in this process. The carefully constructed interview agenda helped make sure that the most important subjects were covered.

The use of audio recorder

The interviews were audio recorded in order to carry out a full analysis of the data. This makes it possible to focus on the conversation. The audio recording does not record the nonverbal communication, although the field notes serve as a support to some extent. It was explained to the participants why the recording was being made, who would listen to it and how the audio file was going to be used later on. All participants agreed to being recorded, and did not show any hesitation to the request. This does however not rule out that being recorded could have influenced what they shared in the interview.

5.1.2 Data analysis

Transcribing

The audio files were re-listened for accuracy, and then transcribed with the FTW transcriber. Because the interviews were transcribed for a grounded theory analysis it was considered

sufficient to transcribe verbatim and not include pauses, intonation, volume of speech. The interviews were transcribed verbatim and incomplete sentences, false starts, laughter and repetition of words was included. It is an important factor to keep in mind, that transcribing always involves an alteration from spoken words into something else and that this means something may get lost on the way(72). It would have been of interest to offer the participants a copy of the transcription to give additional comments, but this was not done due to the time frame of the study.

Coding

The coding was done in the qualitative software program Nvivo 10. This program made it possible to explore the data and to get an overview in a systematic way. The program gives advanced software with a multiple of features for exploring and analyzing data. Related instruction videos and instruction manuals gave the necessary knowledge to conduct analysis in the software.

The young age group included in this study required awareness of linguistic variability. What was important in transcripts was what they meant and not the lexical meaning of what was being said. This could have been further supported by having the participants giving feedback on the findings to ensure a correct representation of their experiences.

Pre knowledge could have affected coding. Researcher triangulation was applied in coding, where the master student and a supervisor initially coded two interviews to compare. The code book was presented to the supervisors to agree on coding and themes identified.

Supporting quotations are included from different participants to add transparency and trustworthiness to the findings and the data.

Reflexivity

The qualitative researcher needs to consider reflexivity and how as a person and researcher this is implicated in the findings. The initiative to the study originated from the Lipid Clinic. The topic of the study was chosen by the supervisor prior to the master student's involvement. FH is a subject in the clinical nutrition, and includes intern days at the Lipid Clinic. Although this is a master degree in clinical nutrition, the student has an additional degree in health psychology. The knowledge was applied in the process and could affect views.

The master student had no relationship with participants and did not meet before or after the interview took place. The master student is a Norwegian female, age 28 with no personal experience with living with a diagnosis requiring dietary restrictions. The social identity of gender and age of the interviewer could influence the participants in what information they choose to share.

5.1.3 Trustworthiness

There are four criteria of trustworthiness; credibility, transferability, dependability and confirmability (75). These are comparable to the internal validity, external validity and reliability in quantitative research.

Credibility

Credibility refers to the confidence in the truth of the data (75). The truth of the data is the extent to which results truly reflects the participants of the study. A threat to credibility in this study is the potential misunderstanding or misinterpretations of participants' statements. The use of follow up questions and rephrasing the questions was used to get a more comprehensive understanding of what was being expressed. The semi-structure nature of the interviews gave flexibility to interpret along the way and to ask questions in order to explore interpretations.

Supportive field notes added information about the experience of the interview of each participant into the interpretation. It would have been of interest to have participants read through the analysis and give additional thoughts on the subject in matter as well as interpretation of the interviews. The time frame of the study did not allow for this.

Transferability

The potential for applying the results to other samples and settings is its transferability (75). In qualitative research this does not mean that it should be transferable to larger populations but to the population it represent. The study included a heterogeneous group of participants, but it is not known whether those who agreed to participate are different from those who did not want to participate. It is also of interest that 1/3 of the adolescents and young adults

initially invited to the study did not show up for their consultation. It could be that those who show for their scheduled appointment are different than those who don't.

The specifics of this study was described in detail to give the context necessary to assess whether it is transferable to a given other setting.

Dependability

Dependability is the degree of consistency between the data and the interpretation of the findings (75). The study conducted should be consistent across time, researchers, and analysis techniques. In this study the master student did all interviewing, transcribing and coding. This does however not imply a consistent interview setting, as the technique might have developed through interviews.

Confirmability

Confirmability refers to the neutrality of the data, meaning the degree to which the meaning of the data was agreed upon by others (75). An audit trail was also made for the analytic process but was not examined by an external auditor. The master student checked the data repeatedly by re-reading and comparing findings with transcriptions, while looking for aspects that may contradict the interpretations. Triangulation was applied for the initial analyses and of the code book.

5.1.4 Limitation and strength

Limitations of the study have been elaborated in this discussion of methodology. It can be added that in-depth interviews as a method give knowledge, and not necessarily causal explanations. With QOL being a broad concept including many aspects, it cannot be fully investigated in one study alone.

This study provides information in an understudied area of dietary treatment of FH, by giving insights about the experience of dietary treatment and the impact on quality on life from the perspective of adolescents and young adults.

5.2 Discussion of findings

5.2.1 Experience of dietary treatment

Integration of concepts from analysis

Adolescence is a period that can be challenging due to all the changes from childhood to adulthood. Adolescence usually involves a changing diet; but for those diagnosed with FH this may involve balancing the dietary habits of peers with the dietary recommendation of FH. They have a social life that involves going to the cafeteria or supermarket while at school, or cafes and restaurants and home cooking in their spare time. This creates an environment that involves choices. The period involves several transition phases of life, from living at home and becoming more and more independent, to moving out and taking full responsibility.

They meet new challenges as time becomes an increasing issue, and issues such as wanting to be the same as others and not wanting to stand out, yet at the same time developing individuality. Context change and they start having money and buying power, later on they may face being short on money and having to prioritize to make ends meet. Changing contextual factors may involve a lack of stable routines on how to handle this new responsibility of taking care of their own health.

The findings revealed that the overall experience of having to follow a lifelong was influenced by a variety of sources of challenges as well as motivation and support. Integrating these considerations and weighing the concerns is crucial for the participants in finding their way of dealing with FH. The most important aspects affecting the experience of dietary treatment are visualized in **(figure 9)**.

The model serves as a map of the complexity of factors that represent the sources of motivation and challenges for the participants in the study. Together they represent the framework within which the participants make their food choices.



Figure 9 Integrated concepts from analysis.

FH readiness

Adhering to dietary treatment is considered a health behavior, a behavior aimed at preventing disease and improving health (76). It can be argued that it is somewhat out of the ordinary to be thinking about preventing disease at this young age. The participants' ideas of what the FH diagnosis entails varied. Beliefs about the diagnosis varied. Some were thinking that the diagnosis does not matter all the time; this has in other studies been related to lower

adherence (77). A belief that illness has serious consequences was related to medication adherence in a study of high cholesterol patients (78).

The trust in the Lipid Clinic was present in all interviews. Through the Lipid Clinic they had acquired knowledge about their risk of getting CVD and this was as a reason for adhering to treatment. They have faith in the Lipid Clinic as being in good hands. It was important for them that the Lipid Clinic took them seriously. These findings are consistent with previous studies of adolescents (79). To feel ownership of the dietary advice and finding a way that suits them, taking control of the situation themselves, seemed to be related to a feeling that they reach their goal. The role of agreement between health professional and patient has previously been shown to be of importance for the patient (80). It was important that they felt they had a choice of how to live and eat and that the advice was viewed as recommendation and not as orders.

Those who got the diagnosis early had given away responsibility to their parents. From early on they developed preferences and habits towards cholesterol-lowering products so that this became a natural choice for them and extra motivation was normally not needed. The diet of their families became their diets, with alternating diets in cases where they grew up in two homes and the parents assessed the necessity of FH diet differently.

The degree of awareness or habit of the dietary treatment was affected by how restrictive they were. Some said that having FH implied no differences, others thought about it constantly. The degree of restriction was related to how high they set their goals and how difficult it was to avoid food that was not good for them. It could be that there is a limit to how much awareness and restriction is beneficial. If demands are too high, breaking “the rules” could lead to “What the hell effect”. One participant described that when she started to eat “bad” food, she ended up having a lot of bad food. Instead of finding a middle way, an attempt to be very strict could lead to giving up and not feeling that the task can be mastered. The pertinent question arises: Are the health personnel setting the bar too high? Will very high goals actually have the opposite effect than intended?

The importance of early diagnosis on adjusting to disease has been seen in studies of other diseases requiring dietary treatment. Diagnosis of IDDM in late-adolescence was associated with a risk of various unfavorable behavioral and health outcomes, whereas adjustment to the

disease during earlier adolescence was a potential predictor of subsequent health-related behavior and health status (81).

Food enjoyment

There are many advices to follow in the dietary treatment of FH. Taste and enjoyment of food was a consideration that often came in conflict with the dietary treatment of FH. Some meant that food low in fat did not taste as good as whole fat products. It is necessary to find a balance in how often it is acceptable to eat food that is considered «bad » for FH. Many mentioned foods they would eat more often if they could. The foods they could not eat became more tempting. Even though many reflected that they thought they would have had the same dietary habits without FH (this was regardless of whether diagnosis had led to changes), others said they would eat completely different if it was not for FH.

For some of the participants, the feeling of guilt put a damper on food enjoyment. To not follow the advice and eat bad foods could lead to inner discomfort. This has been found in previous studies on guilt and shame in adult patients with FH (68). In the present study, those experiencing guilt differed in the length of that feeling, some got over it quickly and made the same mistake. Others regained balance by being extra strict afterwards. Guilt could represent a problem, but it was also a factor that helped them stay on track. The limits to when they felt guilt varied a lot. Some might benefit from having more guilt and others from less.

Whether food enjoyment or guilt was prevalent was person dependent but also situational. Evaluations on whether a situation represented an exception or not, and whether it was possible to make another choice or not, affected what they gave more importance.

Social considerations

Adolescents and young adults are in some ways at the mercy of others to a larger extent than adults. They eat at home or at friends, and are often not the only ones involved in deciding the menu. While still living at home, they rarely make the food all by themselves. They have most of the food served, and fridge and dinner could be FH friendly, or not. They are usually not the ones taking responsibility for the food at home while still living with the parents. Being in a context where others eat junk food and drink a lot of alcohol could be a challenge if wanting to do as the others, or if these contexts lack a healthier option.

Some of the food typical of young culture, like pizzas, hamburgers and kebab were normal among friends, but the participants needed to limit the consumption of these products. Making food with friends or going for a night snack after a night out were situations where it could be difficult to choose according to dietary recommendations. Attention from other, consideration and getting special treatment were something some attempted to avoid.

For friends it was hard to know what to serve, as healthy for others could be related to losing weight, for example with the low carb diet, and this is not combinable with FH. The friends may get it wrong, and some don't understand the need for adjusting the diet at all. In some situations all choices would lead to guilt, since they could refrain from eating "FH bad food" and thereby please themselves (or those who care about them) or eat the food and please the person serving food, this made it impossible to avoid guilt.

Friends and partners could be a motivation when they promoted a healthy lifestyle and good dietary habits; but a challenge if they didn't. It could be of interest to ask about dietary habits of friends and partner in the consultations at the Lipid Clinic. The general focus on healthy eating on a society level makes it more accepted to take care of diet. This would ease the feeling of FH adolescents of being atypical.

Because FH is a familial problem, children are often on a diet relatively low on fat even before diagnosis. The fact that family habits have an impact on the choices of adolescents aged 10 - 13, was seen in a study conducted in Oslo (82). The process of adapting habits can be seen as a process of social learning (83). Parents who control diet for their children can do so in an overt or covert way. With overt control restricted food may become more tempting. But greater parental control was associated with higher intake of healthy snacks (83). Controlling the child's environment with covert control, parents can successfully control their children's diet by controlling what is served (84). The way the participants in this study talked about growing up in a home with FH dietary adjustments indicate that overt control and covert control was applied.

The parents' support was of great importance and they should know how important they are for the adolescents. Family support is a factor in reducing illness in other diagnosis (85). A lack of support in adhering to dietary treatment on the other hand could complicate the adherence. Other studies have also found that family functioning with less conflict made better dietary choices (86) Support is defined as both people giving advice and people giving

physical help (cooking, buying food). In addition to this they could serve as a role model. The comfort of a sibling with the same condition was for some so great that they were glad that they had it. This meant they didn't feel alone. Many of the participants mostly talked with their family about the diagnosis and challenges related to this, as it was seen as a family matter. Not telling others could limit the availability of FH recommended choices, as others were not given the chance to make the dietary adjustments.

Practicalities

The participants were missing more practical advice, this could be due to the fact that they are still quite new to buying and cooking food, as well as taking care of expenses. It could be difficult to make things with the products recommended in the consultations, since the food they want are not included. They eat more food on the go. All diagnosed with FH should receive individualized FH dietary and lifestyle treatment (87)

Some challenges were related to age specific scenarios, like growing up with divorced parents or having to choose between healthy foods or having money to spend on a tight student budget. A report from SIFO in 2007 concluded that there was a relative difference of approximately 40 % added cost with a FH-menu compared to the food expenses in the SIFO standard budget (88). This was calculated for women aged 18 -30 years (88).

The current period of life was by some described as characterized by not having a predictable everyday life, and always being on the run. Of those participants currently studying some explained that making FH friendly dinner took time from studying and that they often resorted to quick solutions like ready-made pizza.

Medical consequences

FH is different from other diseases due to its asymptomatic state and longtime perspective in adolescence. Previous studies have found adherence to be low in this age group. Asthma is a disease where the symptoms vary, and stays asymptomatic for longer periods. Having long asymptomatic periods can lead to a perception of not having a problem, because it is not apparent (89).

Adherence to dietary recommendations in children with FH has been studied and found to be related to psychosocial factors and to parent's education level (90). With the FH diagnosis,

the adolescents cannot physically feel symptoms and this could have implication on their motivation to adhere to advice (91). They do however have potential positive experience with effects on health and feeling of safety when cholesterol levels are under control.

The participants seemed to have a need for measurable results. They see the cholesterol levels as the verdict. Fear of health risk has been shown to be a potential motivation for behavior change (92). Without measurable results it was for some difficult to know if they were doing it right. The measurements could also represent a challenge when the results did not go their way. On the other hand, the measurements were comforting when they did go their way. Although some of the participants did not go for measurements very often, they do use the few times they measure as important indicators of overall status. In between visits to the Lipid Clinic they compare habits to others and to family members in particular, in order to motivate themselves.

5.2.2 Comparison of dietary treatment and medication

In this study there were both participants who considered the dietary treatment to be the most difficult, and those who on the other hand considered the drug treatment to be the most challenging. Medication could be considered more difficult because it is being less normal in this age group. The thoughts they had on taking medication the rest of their lives was difficult to accept for some. Negative medication beliefs have been in previous studies appears to be common among adolescents (93). Medication was considered something they would normally avoid, due to various reasons. It was also revealed that some had more general hesitation towards medication, and even associated it with unnecessary expenses for the Norwegian government.

The dietary treatment was by many considered as less challenging than the medical treatment. This could be because taking medication is still a new task for some of the participants, and not yet a habit. They didn't like taking medication in public. Others didn't think much about the pill but found the dietary part of treatment to be more challenging, as they had the medication part as a habit that they considered simple, whereas dietary treatment was more complex and more difficult to implement. They did not seem to have reflected that much about what was most important, but when asked they used the impact on cholesterol levels or the degree of change it involved to make up an opinion. Most said they needed both, but some

also said that the medication was a safety net which was good to have, if the dietary treatment was not enough to keep the cholesterol levels down.

5.2.3 Impact on quality of life

The participants in this study all explicitly said that FH and dietary treatment did not have an impact on QOL, yet most of them revealed experiencing challenging aspects. Although this may seem contradictory, this could be explained by the cognitions they have about QOL or their ability to cope with life with FH. Similar findings were found in a study on children and youth aged 10 -18 (94).

The way they thought about quality of life, a good life and overall impact of life, might just not include FH and dietary considerations. Another explanation could be that they have found ways of coping with the dietary recommendations that prevents impact on QOL.

The initial experience of getting the FH diagnosis for some of those being diagnosed in adolescence had, in contrast to current state, a big impact on life quality. There seems to be a clear difference regarding time of diagnosis in how they experienced to get the diagnosis, where those being diagnosed after early adolescence had a harder time initially. The experience of being diagnosed with FH later in adolescence led to uncertainty and worries about the consequences of the diagnosis and impact on life. The feeling of being branded as sick or that there was “something wrong” with them was also an uncomfortable feeling.

It could be that there is a vulnerable period for diagnosis in middle adolescence as suggested by one of the participants. Middle adolescence has characteristics that differ from those of the early and later adolescent periods (52). In a study on adults they found that 30% had psychological or physiological reactions to being informed of the FH diagnose (95). This is in contrast to a previous study, where parents thought it would be better if their children were told later, 11 % of parents of children age 6 - 16 years, thought their children’s quality of life would have been better had they not known about the disease until later in life (96).

This view on the impact of FH on life changed from time of diagnosis to the time of the interview, indicating that there had been a responsive shift. Responsive shifts are related to changes in an individual’s internal standards and correlated with active coping strategies (97). They compare with other diseases that are considered more challenging. They also compare

with those who have FH without knowing or when reaching a high risk level in blood lipids through bad eating.

The abilities to think abstractly and to reason increase in middle adolescence, along with a new sense of individuality (52). This period is characterized by feelings of omnipotence and immortality, which often leads to risk-taking behavior (52, 85). The postponing of taking action could be related to adolescents being less focused on concerns about the future. 90 % of the adolescents with poor compliance in a study of asymptomatic epilepsy explained it with treatment not being compatible with their lifestyle (89). This is seen in relation to wanting to belong to the group.

Preventive health behavior is the opposite of taking risks. The way most participants either talked about a close relative dying, or about their own risk of developing CVD, even though this was not a subject introduced by the interviewer, indicates that awareness of increased risk is present. Others talked about how they might die of other causes too and that you never know. FH is a condition where they cannot feel the symptoms and do not feel sick, but do know that they have an increased risk for serious disease in the future. This is a characteristic of FH that they need to handle. They choose how they live with this risk and how they will react to this health threat. Their perceptions of risk also affected their perceived necessity of dietary treatment.

When it comes to risk perception, they did express risk compensating statements like I can eat this because I gym or I can eat fatty foods because I eat fruits. From this perspective they see a set of risky behavior being neutralized or compensated by another, such beliefs have been associated with lower readiness to health behavior (98). These statements were in this study associated with those who had previous or current problems with adjusting dietary intake. Compensatory thinking can be a way of resolving the dissonance between wanting to eat according to recommendations but wanting to eat food that is “forbidden” on the recommendations.

Participants did not feel ashamed about having FH, but were afraid of misconceptions. The evaluations and thought of others are important to adolescents. Adolescence is a period of insecurity and developing a social identity. Chronic illness is conceptualized as a particular type of disruptive event (99) It is not common to want to stand out, but rather to fit in.

Wanting to be healthy is perhaps an even stronger desire in adolescents, and something they may take more for granted. The ideals of the adolescent are to be strong, invulnerable, and invincible. It could impact the social identity to have a diagnosis (80). They were also uncomfortable with there being “something wrong” with them. They felt like they weren’t sick, did not want people to know, not wanting to stand out, thinking of others perception of FH, referring to it as an allergy/family matter etc. because it was easier, or they could choose to be the “healthy eating” one without further explanations. It was important to some of them to point out that there was not an immediate response. Explaining was considered difficult for several of the participants, as they often perceived it as more dramatic than they would want them to react or the other way around, not understand the importance of eating in the required way. Both the medical difficulties of explaining cholesterol and implications of diagnosis occurred. This could be related to prevention and cholesterol levels being a rare consideration to make for this young age group. The FH dietary treatment importance combined with the lack of immediate reaction was difficult to communicate.

5.2.4 Coping

Getting diagnosed with FH can be seen as a crisis because it challenges identity and future prospects on diet and health. For those diagnosed earlier there was no crisis per se, but there was a change in life as they reached an age where they became responsible for their dietary choices. Although not dramatic, living with the diagnosis represents a health threat that they are given responsibility for. They differ in how they deal with these requirements to taking care of their own health.

How they dealt with the challenges related to FH differed. There are different theoretical approaches to understanding why people cope with health threats in different ways; one is the theoretic framework of crisis theory developed by Moos and Schaefer (100). The theory is also applied on people at risk of developing disease, such as a familial cancer risk (101)

Within crisis theory, a health threat is seen as a disruption and the reaction is motivated by the need to return to a state of equilibrium (100). There are three processes that constitute the coping process: cognitive appraisal, adaptive tasks and coping skills, shown in **figure 10**.

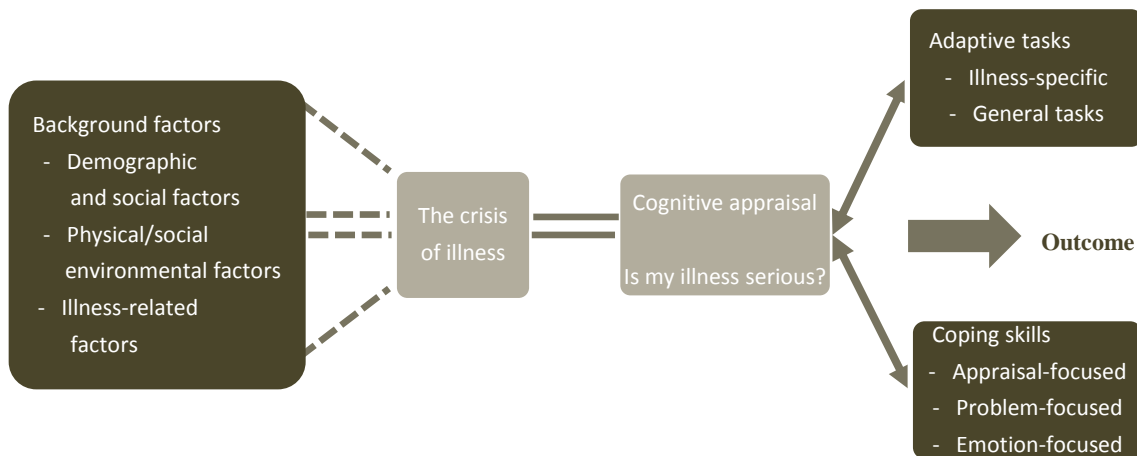


Figure 10 Coping with the crisis of illness (100), based on illustration from Ogden (80).

The use of coping skills depends on cognitive appraisal of the crisis of illness which is influenced by the background factors; demographic and personal factors, physical and social/environmental factors and illness-related factors. The background factors that emerged to be of importance to evaluation of FH were summarized in **figure 9**. The cognitive appraisal has been elaborated in chapter 4.2. This part will deal with the adapting tasks and coping skills. The three types of coping skills are presented in **table 2**.

Table 2 Three types of coping skills, table adapted from Ogden (80)

Three types of coping skills
Appraisal-focused
- Logical analysis and mental preparation
- Cognitive redefinition
- Cognitive avoidance or denial
Problem-focused
- Seeking information and support
- Taking problem-solving action
- Identifying rewards
Emotion-focused
- Affective regulation
- Emotional discharge
- Resigned acceptance

Appraisal-focused coping skills are about understanding the illness and searching for a meaning. The logical analysis and the search for meaning, involves dividing problems into manageable parts and positive reappraisal, accepting the basic reality of the situation, but redefining it in a more positive light. In the present study, thinking it could have been worse, like with self-inflicted high cholesterol, is an example of this. Another is the redefining of diagnosis to it not being a disease. Avoiding thinking about it or denying it in order to minimize the seriousness of a crisis in regards to significance and consequence was seen in one participant. This is a self-protective behavior that can protect for a short term and give time for engaging other coping strategies, as seen in the story of this participant who later accepted the realities. Some tried to ignore FH in certain situations where they were eating food that was bad for FH, but the constant awareness made it difficult.

Problem-focused coping is about attempts to take action by either reducing the demands or increasing the resources available. Gaining knowledge was important for many of the participants in the present study and they increased their resources through seeking information from family members and online searches in addition to the advice from the Lipid Clinic. Knowing more about how to control cholesterol levels helped reduce diagnosis related worries. They were seeking support from others to different degrees, some barely talked about it at all, whereas others had friends who found the subject of FH exciting and who made attempts to make necessary adjustments. Talking to parents or siblings about results can be seen as a way of seeking support. Taking problem solving action is to seek a sense of control and dealing directly with the situation. These skills involve dealing with symptoms, here cholesterol. This meant adhering to diet, avoiding smoking, and increasing physical activity. Identifying rewards was seen, as some participants considered FH to be positive or enriching, due to it contributing as an extra motivation to stay healthy. In this way they did a positive reframing, looking for something good (better health and habits) replacing what they lose out on (dietary freedom).

Emotional-focused is about managing feelings related to having FH. This could be behavioral or cognitive approaches. Emotion focused coping skills include affective regulation, Self-distraction and Emotional discharge, venting feelings. Emotional-focused coping skills were not frequently mentioned by participants.

These ways of coping can also be organized in the broad categories avoidance and approach. Approach coping are those characterized by confronting the problem, gathering information and taking action, whereas avoidance coping on the other hand is characterized by minimizing the importance of the event (102). The skills are not used singly or exclusively, but can be used in combination, with different situational factors triggering different coping strategies.

There could be different success in handling challenges related to the diagnosis with the different coping strategies. The overall goal is to result in healthy adaptations, and the types of skills applied may affect the outcome of longevity as well as QOL.

Other diagnoses requiring self-efficacy have been approached with coping skills training, targeting difficult social situations (103) (104) with good results. The importance of meeting each individual patient on his or her level and to support the strategies chosen by that patient too balance life towards harmony has been studied in an FH population (105).

6 Conclusion and clinical relevance

This study explored the experience patients with FH have of dietary advice and impact of dietary treatment on life as an adolescent. The findings of this study revealed that the adolescents and young adults did not consider the diagnosis to overall impact quality of life (QOL), but that they did however experience some challenges.

The findings suggest that health care professionals should take special care to consider the context when consulting adolescents with FH. The concepts FH readiness, Social consideration, Food enjoyment, Practicalities and Consequences was presented in an integrated model. The impact dietary treatment had on the individual participant was related to the sources of motivation and challenges within these areas. Some of the central subcategories were age of diagnosis, internalization of advice, current stage of life, and degree of social support.

The findings indicate that early diagnosis is of importance to impact of dietary treatment to life as an adolescent. This seems to be related to the internalizing of dietary advice as habits or lifestyle, instead of applying constant conscious awareness and control. It is known that early initiation of treatment is better for lipid profile measures and medical prognosis. This study illustrates how early diagnosis could be of equal importance in how adolescents experience getting the diagnosis and to coping with FH. This study could support those parents that are unsure of what is best for their child regarding timing, or those hesitant to alert family members. At the same time this is of relevance when treating patients who are diagnosed at a later age. They may need a closer follow up in the initiation phase, compared to those diagnosed early on.

It is a new finding that age at diagnosis of FH may be of great importance. The diagnosis has consequences for the entire life span for those affected. To be diagnosed in a vulnerable young age may entail an undesired extra additional burden that might complicate treatment. Being diagnosed at an early stage in life, so that the time for diagnosis cannot be memorized, may bring the advantage of the diagnose being an integral part of a self which is in contrary to getting a disease at a given time in life. FH is a mutation that the affected individuals has carried with him throughout life and it thus may be an advantage to perceive FH as part

themselves and how one was born with a certain risk factor, more than perceiving it as a disease.

These findings suggest that health care professionals should take special care to consider the context when consulting adolescents with FH. Potential ways to apply knowledge from this study is to implement dietary counselling that is life situation specific or step by step dietary counselling. The food recommendations should include “Youth food` and advice on how to make adaptations and solve difficult social situations with peers. It seems like many adolescents have a need for more practical advice on how to implement a cholesterol lowering diet. This age group might prefer a more practical approach to dietary knowledge with advice on specific recipes, youth gatherings or cooking classes. They also requested an option for easy access to answers regarding FH. This could be approached with a blog or online doctor specializing on FH.

These findings are based on the participant’s views. This knowledge would be of interest for clinical nutritionists and health care providers with the potential of adapting the dietary treatment and counseling for adolescents and young adults with FH. This knowledge might contribute to a way of communicating dietary advice and nutritional therapy in a way that doesn’t involve unnecessary stress. This would benefit adolescents and young adults with FH.

More research is needed to explore whether the concepts identified in this study is applicable on a broader population of adolescents and young adults with FH.

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Appendices

Original til: ✓
Kopi til:

Deres ref.:

Vår ref.: kretters/sisoeb

Skrevet dato: 27.08.14

Pasient:

Vil du bidra til bedre veiledning for unge med FH?

Dette brevet sendes til deg som har ordinær timeavtale på Lipidklinikken i september 2014. Det er en forespørsel om du kan tenke deg å bli intervjuet av en masterstudent i ernæring når du kommer til timeavtalen på Lipidklinikken. Dette er en mulighet til å si hva akkurat du tenker, i dette prosjektet er *du* eksperten.

Bakgrunn og hensikt for forespørselen

Målsetning med dette prosjektet er å studere om det er noen spesielle kostutfordringer hos ungdom og unge voksne med familiær hyperkolesterolemi (FH). Målsetningen er å studere om det er noen spesielle forhold vedrørende kostholdsråd knyttet til FH som er vanskelig. Det er et mål å studere om det er mulig å kommunisere kostråd og kostbehandling på en måte som er minst mulig belastende, men likevel effektivt. Analysene skal inngå i en masteroppgave i ernæring ved universitetet i Oslo.

Hva innebærer studien?

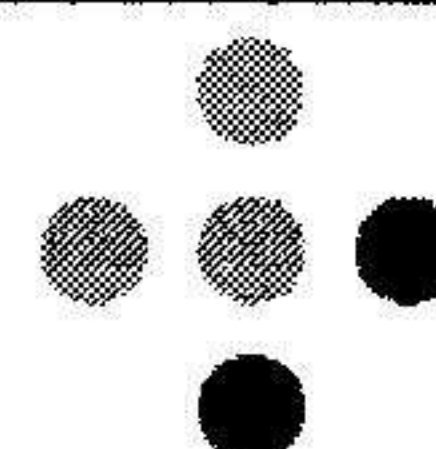
I intervjuet skal studenten samle kunnskap om viktige utfordringer med å følge kostrådene slik pasienten med FH ser det. Intervjuet vil finne sted i Lipidklinikken lokaler. Intervjuene skal tas opp, skrives ned og analyseres kvalitativt. Intervjuene vil foregå etter en fastsatt plan, men vil likevel ha preg av en vanlig samtale om kosthold og ulike forhold knyttet til det. Intervjueren er ikke ansatt ved Lipidklinikken. Intervjuene vil ta 1-1,5 time for prosjektdeltakeren og vil foregå utenom de vanlige undersøkelsene.

Studien er forhåndsvurdert av Regional etisk komité for medisinsk og helsefaglig forskningsetikk Sør-øst og Oslo universitetssykehus.

Deltakelsen er frivillig. Dersom du ikke ønsker å delta behøver du ikke foreta deg noe.

Hva skjer med informasjonen om deg?

Intervjuene blir skrevet for analyse. Intervjuene vil være aidentifisert, det vil si at de blir merket med en kode, ditt navn eller fødselsnummer vil ikke være påført. Prosjektledere og masterstudenten vil mens prosjektet pågår kunne finne din identitet ved hjelp av en kodenøkkel, men denne vil bli makulert etter at prosjektet er avsluttet. Informasjon gitt under intervjuet vil ikke bli lagret i pasientens journal.



Dersom du kan være interessert i å bli med på et slikt intervju eller ønsker å vite mer, kan du kontakte masterstudent Silje Isabelle Søbye på E-mail: siljesoebye@hotmail.com eller på sms til telefon 415 45 645.

Det kan være du blir kontaktet per telefon for å bekrefte at invitasjonsbrevet er mottatt.

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Vennlig hilsen

Kjetil Retterstøl
overlege dr. med.
(sign)

Forespørsel om deltakelse i forskningsprosjektet

Familiær hyperkolesterolemi. Livskvalitet og ernæring.

Bakgrunn og hensikt

Dette er et spørsmål til deg om å delta i en forskningsstudie for å studere om det er noen spesielle kostutfordringer hos ungdom og unge voksne med familiær hyperkolesterolemi (FH).

Hva innebærer studien?

Studien innebærer å delta på et intervju med en masterstudent i klinisk ernæring. I intervjuet vil dere snakke om kosthold og forhold rundt dette, prosjektet handler om å undersøke om det er noen spesielle utfordringer knyttet til kostholdet.

Mulige fordeler og ulemper

Kostbehandling er en sentral del av behandlingen av FH. Prinsippene i den ordinære kostbehandlingen som gis ved FH følger i hovedsak vanlige råd for et sunt kosthold slik som de sammenfattet i de nasjonale kostrådene. Studien kan bidra økt kunnskap om hvordan en kan tilrettelegge kostveiledning for unge med FH.

Hva skjer med prøvene og informasjonen om deg?

Alle opplysningene fra intervjuet vil bli behandlet uten bruk av navn og fødselsnummer eller andre direkte gjenkjennerende opplysninger. En kode knytter deg til dine opplysninger og prøver gjennom en navneliste. Det betyr at opplysningene er aidentifisert

Det er kun autorisert personell knyttet til prosjektet som har adgang til navnelisten og som kan finne tilbake til deg. tidspunkt for sletting av informasjonen som samles er satt til 1.1 2017. Det vil ikke være mulig å identifisere deg i resultatene av studien når disse publiseres i form av en masteroppgave.

Frivillig deltakelse

Det er frivillig å delta i studien. Du kan når som helst og uten å oppgi noen grunn trekke ditt samtykke til å delta i studien. Dette vil ikke få konsekvenser for din videre behandling. Dersom du ønsker å delta, undertegner du samtykkeerklæringen på siste side. Om du nå sier ja til å delta, kan du senere trekke tilbake ditt samtykke uten at det påvirker din øvrige behandling. Dersom du senere ønsker å trekke deg eller har spørsmål til studien, kan du kontakte masterstudent Silje Søybye eller Kjetil Retterstøl

Kjetil Retterstøl
Overlege, professor
Universitetet i Oslo
og Lipidklinikken
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Masterstudent i ernæring
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Ytterligere informasjon om studien finnes i kapittel A – utdypende forklaring av hva studien innebærer.

Ytterligere informasjon om biobank, personvern og forsikring finnes i kapittel B – Personvern, biobank, økonomi og forsikring.

Samtykkeerklæring følger etter kapittel B.

Kapittel A- utdypende forklaring av hva studien innebærer

Kriterier for deltakelse

Personer i alderen 16 til 25 år med diagnosen familiær hyperkolesterolemi.

Bakgrunnsinformasjon om studien

Kostbehandling er særlig fokus på å redusere inntaket av mettet fett, transfett og kolesterol ved FH. I en tidligere studie oppga pasienter med FH at kostbehandlingen opplevdes som mer belastende enn medikamentell behandling til tross for at mange brukte maksimale doser av lipidsenkende behandling. Målsetningen med dette prosjektet er å studere hva som stresser pasientene og om det er mulig å kommunisere kostråd og kostbehandling på en måte som ikke medfører slikt stress.

Prosjektet er en masteroppgave for en student i klinisk ernæring. Studenten skal utvikle en intervjuguide som skal benyttes til at samme student skal intervju 10-15 ungdommer/unge voksne med FH. Intervjuene skal skrives ned og analyseres med kvalitative forskningsmetoder. Basert på analysen av intervjuene samt erfaring fra kliniske ernæringsfysiologer og leger på Lipidklinikken skal det undersøkes om det er mulig eller hensiktsmessig å utvikle et enkelt spørreskjema for å identifisere sosiale og psykologiske utfordringer i kostbehandlingen.

Tidsskjema – hva skjer og når skjer det?

I forbindelse med konsultasjonen på Lipidklinikken vil en masterstudent i klinisk ernæring intervju deg i 1 til 1,5 time.

Mulige fordeler

Studien kan bidra økt kunnskap om hvordan en kan tilrettelegge kostveiledning for unge med FH.

Mulige ubehag/ulemper

Intervjuet tar 1- 1,5 time å gjennomføre.

Vitenskapelig signifikans/klinisk signifikans: Lipidklinikken har samlet en av verdens største pasientpopulasjoner på FH. Det er et av de få stedene der det er mulig å rekruttere et tilstrekkelig stort antall barn og unge. Dette er et godt utgangspunkt for ny kunnskap.

Kapittel B - Personvern, biobank, økonomi og forsikring

Personvern

Opplysninger som registreres om deg er fra intervjuet. Det blir gjort lydopptak av intervjuet som etterpå vil skrevet ned og analysert. De enkelte intervjuene vil ikke være påført navn eller personnummer, men vil bli merket med en kode. Koden som skal gjøre det mulig å koble deg til intervjuet er på et papir som oppbevares innelåst på et kontor på Lipidklinikken og som slettes senest 1.1.2017

Oslo universitetssykehus ved administrerende direktør er databehandlingsansvarlig.

Rett til innsyn og sletting av opplysninger om deg og sletting av prøver

Hvis du sier ja til å delta i studien, har du rett til å få innsyn i hvilke opplysninger som er registrert om deg. Du har videre rett til å få korrigert eventuelle feil i de opplysningene vi har registrert. Dersom du trekker deg fra studien, kan du kreve å få slettet innsamlede prøver og opplysninger, med mindre opplysningene allerede er inngått i analyser eller brukt i vitenskapelige publikasjoner.

Økonomi

Dette er et masterprosjekt uten noen sponsorer.

Forsikring

Deltakere er forsikret gjennom pasientskadeerstatningsordningen.

Informasjon om utfallet av studien

Deltakere som ønsker det har rett til å få informasjon om utfallet/resultatet av studien.

Samtykke til deltakelse i studien

Jeg er villig til å delta i studien

(Signert av prosjektdeltaker, dato)

Jeg bekrefter å ha gitt informasjon om studien

(Signert, rolle i studien, dato)

Intervjuguide

Introduksjon

Litt uformell prat, presentasjon av tema. Forklare begreper.

Praktiske opplysninger om tid, lydbåndopptaker, anonymitet og deres rolle som intervjuobjekter, samt min rolle som forsker og intervjuer. Underskriving av samtykkeskjema.

Interview guide

Introduction

Informal chat, presenting subjects. Explaining concepts.

Practical information about timeframe, tape recorder, anonymity and their role as interviewees, as well as my role as a researcher and interviewer. Signing the consent form.

TEMA	HOVEDSPØRSMÅL	UNDERSPØRSMÅL	HJELPESPØRSMÅL
SUBJECT	MAIN QUESTIONS	SAMPLE QUESTIONS	ADDITIONAL QUESTIONS
INTRO	Kan du fortelle litt om deg selv?	Alder, bosted, boform, sivilstatus, yrke, diagnosetidspunkt, medisinerer?	Hvor du bor og med hvem, hva du gjør, hvor lenge du har hatt FH, hvilke medisiner osv..
	Please tell a bit about yourself?	Age, residence, living arrangements, marital status, occupation, time of diagnosis, medication?	Where you live and with whom, what you do, how long you've had FH, which medicines etc..
	Hva gjorde du i går?	Hva spiste du i går? I hvilken grad var valgene av matvaren preget av at du har FH?	Til de forskjellige måltidene?
	What did you do yesterday?	What did you eat yesterday? To what extent were the choices of foods influenced by having FH?	For the different meals?
	Hva liker du best å spise?	Hva er yndlingsretten din? Hvor ofte spiser du det?	
KOSTVANER/ DIETARY HABITS	What do you like to eat?	What is your favorite dish? How often do you eat it?	
	Hvem lager maten?		
	Who cooks the food?		
	Er du glad i mat?	Opplever du stress med mat?	
		Opplever du at du koser deg med mat?	
Do you love (like) food?	Do you experience stress with food? Do you feel that you are enjoying food?		
KOSTRÅDGIVNING NUTRITION COUNSELING	Hvilke konkrete kostråd har du fått?	Hvordan har du opplevd det å få kostråd fra Klinisk ernæringsfysiolog?	
	What specific dietary advice have you been given?	How have you experienced getting dietary advice from a dietitian?	
	Hvordan synes du oppfølgingen har vært på de rådene du har fått på kosthold og fysisk aktivitet?	Hvordan har du opplevd oppfølging fra Lipidklinikken? Hvordan har du opplevd oppfølging fra fastlege og lokale helsetjenester?	
	How has the advice you have been given on diet and physical activity been followed up?	How have you experienced supervision (following up) at the Lipid Clinic? How have you experienced support from physicians and local health services?	
	Har du noen forslag til hvordan dette kunne	Hvordan rådene blir gitt eller hvordan de blir fulgt opp?	

vært gjort på en annen måte?	Hva en bør si til nye pasienter?	
Do you have any suggestions on how this could have been done differently?	How advice is given or how they are followed up? What one should say to new patients?	
Hvordan opplever du kostråd i media og fra venner sammenholdt med råd fra Lipidklinikken?	I hvor stor grad føler du at du kan vite hvilke råd som er best for deg? Hvilke råd stoler du mest på; råd fra KEF, legen, blogger eller media? Hvordan opplever du det dersom andre rundt deg gir råd om mat?	Hva gjør du da? (eksempel: oppleves det privat, hjelpende, slitsomt)
What do you think of dietary advice in the media and from friends in comparison with advice from the Lipid Clinic?	To what extent do you feel that you can decide what advice that is best for you? What advice do you trust most; advice from KEF, doctor, blogs or media? How do you experience when others around you give advice about food?	What do you do? (example: does it feel private, helping, exhausting)
I hvor stor grad synes du at du følger de rådene du får i praksis?	Hva tenker du om dette? Hvor mye av rådene må du følge for at du selv skal være fornøyd?	
To what extent do you think that you follow the advice given?	How do you feel about this? To what extent do you need to follow the advices in order for you to feel satisfied?	
Hva motiverer deg til å følge rådene?	Hva ønsker du selv å oppnå? Hva tenker du er konsekvensene på kort sikt om du ikke følger rådene? Hva tenker du er konsekvensene på lang sikt om du ikke følger rådene? Hva betyr dette for deg?	
What motivates you to follow the advice?	What do you want to achieve? What do you think are the consequences in the short term if you do not follow the advice? What do you think are the consequences in the long term if you do not follow the advice? What does this mean for you?	
Hvordan synes du det er å følge kostrådene?	Hvilke råd synes du er lett å følge? Hvilke råd synes du er vanskelig?	Hvorfor er de lette, når, sammen med hvem? Hvorfor er de vanskelige, når, sammen med hvem?

ETTERLEVELSE OG SAMVITTIGHET/ COMPLIANCE AND CONSCIENCE

Har dette endret seg underveis, hva som er lett og vanskelig?

<p>What do you feel about followeing dietary recommendations?</p>	<p>What advice do you think is easy to follow? What advice do you think is hard? Has this changed along the way, what is easy and what is difficult?</p>	<p>Why are they easy, when, together with whom? Why are they hard, when, together with whom?</p>
<p>Hvordan synes du om tilretteleggingen i miljøet er?</p>	<p>Hvordan synes du det er å finne kolesterolvennlig mat på offentlige spisesteder, slik som kantine, kafe og restauranter?</p>	<p>(eksempel: mat i barnehage, kantine, jobb.)</p>
<p>Hvordan er det når du spiser sammen med jevnaldrende venner?</p>	<p>Takker du ja/nei? Forklarer du hvorfor?</p>	
<p>Hvordan opplever du situasjoner der du blir servert mat du vet ikke er bra?</p>	<p>Føler du det stilles spørsmål? Hva gjør du i disse situasjonene? Hvilke reaksjoner og følelser forbinder du med disse situasjonene?</p>	
<p>Er det noen andre situasjoner du synes er vanskelig?</p>	<p>Hvilken betydning har hvem som er rundt deg, eget humør, stress eller lignende for hva du velger å gjøre?</p>	
<p>MILJØ OG SITUASJONER/ ENVIRONMENT AND SITUATIONS</p>	<p>Hvilke løsninger?</p>	
<p>What do you think of adaptation of the environment is?</p>	<p>How do you think it is to find cholesterol friendly foods at public eating places, such as canteen, cafe and restaurants?</p>	<p>(example: food in kindergarten, canteen, job.)</p>
<p>What do you feel about eating together with peers friends?</p>	<p>Thank you yes / no? You explain why?</p>	
	<p>Feeling is questioned?</p>	
	<p>What do you do in these situations?</p>	
	<p>Which reactions and feelings you associate with these situations?</p>	
	<p>What is the significance who is around you, your mood, stress or similar to what you choose to do?</p>	
	<p>What solutions?</p>	
<p>UTFORDRINGER/ CHALLENGES</p> <p>Er det noe du opplever som vanskelig ved å ha FH? /hva er mest tyngende?</p>	<p>Ferdigheter til å håndtere FH? Rent praktisk.</p> <p>Sosiale aspekter ved FH?</p>	<p>(sette av tid til å handle og lage mat, kunnskap om diett, tilgjengelighet av riktig mat, økonomi.)</p> <p>(Stressende hendelser på</p>

jobb/privat, relasjoner til andre, andres spisemønstre/misunnelse, fristende situasjoner.)

Motivasjon til å håndtere FH?

(Eksempel: lyst på mat man ikke kan spise, kontroll i situasjoner, håndtering av stress eller psykiske problemer som ødelegger fokus.)

Tanker rundt FH:

(Eksempel: Risiko, fremtiden, familiens helse, fremtidig graviditet, at FH er genetisk.)

Is there anything you perceive as difficult by having FH? / What is most burdensome?

Skills to handle FH? In purely practical.

(Setting aside time to shop and cook, knowledge about diet, availability of appropriate food, finance.)

Social aspects of FH?

(Stressful events at work / private relationships to others, others eating pattern / envy, tempting situations.)

Motivation to handle FH?

(Example: fancy food you cannot eat, control situations, dealing with stress or psychological problems that destroy the focus.)

Thoughts around FH?

(Example: Risk, future, family health, future pregnancy, that FH is genetic.)

Hvem tok initiativ til at du ble testet?

(eksempel: Familie, lege, du selv, eller noen andre)

DIAGNOSTISERING/ DIAGNOSIS

Who took the initiative to have you tested?

(Example: Family physician, you or someone else)

Hvordan opplevde du å få vite at du hadde FH?

Husker du da du fikk vite det?

Hva tenkte du da?

How did you come to know that you had FH?

Do you remember when you were told about you having FH?

What did you feel about it?

Hva betyr det for deg å ha FH?

What does it mean for you to have FH?

Skulle du ønske du ikke visste at du hadde FH? I så fall hvorfor?

Do you wish you never knew you had FH? If so, why?

Synes du tidspunktet du fikk diagnosen var riktig?

Hadde det vært bedre om du hadde fått vite det tidligere eller senere?

Do you think the time you were diagnosed was right?

Had it been better if you had learned it earlier or later?

Hvordan tror du matvanene dine hadde vært dersom du ikke hadde hatt FH?

Hva hadde vært likt eller ulikt?)

(eksempel: kose seg med mat, feire, feste, spise snacks, hverdagsmat, mat på skole/jobb

Tror du at du hadde hatt de samme eller andre treningsvaner dersom du ikke hadde fått FH?

Har det påvirket hva du spiser eller i hvilken grad du er aktiv/trener og i så fall hvordan?

Hvordan har det virket inn på hvordan du tenker om matvaner/trening?

(eksempel: verdi, fokus, motivasjon)
Hvordan påvirker FH din matglede?

**BETYDNING AV FH FOR VANER/
SIGNIFICANCE OF FH FOR HABITS**

How do you think you're eating habits would have been if you had not had FH?

What had been equal or not?)

(Example: indulge in food, celebrate, party, eat snacks, every day, food at school / work

Do you think you would have had the same or other exercise habits if you had not gotten FH?

Has it affected what you eat or the extent to which you are active / exercising and if so, how?

How has it affected the way you think about eating habits / training?

(Example: value, focus, motivation)
How does FH affect your enjoyment?

**MEDIKAMENTELL BEHANDLING/
MEDICINAL TREATMENT**

Hvor viktig tenker du at sunn mat og livsstil er sammenlignet med riktig medisin?

How important do you think that healthy food and lifestyle is compared with the right medicine?

Hvordan synes du det er å følge medisin delen av behandlingen?

Hvordan synes du det er å ta medisiner?

Hvordan har du det med bivirkninger?

Har du hatt problemer med hjertet?

How do you think it is to follow the medical part of the treatment?

How do you think it is taking medication?

How are you with side effects?

Have you had problems with your heart?

Hva betyr livskvalitet/et godt liv for deg?

Hva ligger i begrepet?

Hvordan påvirker FH din livskvalitet?

Hva trenger du for å ha god livskvalitet?

Hadde livet vært annerledes uten FH?

What does quality of life / a good life mean for you?

What is the concept (term)?

How does FH influent your quality of life?

What do you need to have good quality of life

Do you think life would be different without FH?

I hvor stor grad snakker du til andre ellers om at du har FH?

Hvem snakker du mest med om FH?

(eksempel: familie, venner, grad av åpenhet ovenfor andre)

Hvem rundt deg vet at du har FH?

To what extent do you talk to others about having FH?

Who are you talking most with about FH?

(example: family, friends, degree of openness towards others)

Who around you know that you have FH?

Hvordan følges rådene om mat opp i familien?

Hvem i familien følger rådene?

I hvor stor grad tas det hensyn ved fest og høytid?

I hvor stor grad opplever du støtte fra familien?

Har det vært noen konflikter rundt kostråd innad i familien og i så fall hvilke?

Hva betyr støtte fra andre for deg i dine valg?

LIVSKVALITET/ QUALITY OF LIFE

SOSIAL STØTTE/ SOCIAL SUPPORT

How is the advice about food followed up in the family?

Who in your family follows the advice?

To what extent is it taken into account at parties and holidays?

To what extent do you experience support from your family?

Has there been any conflicts around dietary advice within the family and if so, which?

What does the support from others mean for you in your choices?

**AVSLUTNING/
ENDING**