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Determinants for Healthy Lifestyle of Patients with Familial Hypercholesterolaemia

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Abstract
Lifestyle modification is a pivotal intervention for Familial Hypercholesterolaemia (FH). This study aims to describe the lifestyles (physical activity and healthy diet) and their associations with sociodemography, illness characteristics, psychological elements, family support and level of barrier. 100 participants were given Pro forma questionnaires to assess sociodemography and illness characteristics. The lifestyles, psychological elements, family support and level of barrier were assessed using the Theory of Planned Behaviour questionnaire. The determinants of healthy lifestyles include the status of receiving treatment, level of barrier and intention for behavioural change. The findings may inform the strategy for lifestyle modification of FH patients.

Keywords: Familial Hypercholesterolaemia; lifestyle; physical activity; healthy diet

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1.0 Introduction
Familial Hypercholesterolaemia (FH) is an important risk factor for cardiovascular diseases (CVDs); the leading causes of morbidity and mortality worldwide. Globally, the prevalence of FH is around 1: 500-200. In Malaysia, recent National Health and Morbidity Survey (2019) indicated that hypercholesterolemia is one of the significant risks for cardiovascular disease. The prevalence of hypercholesterolemia is 38.1%; indicating one in three Malaysians may have this condition (National Institute of Health, Malaysia (2020). Other major risk factors are diabetes mellitus, obesity and hypertension. FH is an essential cause of hypercholesterolemia among the Malaysian population, with an estimated frequency of 1:100 (Vallejo-Vaz et al., 2018). Researchers have identified various causes of hypercholesterolaemia; one of the essential causes is primary hypercholesterolaemia, including FH. It is primary dyslipidaemia which involved a genetic mutation in cellular transportation and catabolism of LDL-C, such as LDL-receptor (LDLR), apolipoprotein B (APOB), proprotein convertase subtilisin/kexin type 9 (PCSK9) and low-density lipoprotein receptor adaptor protein 1 genes (LDLRAP1) (Al-Khateeb et al., 2016). On the other hand, secondary dyslipidaemia is often associated with the elevated LDL-C which most often caused by external factors including taking high-fat diet, lack of physical activity and exercise leading to obesity, smoking or, from other diseases such as hypothyroidism, liver disease or chronic renal failure (Al-Khateeb et al., 2016).

FH may lead to severe CVDs and other complications, and if untreated, FH patients will suffer reduced life expectancy by up to 30 years compared those without FH (Alonso, Mata, & Mata, 2005). Without early treatment, CVDs and other complications caused FH patients to have a poor quality of life (Razali, Ismail, Yung et al., 2019). Hence, preventive measures of CVDs including taking lipid-

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lowering agents, stress management and lifestyle interventions (such as taking healthy diet, performing vigorous physical activities, exercise and smoking cessation) are vital. Moreover, positive illness perceptions and belief on the illness is crucial for adherence to treatment and early preventive measures (Razali, Ismail, & Abdullah et al., 2019). In order to ensure life-long behavioural modification, the underlying health-related psychological process that shapes the intention for behavioural changes must well be understood to inform effective interventions (Hagger et al., 2016). These underlying psychological processes in behavioural change has been explained by many theories (Bandura, 1986; Prochaska, 1998; Ajzen, 1985). One of the popular theories is the Theory of Planned Behaviour (TPB) which was introduced by Icek Ajzen in 1985. The theory suggested that a 'behaviour' is dependent on one's intention to perform the behaviour and the intention is dependent on the attitude (beliefs and values about the outcome of the behaviour), subjective norms (beliefs about what other people think the person should do or general social pressure) and perceived behavioural control or one's perceptions of his ability or feelings of self-efficacy to perform the behaviour (Ajzen, 1985, 2011). To date, there is still sparse knowledge and awareness of these concepts among both the public, patients and health practitioners. Hence, this study aims to: i) describe the lifestyle of FH patients (including engagement with physical activity and taking healthy diet) and, ii) determine the associations between the lifestyles and sociodemographic factors, illness characteristics, the underlying health-related psychological elements (including intention, attitude, subjective norms and perceived behavioural control), family support and level of barrier.

2.0 Methodology

2.1 Study design, setting and data collection

This study was a cross-sectional study which recruited participants from the Specialist Lipid and Coronary Risk Prevention Clinics in a Teaching Hospital in Malaysia. Convenient sampling was used, and the participants aged 18 years or more who were patients diagnosed with FH according to Dutch Lipid Clinic (DLC) criteria were enrolled. The DLC criteria is a validated set of criteria based on the patient's family history of premature cardiovascular disease (CVD) in their first-degree relatives, personal coronary heart disease (CHD) history, their untreated LDL-c level and physical signs such as tendon xanthomata or arcus cornealis prior to the age of 45. Prior to the commencement of the study, written informed consent was granted from all participants. The study was approved by the Institutional Research Ethics committee (600-RMI (5/1/6).

2.2 Assessment tools

Sociodemographic background, illness characteristics, family support and barrier for performing physical activity and taking healthy diet were assessed using self-reported pro forma questionnaires. Sociodemographic variables include information regarding gender, age, marital status, level of education and their total household income per month. Illness characteristics include the presence of CVDs, type of CVDs (including coronary heart disease, angina, stroke atherosclerosis and peripheral vascular disease) treatment for FH, and risk factors for coronary artery disease (including smoking status, high blood pressure, depression and high stress). The underlying health-related psychological concepts (such as intention, attitude, subjective norms, perceived behavioural control) were assessed using questionnaires constructed based on the TPB (Ajzen, 2011).

2.3 Statistical Analysis

Statistical Package for the Social Sciences version 24 was used to analyse the data. Data were mostly recategorised into dichotomous data. The associations between sociodemographic factors, illness characteristics, domains of TPB (attitude, subjective norms, perceived behavioural control and intention), family support and level of barrier and domains of lifestyles (engagement with physical activity and taking healthy diet) were analysed using Chi-Square analysis. Multiple regressions were carried out to identify the determinants of engagement with physical activity and taking healthy diet.

3.0 Results

3.1 Sociodemography

A total of hundred participants (37% male and 63% female), predominantly in the late forties (mean±SD: 49.8±11.4 years old) and ever-married individuals (92%) participated in the study. They were mainly from a lower socioeconomic position with which 55% of the participants had a total household income less than RM3000 a month, and 52% of studied participants attained only up to the level of secondary education (Refer to Table 1).

3.2 Illness characteristics

Of the total participants who had FH, 41% had CVDs; mainly coronary heart disease (n=35; 85.4%), angina (n=8; 19.5%), atherosclerosis (n=4; 9.8%), stroke (n=4; 9.8%) and one participant had peripheral arterial disease. About two-thirds (69%) of the participants received lipid-lowering agents. More than a third (40%) of the participants had hypertension, 13% were smokers, and 8% reported feeling stressed up and complained of feeling depressed.

3.3 Lifestyle pattern

The majority 66(68.8%) of FH patients in the study reported that they had been taking healthy diet. However, less than half of the patients reported that they engaged with physical activity (Figure 1). Only 13 (13%) of FH patients in the study were still smoking during the study period.

Table 1: Sociodemographic Background of the Participants

Variable	N	%
Sociodemography		
Gender		
Female	37	37.0
Male	63	63.0
Marital status		
Ever married	92	92.0
Unmarried	8	8.0
Education		
Pre-university and university	48	48.0
Secondary	44	44.0
Primary and below	8	8.0
Total household income per month (RM)		
<3000	55	55.0
3001-10000	36	36.0
>10000	9	9.0
Illness Characteristics		
Cardiovascular disease		
Yes	41	41.0
No	59	59.0
Types of CVS disease		
Coronary heart disease	35	35.0
Angina	10	10.0
Atherosclerosis	5	5.0
Stroke	4	4.0
Peripheral vascular disease	1	1.0
Currently received treatment for FH		
Yes	69	69.0
No	31	31.0
Present of risk factor		
Smoker	13	13.0
High blood pressure	40	40.0
Depression	8	8.0
High stress	8	8.0

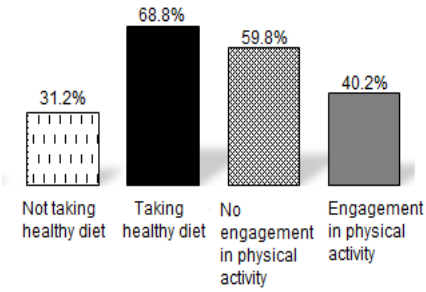

Figure 1. Percentages of the Lifestyles (Engagement in Physical Activity and Taking Healthy Diet)

3.4 Determinants of the lifestyle of FH patients

3.4.1 Factors for engagement in physical activity

There were significant associations between the engagement with physical activities, and the status of receiving treatment, the intention to perform the physical activity and the level of barrier. FH patients engaged in physical activity were significantly higher ($X^2(1) = 4.895$; p=0.027) among those who were receiving treatment (n=22;56.4%) than those who were not (n=17(43.6%). Those who engaged in physical activity were also significantly higher ($X^2(1) = 11.379$; p=0.001; Yates correction:$X^2(1) = 9.734$; p=0.002) among FH patients who had intention (n=37;68.3%) than those who had no intention to perform the physical activity (n=18(32.7%). Moreover, in terms of the level of barrier, the patients engaged in physical activity were significantly higher ($X^2(1) = 15.303$; p=0.000; Yates correction: ($X^2(1)=13.663$;p=0.000) among those who had a low level of barrier (n=34;87.2%) than those who had a high level of barrier (n=5;12.8%) (Refer to Table 2).

Multiple logistic regressions were performed to identify the determinants for engagement with physical activity. The independent variables included in the model development were gender, age, total household income, presence of CVD, the status of receiving treatment, intention, family support and the level of barrier. The Omnibus test for model coefficient showed that the model was significant

(X^2 (8) = 34.929; p<0.001; the Nagelkerke R^2=0.413; Cox & Snell R^2=0.305) and the predictive accuracy of the model for the training sample was 78.10%. There was no multicollinearity exist between independent variables; the values for tolerance were more than 0.1, and VIF was less than 10 for each variable. The significant determinants for engagement of physical activity of the FH patients were the intention to perform (B=2.213; AOR=9.145; p=0.020) and the level of barrier (B=-1.892; AOR=0.151; p=0.002).

Table 2: Engagement with Physical Activity and Possible Contributing Factors

Variable:	Physical activity	
	Yes	No
Sociodemography		
Age	38(49.5 ±13.2)	58(49.9 ± 9.3)
Gender		
Female	12(30.8%)	24(41.4%)
Male	27(69.2%)	34(58.6%)
Marital status		
Ever married	35(89.7%)	55(94.8%)
Unmarried	4(10.3%)	3(5.2%)
Education		
Pre-university and university	34(61.8%)	11(26.8%)
Secondary	17(30.9%)	27(65.9%)
Primary and below	4(7.3%)	3(7.3%)
Income (RM)		
<3000	21(53.8%)	32(55.2%)
3001-10000	17(43.6%)	18(32.1%)
>10000	1(2.6%)	8(13.8%)
Illness Characteristics		
CVD		
Presence	15(87.2%)	26(44.8%)
Absent	24(12.8%)	32(55.2%)
Receiving FH Treatment *		
Yes	22(56.4%)	45(77.5%)
No	17(43.6%)	13(22.4%)
Comorbidity		
Single	14(93.3%)	20(71.4%)
Presence	1(6.7%)	8(28.6%)
Risk Factors		
Single	17(85,0%)	23(71.9%)
Multiple	3(15.0%)	9(2.8%)
Psychological element in Theory of Planned Behaviour		
Subjective norms		
Yes	38(97.4%)	55(96.5%)
No	1(0.6%)	2(3.5%)
Perceived behavioural control		
Yes	37(94.9%)	55(98.2%)
No	2(5.1%)	1(1.8%)
Attitude		
Good	39 (100.0%)	56 (96.6%)
Bad	0 (0%)	2 (3.4%)
Excited	39 (100.0%)	55 (58.5%)
Boring	0 (0%)	3 (100%)
Fun	39 (100.0%)	53 (94.8%)
Unpleasant	0 (0.0%)	5 (5.2%)
Intention**		
Yes	37(68.3%)	40(95.2%)
No	18(32.7%)	2(4.7%)
Family Support		
Yes	35(89.7%)	45(77.6%)
No	4(10.3%)	13(22.4%)
Level of Barrier**		
Low	34(87.2%)	28(48.3%)
High	5(12.8%)	30(51.7%)

*Chi-square tests were used in the analyses of associations between engagement with physical activity and the possible determinants except for age. Yates corrections were performed when the cell frequency was less than 10. * p-value <0.05.; ** p-value <0.01.*

3.4.2 Factors for taking healthy diet

There were significant associations between taking healthy diet and the status of receiving treatment and the level of barrier. FH patients taking healthy diet were significantly higher (X^2(1) =8.107; p=0.004) among those who were receiving treatment (n=57;78.8%) than those who were not (n=14;21.2%). Those who were taking healthy diet were also significantly higher (X^2 (1) =7.822; p=0.005; Yates correction: (X^2 (1) =6.465; p=0.011) among FH patients who had low level of barrier (n=55;83.3%) than those who had high level of barrier (n=11;16.7%). Refer to Table 3 for further details.

In the model development, we included gender, age, total household income, presence of CVD, the status of receiving treatment, and level of barrier in the analysis. The Omnibus test for model coefficient showed that the model was significant (X^2 (6) = 19.086; p<0.001; the Nagelkerke R^2=0.257; Cox & Snell R^2=0.182) and the predictive accuracy of the model for the training sample was 75.80%. There was no multicollinearity exist between independent variables; the values for tolerance were more than 0.1, and VIF was less than 10 for each variable. The significant determinants for taking healthy diet in FH patients were the status of receiving treatment (B=1.376; AOR=3.961; p=0.024) and the level of barrier (B=-1.650; AOR=0.192; p=0.003).

Table 3: Status of Taking Healthy Diet and Possible Contributing Factors

Variables	Healthy Diet	
	Yes	No
Sociodemography		
Age	38(49.5 ±13.2)	58(49.9 ± 9.3)
Gender		
Female	12(30.8%)	24(41.4%)
Male	27(69.2%)	34(58.6%)
Marital status		
Ever married	35(89.7%)	55(94.8%)
Unmarried	4(10.3%)	3(51.7%)
Education		
Pre-university and university	34(61.8%)	11(26.8%)
Secondary	17(30.9%)	27(65.9%)
Primary and below	4(7.3%)	3(7.3%)
Income (RM)		
<3000	21(53.8%)	32(55.2%)
3001-10000	17(43.6%)	18(31.0%)
>10000	1(2.6%)	8(13.8%)
Illness Characteristics		
CVD		
Presence	31(47.0%)	10(33.3%)
Absent	35(53.0%)	20(66.7%)
Receiving FH Treatment *		
Yes	52(78.8%)	15(50.0%)
No	14(21.2%)	15(50.0%)
Comorbidity		
Single	26(81.3%)	8(72.7%)
Presence	6(18.7%)	3(27.3%)
Risk Factors		
Single	31(77.5%)	9(75.0%)
Multiple	9(2.25%)	3(25.0%)
Psychological element in Theory of Planned Behaviour		
Subjective norms		
Yes	64(97.0%)	28(96.6%)
No	2(3.0%)	1(3.4%)
Perceived behavioural control		
Yes	64(97.0%)	28(93.3%)
No	2(3.0%)	2(6.7%)
Attitude		
Good	66 (71.7%)	26 (86.7%)
Bad	0 (0%)	4 (13.3%)
Excited	64 (98.5%)	25 (83.3.1%)
Boring	1 (1.5%)	5 (16.7%)
Fun	62 (96.8%)	24 (80.0%)
Unpleasant	2 (3.1%)	6 (20.0%)
Intention		
Yes	64(97.0%)	22(73.3%)
No	2(3.0%)	8(26,7%)
Family Support		
Yes	62(94.0%)	23(79.3%)
No	4(6.0%)	6(20.6%)
Level of Barrier**		
Low	55(83.3%)	17(56.7%)
High	11(16.7%)	13(43.3%)

*Chi-square tests were used in the analyses of associations between taking healthy diet and the possible determinants except for age. Yates corrections were performed when the cell frequency was less than 10. * p-value <0.05.; ** p-value <0.01.*

4.0 Discussion

This study is essential to inform clinicians of the possible factors that influence the lifestyles of FH patients. We found that the lifestyle of our FH patients relates to their illness condition, i.e. their status of receiving treatment. It is easy to speculate that those FH patients

who were receiving treatment were among those who have good insight and awareness of the needs for treatment (Eriksson et al., 2006). Perhaps, the mediating factor is the fear of having the complication may motivate FH patients who were receiving treatment to have a better healthy lifestyle. FH patients who received treatment may have continuous counselling on the need for healthy lifestyle every time they visit health care facilities. It is crucial for clinicians to provide counselling on both adherence to medications and a healthy lifestyle as part of the intervention for FH patients.

In our study, barriers hindered FH patients from having healthy lifestyles. In terms of physical activity, a local study in managing weight problem indicated that the main barriers in performing exercise and physical activity include lack of family and friend's involvement, poor weather, lack of discipline and suitable time as well as a financial problem (Ibrahim et al., 2013). For healthy diet intake, factors such as time, food taste and price were suggested to be the main challenges to comply towards dietary counselling (Sulaiman et al., 2016). Hence, it is critical to minimise barriers to ensure that FH patients maintain their lifestyle behaviour and modification. In a study examining the barriers experienced by patients with hyperlipidaemia, a group of health providers have divided the barriers into; i) provider barriers (including poor tracking and patient follow-up, poor understanding of guidelines and the literature, controversy over guideline recommendations, poor understanding of patient needs, and inadequate training in facilitating behavioural change in patients); ii) patient barriers (including poor adherence to referrals, asymptomatic nature of the diseases, linguistic and cultural difficulties, psychosocial challenges blunting efforts to adhere, poor patient's acceptance of the disease, and difficulty of lifestyle changes); and iii) practice/system barriers (including poor multidisciplinary cooperation, documentation burdens, difficulty educating patients at the right educational level, and difficulty coordinating care with the hospital) (Cook et al., 2006). Addressing all these barriers is crucial for the comprehensive management of FH patients.

A few scholars in psychology have demonstrated through their proposed theory of the link between intention and lifestyle behaviour (Fishbein, 1980; Fishbein & Ajzen, 1975; Ajzen, 1985, 1991; Triandis, 1980; Rogers, 1983). Our study supported this association and indicated that FH patients should have strong intention in order to engage with physical activities. In other study investigating lifestyle of FH patients using integrated psychological model, Hagger and colleagues (2016) have demonstrated that not only the intention but also attitude plays as an essential mediator for lifestyle changes in FH patients. Given the importance of intention in behavioural modification strategy, clinicians in particular health psychologist should enhance FH patients understanding on this psychological element when providing counselling on the self-management support service for FH patients.

Our findings also supported and added to other determinants that were found by other researchers who examined the lifestyle of general populations (Chan et al., 2015; Cheah & Poh, 2014). In their studies, other factors influencing lifestyles include age, income, gender, education, marital status, region, house locality, job characteristics, and medical conditions have been suggested (Cheah & Poh, 2014). In order to ensure FH patients have optimum quality of life, apart from practising health lifestyle, FH patients should also equipped themselves with positive perceptions and enough knowledge on the illness itself and its complications (Razali et al., 2019).

5.0 Conclusion and Recommendations

FH Patients who engaged with physical activity are those who were receiving treatment, experiencing a low level of barrier and had the intention to perform the physical activities. Those patients who were receiving treatment and experiencing a low level of barrier were also more likely to take a healthy diet. Further studies to understand the barriers of practising healthy lifestyle among them is crucial. Clinicians should be aware of these elements to ensure effective advice for lifestyle modification of FH patients. However, the results should be interpreted with care because this study is limited with small sample size, and we used self-perception in describing the level of engagement with physical activities and taking healthy diet. Furthermore, there are many other cultural beliefs and perceptions that may not be captured by the questionnaires that may influence the lifestyles of FH patients. In future, more improvement in the study methods is required for more impactful findings.

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