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Illness Perception, Level of Education and Presence of Cardiovascular Disease among Patients with Familial Hypercholesterolaemia

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Abstract

Illness perception determines the healthy lifestyle of patients with Familial Hypercholesterolaemia (FH). Despite the availability of advanced treatment and preventive measures, there is still sparse data on illness perception of FH patients. Hence, this study aimed to describe the illness perception of FH patients and investigate its association with sociodemographic and illness-related factors. 100 FH patients were assessed using Pro forma questionnaires and revised illness perception questionnaire (IPQ-R). Illness perception of FH patients varies according to the level of education and the presence of cardiovascular disease (CVD). These findings may help clinicians to improve the interventions suitable for FH patients.

Keywords: Familial hypercholesterolaemia; illness perception; sociodemography; cardiovascular disease

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1.0 Introduction

In Malaysia, according to National Health and Morbidity Survey (2015), about half of the adults in this country may have hypercholesterolaemia, and the trend is increasing (Institute for Public Health (IPH), 2015). While various factors have been identified to cause this condition, one of the primary hypercholesterolaemia is Familial Hypercholesterolaemia (FH); an autosomal dominant inherited lipid disorder which linked to low-density lipoprotein receptor (LDLR) and apolipoprotein B100 genes mutation (Al-Khateeb et al., 2016; Azian et al., 2006).

A large percentage of CVDs is preventable through a combination of lipid-lowering medications and reduction of behavioural risk factors (Hagger, Hardcastle, Kwok & Nawawi et al., 2018a). In the past, one way of reducing unhealthy behaviour and promoting healthy lifestyles was by changing the patient's coping cognition on the illness (Hsiao, Chang, & Chen, 2012). However, since it has been shown that changing patients' illness perception leads to improved adherence to cholesterol-lowering medication (Senior, Marteau, & Weinman, 2004) and recovery following CVDs such as myocardial infarction (Petrie, Cameron, Ellis, Buick, & Weinman, 2002), it would be more effective to change patients' illness perceptions or beliefs in the very beginning rather than teaching them coping strategies much later (Hsiao et al., 2012).

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2.0 Literature Review

The self-regulation model was developed by Leventhal and colleagues (1984) to understand the processes by which people make sense of illness. It is believed that individual symptoms and emotions experienced after a diagnosis influence the perception of illness and guide subsequent coping behaviour (Leventhal et al., 1984). It is proposed that situational stimuli such as symptoms of diseases generate cognitive and emotional representations of the illness which are processed in three stages, namely the depiction of the health threat, the behaviours to cope with it and lastly the appraisal of the efficacy of these behaviours (Leventhal et al., 1984).

The five dimensions identified within the cognitive representation of illness include identity, consequences, cause, timeline and cure or control while the emotional representation includes negative reactions such as fear, anger, and distress (Witteman, Bolks, & Hutschemaekers, 2011). Strong illness identity, severe perceived consequences, low perceived controllability, and chronic perceived timeline of illness have been shown to be related to poor well-being in various chronic illnesses (Hagger & Orbell, 2003).

Assessment of patient's illness perception is vital to healthcare practitioners to individualise clinical management (Frich, Ose, Malterud, & Fugelli, 2006). The understanding of patient's illness perception assists in preventing irrelevant expectations from treatment whereby the doctor can structure the patient's complaints and further divide them according to the related diseases influenced and not influenced by the therapy (Morgan, Villiers-Tuthill, Barker, & McGee, 2014). Previous experts have demonstrated that illness belief and perception among individuals at risk for CVDs are influenced by their socio-cultural background (Beaglehole, Reddy, & Leeder, 2007; Forouhi & Sattar, 2006). It is crucial to understand these elements so that strategic planning and intervention are addressed according to local needs and expectations.

There is a gap that most of the evidence on illness perceptions have been informed by findings from Western countries and very limited information from Malaysia and its surrounding Asian countries. Without local references, the predicament may serve as a hurdle for health care workers to provide comprehensive management of FH for the local population. Only recently, understanding on FH and its correlates have gained the interest of researchers from the Asia-Pacific Region and the Southern Hemisphere including Malaysia (Pang et al., 2017; Watts et al., 2016). This 'Ten Countries Study' focused its attention to understand further about FH patients on topics such as illness perception, health literacy, diagnostic, epidemiological and service aspects and physician practices of FH (Hagger, 2018b; Pang et al., 2017; Razak et al., 2016; Watts et al., 2016). The sparse of data on illness perceptions in our local setting warrants further investigation, so that future interventions are well informed by evidence.

Recognising the limited data locally on illness perceptions among FH patients and its contributing factors, this study aimed to i) identify the pattern of illness perception of FH patients and ii) determine correlated factors for illness perceptions including the role of background sociodemography and FH illness-related factors. We hypothesised that FH patients have various patterns of illness perception and those with high education and multiple complications would have acceptable illness perception.

3.0 Methodology

A cross-sectional study was conducted, and selected participants from the Specialist Lipid and Coronary Risk Prevention Clinics in a Teaching Hospital in Malaysia using convenient sampling. Participants include patients diagnosed with FH according to Dutch Lipid Clinic Criteria (DLCC) and aged 18 years or more. The DLCC 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 levels and physical signs such as tendon xanthomata or arcus cornealis before the age of 45. Before 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).

Sociodemographic background and illness-related factors 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. Information gathered about their illness characteristics including 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).

Participants' illness perception was measured by a revised illness perception questionnaire (IPQ-R) (Moss-Morris et al., 2002). The questionnaire was divided into three subdivisions. The first subdivision which asks questions about 'identity', lists some potential physical symptoms of FH and requires participants to respond Yes or No, whether they have ever experienced any of the symptoms as a result of their condition. The second subdivision measures the 'timeline' component which specifies perceptions of the likely period of the illness such as lasting for a short time or passes rapidly; enduring rather than brief; the timeline 'cyclical' component, on the other hand, describes fluctuations of symptoms of illness either changes a countless deal from day to day; wax and wane in cycles; very erratic; the 'consequences' component measures the one's beliefs about the illness severity and the possibility of effect on physical, social and psychological functioning; and the 'personal control' component reflects the 'treatment control' which shows the degree to which the patient believes their ailment is amenable to cure or control. Further, the 'illness coherence' component indicates their degree of understanding of the illness such as whether they have a poor or strong understanding of the illness. Finally, the 'emotional changes' components described their emotional states as a result of having the illness including feeling distress, afraid, angry, worry, anxious or upset with the illness. Participants were required to respond to questions on a 5-point Likert-type scale (from disagree strongly to agree strongly).

The third subdivision of the questionnaire lists some 'potential causes' and asks participants to rate on a 5-point Likert-type scale (from strongly disagree to strongly agree) the extent to which they believe each factor caused their FH.

Statistical Package for the Social Sciences (SPSS) version 24 was used to analyse the data. Descriptive data were presented in the form of mean scores, frequencies and percentages. Independent t-test was used to compare the difference between score means of different domains. For possible associations between respondent characteristics and domains of illness perceptions, Mann Whitney test and Kruskal Wallis test were used. Two-tailed tests were used and p values below 0.05 were considered statistically significant.

4.0 Results

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

4.1 Illness characteristics

Of the total participants who have FH, 41% have 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 has 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 (See Table 1 below).

Table 1: Background sociodemographic and illness-related factors of the participants

Variable	N	%
Sociodemography		
Age Mean =49.8 ± SD=11.40)		
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-related factors		
Cardiovascular disease		
Yes	41	41.0
No	**59**	**59.0**
Types of CVD		
Coronary heart disease	**35**	**85.4**
Angina	8	19.5
Atherosclerosis	4	9.8
Stroke	4	9.8
Peripheral vascular disease	1	2.4
Currently received treatment for FH		
Yes	69	69.0
No	31	31.0
A Present of risk factor		
Smoker	13	13.0
High blood pressure	**40**	**40.0**
Depression	8	8.0
High stress	8	8.0

4.2 Illness perceptions

Majority of the respondents (more than 90%) did not experience most physical symptoms as a result of FH, except for fatigue (16%) and sleeping difficulties (12%). It was found that the rating of a number of symptoms that the patient sees as part of the illness or 'identity' component was significantly higher among those who were receiving treatment compared to those were not (z=-2.662, p=0.008)(See Table 2 and Table 3).

4.3 Relationship between sociodemography and illness perceptions

In terms of relationships between sociodemography and component of illness perceptions, there was no difference in illness perceptions of patients in different groups according to age, gender and marital status. This study found that FH patients who had successfully attained at least secondary education had the highest score for 'treatment control' (median score = 18.0; IQR=2.75) than others in different levels of education (Refer Table 2). Also, patients who attained an only primary level of education had the highest score for 'cyclical' component (median score = 13; IQR = 3.0) followed by those who attained secondary education and then tertiary (or pre-university and university level of education).

4.4 Relationship between illness factors and illness perceptions

There was no difference in terms of 'personal control', 'treatment control' and 'illness coherence' between different groups of illness factors. Analysis on the relationship between illness factors and illness perceptions found that FH patients who had CVDs reported higher scores in 'consequences' components than those who did not have CVDs (t=0.385, p<0.001). This group of participants also reported significantly experiencing that their illness was 'cyclical' in nature higher than those without CVDs (t = -3.047; p= 0.003). They also significantly experienced higher score in 'emotional changes' than those without CVDs (t=-2.409; p=0.018). Also, participants with multiple risk factors also have significantly higher 'cyclical' component than those with only a single risk factor (z=-1.847; p=0.038)(See Table 3).

4.5 Possible causal factors

Perceived potential causes of FH were determined by 18 causal items or questions based on 5-point Likert-type scale (1 disagree strongly, 2 disagree, 3 agree moderately, 4 agree strongly and 5 for agree strongly). The causal items were divided into four factors as described by Morris et al. (2002). 'Psychological attribution' gives Cronbach alpha of 0.85, 'risk factors' of 0.71, 'immunity' of 0.51 and 'accident or chance' of 0.36. Majority of the respondents agreed to the stress or worry (64%), hereditary and diet (89%), diet or eating habits (88%), their behaviour (63%) are the potential causes for FH (See Table 4 below).

Table 2: Relationship between background demography and illness perception

	***Age*: Median (IQR)**			**Gender: Median (IQR)**			***Marital Status*: Median (IQR)**		
Component of Illness perception	***< 45***	***≥ 45***	***[a]p value***	***Male***	***Female***	***[b]p value***	**Ever married**	**Unmarried**	***[c]p value***
Identity	0 (1.0)	0 (1.00)	0.274	0 (1.00)	0 (2.00)	0.241	0 (1.00)	0 (0.0)	0.113
Timeline	17(7.0)	16(3.64)	0.222	16.3(3.88)	16.2 (3.71)	0.956	16.2(4.22)	16.8(3.79)	0.697
Cyclical	12(2.8)	12(2.00)	0.358	11.7(2.30)	11.3(2.74)	0.508	11.5(2.37)	11.5(3.51)	0.966
Consequences	17(3.9)	15(2.97)	0.265	15.7(3.26)	15.7(3.76)	0.871	15.7(3.40)	16.6(3.99)	0.510
Personal control	20(5.5)	20(2.39)	0.940	19.6(2.68)	19.7(3.00)	0.830	19.8(1.53)	18.0(2.82)	0.108
Treatment control	17(2.5)	18(2.00)	0.481	17.2(2.29)	17.9(2.48)	0.213	17.5(2.41)	16.7(1.75)	0.389
Illness coherence	14(3.8)	16(3.36)	0.072	14.6(3.44)	15.3(3.39)	0.375	14.9(3.30)	14.0(5.29)	0.578
Emotional changes	18(4.0)	13(3.71)	0.460	14.9(4.14)	14.6(4.30)	0.698	14.8(4.12)	15.0(5.07)	0.904

	Educational Level: Median (IQR)				**Total Household Income (RM) (Median (IQR)**			
Component of Illness perception	**Primary and below**	**Secondary**	**Tertiary**	***[d]p value***	***≤3000***	***3001-5000***	***>5000***	***[e]p value***
Identity	0(0.75)	0(1.00)	0(0.75)	0.081	0(1.00)	0(0.00)	0(0.96)	0.225
Timeline	21.0(0.00)	15.0(5.25)	17.0(4.08)	0.080	16 (5.00)	4.1(6.00)	16(7.75)	0.885
Cyclical	13(3.00)	12.0(3.00)	11.0(2.70)	**0.004**	12.5(3.00)	12(2.00)	11.5(2.00)	0.173
Consequences	14.0(0.00)	15.0(5.50)	15.0(4.00)	0.459	15.5(3.28)	14(5.00)	15(4.50)	0.111
Personal control	20.0(0.00)	19.5(4.00)	20.0(2.69)	0.954	19 (4.25)	20(4.50)	20(2.94)	0.136
Treatment control	17.0(2.65)	18.0(2.75)	16.0(3.00)	**0.008***	17(2.28)	18(1.71)	17(2.02)	0.724
Illness coherence	18.0(0.00)	15(6.00)	16.0(5.00)	0.592	15(6.25)	16(3.50)	16(6.50)	0.137
Emotional changes	12(3.50)	16.5(5.00)	14.0(7.00)	0.344	16(6.00	13(7.25)	13.5(6.50)	0.086

*[a,b,c] Mann Whitney test [de]Kruskal Wallis test; Additional test *Mann Whitney test of individual paired showed significant different between secondary and tertiary p=0.018, z=2.364*

Table 3: Relationship between illness-related factors and illness perceptions

	Presence of CVDs Mean (SD)			**Type of CVDs Median (IQR)**			**Receive FH Treatment Median (IQR)**			**Risk Factors Median (IQR)**		
Component of Illness perception	*CVD (+)*	CVD (-)	^{f}p value	Single	Multiple	^{h}*p value*	Receive	Did not Receive	^{g}p value	*Single*	*Multiple*	^{i}*p value*
Identity	1.0(1.56)	0.6(1.29)	0.098	0.6 (1.07)	1.3(1.92)	0.274	0 (1.57)	0(0.78)	**0.008**	0.3(0.58)	0.9(1.74)	0.085
Timeline	17.2(3.81)	15.6(3.70)	0.067	16.7(3.02)	17.5(4.01)	0.534	16.7(4.14)	15.4(2.97)	0.107	16.9(3.27)	17.7(4.42)	0.438
Cyclical	12.4(2.18)	10.9(2.49)	**0.003**	11.3(2.73)	12.5(1.70)	0.065	11.6(2.62)	11.3(2.10)	0.561	11.7(1.88)	12.6(1.77)	**0.038**
Consequence	17.3(3.50)	14.7(2.98)	**<0.001**	15.3(3.88)	17.0(3.25)	0.059	16.0(3.65)	15.2(2.90)	0.278	16.2(3.34)	16.6(3.03)	0.075
Personal control	20.0(2.25)	19.4(3.11)	0.284	20.4(2.57)	19.7(2.32)	0.326	19.9(2.61)	19.0(3.08)	0.168	20.1(2.50)	20.0(2.36)	0.294
Treatment control	17.3(1.97)	17.6(2.63)	0.525	17.9(2.50)	17.0(1.96)	0.105	17.6(2.39)	17.3(2.36)	0.582	16.8(2.10)	16.6(1.83)	0.128
Illness coherence	14.4(3.56)	15.1(3.32)	0.329	15.8(2.70)	14.3(4.04)	0.238	15.2(3.58)	14.2(3.03)	0.216	15.6(2.63)	14.7(4.45)	0.112
Emotional changes	16.1(4.21)	14.0(3.98)	**0.018**	14.4(4.41)	15.9(3.99)	0.224	15.1(4.48)	14.3(3.53)	0.413	15.4(4.17)	15.4(3.77)	0.168

^{f}*Independent t test,*^{g,h,i} *Mann Whitney test*

Table 4: Potential causes of Familial Hypercholesterolaemia

Causal items (Cronbach alpha)	**Agree %**	**Disagree %**
Psychological attribution (=0.85)		
• Stress or worry	64	35
• Overwork	45	54
• My emotional state	42	58
• My mental illness	39	61
• Family problems or worries	31	69
• My personality	29	71
Risk factors (=0.67)		
• Hereditary - run in family	89	11
• Diet or eating habits	88	12
• My own behaviour	63	36
• Poor medical care in my past	61	39
• Ageing	50	50
• Smoking	23	77
• Alcohol	13	87
Immunity (=0.55)		
• A germ or virus	22	78
• Altered immunity	36	63
Accident or chance (= 0.23)		
• Chance or bad luck	26	74
• Accident or injury	11	89

5.0 Discussion

From our knowledge, this is the first attempt to investigate illness perception among FH patients in this country. In this study, we found that FH patients rarely complained about their symptoms. However, those who had CVDs, multiple types of CVDs and several risk factors were found to be more affected by their illness than those with FH only. They described the course of their ailment as 'cyclical' in nature. It is crucial to understand that despite having such serious conditions, these groups of patients had no additional quality in terms of 'personal control', or 'treatment control' and 'illness coherence' which reflect lack of ability of these patients to regulate their illness, poor understanding of the illness and lack of belief in the effectiveness of their treatment. This condition is a worrying finding because these elements are central for good quality of life in patients with CVDs (such as myocardial infarction and other CHDs)(Foxwell, Morley, & Frizelle, 2013).

Furthermore, this study indicated that the awareness of FH patients on the consequences of their disease occurred only in the later stage of illness; when they had already experienced CVDs especially coronary heart disease. Perhaps, this happens because FH alone at early stage comes without clear signs and symptoms; apart from high cholesterol level and the presence of lipid stigmata which is found in a small proportion of patients and present with only subtle changes making early detection is difficult (Alicezah, Rahman, & Koshy, 2014). It may be possible that if awareness of FH patients can be taught at the initial stage of the disease, before the onset of CHD, the global clinical consequence of the patients can be further improved. In our study, we found a majority of respondents did not report experiencing physical symptoms as a result of FH. Low level of awareness on the consequences of illness has also been described in other medical conditions which have minimal signs and symptoms at the early stage of illness such as hypertension and diabetes mellitus (Petriček et al., 2009; Ross, Walker, & MacLeod, 2004). The presentation of such illness perception is in keeping with the self-regulation model which explains that the presence of symptoms serves as a threat or stimulus (Leventhal et al., 1984). This stage of illness then triggers subsequent stages of coping, planning and appraisal of how to manage the illness including treatment adherence and lifestyle modification (Leventhal et al., 1984). However, such illness representation reflects a poor preventive measure. Ideally, regulating FH should begin earlier, even before the emergence of symptoms and consequences of illness. Hence, a few researchers have suggested that more comprehensive preventive measures should be implemented by integrating principles of self-regulation model, social self-efficacy, health literacy, individual attitudes, subjective norms and perceived behavioural control (Gaughan, 2003; Hagger et al., 2016; Hagger et al., 2018).

FH patients with CVDs in this study described significant emotional disturbances (such as feeling distressed, afraid, angry, worry, anxious or upset) compared to those without CVDs. Furthermore, a high percentage of patients in this study attributed their stress as part of the causal factors of their illness. These findings support the recognised connection between CVDs and psychological conditions such as chronic distress, depression, anxiety and dementia (Cohen, Edmondson, & Kronish, 2015). Presence of emotional disturbances adversely impacts daily activities, disease course concerning the quality of life, functional impairments, and mortality of individual with CVDs (Foxwell et al., 2013). Thus, to effectively manage FH patients, those with psychological disturbances should be closely monitored and managed by using comprehensive interventions that are composed of effective psychotropic treatments (where indicated) in combination with supportive, collaborative care.

6.0 Conclusion

Findings of this study can highlight the importance of understanding illness perception among FH patients. Appropriate illness perception is vital in implementing comprehensive management of FH patients. Preventive measures and management of FH patients should include not only lipid-lowering agent and lifestyle modification, but also knowledge enhancement on illness and its treatment and addressing psychological disturbances at every stage of the illness. This multipronged approach is envisaged to improve the outcome of interventions and management of FH patients.

There are a few limitations to the study. It is important to highlight that the study is limited with small sample size and there are many other cultural beliefs and perceptions that may not be captured by the questionnaires used in the study. In future, it is vital to address larger cohort of FH patients worldwide and to include a more structured questionnaire or qualitative interview to assess other underlying perceptions, beliefs or psychological symptoms. Furthermore, prospective studies examining impactful improvement is required.

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