Patients’ and physicians’ perceptions and experience of hypercholesterolaemia: a qualitative study

Isabelle Durack-Bown, Philippe Giral, Jean-François d’Ivernois, Cécile Bazin, Rita Chadarevian, Asri Benkritly and Eric Bruckert

SUMMARY
Background: A better understanding of patients’ and physicians’ perceptions and experience of hypercholesterolaemia will help to improve cardiovascular disease prevention and aid the development of appropriate educational strategies.
Aim: To identify perceptions, experience, educational needs, and barriers to learning in hypercholesterolaemic patients at high risk of cardiovascular disease.
Design of study: A qualitative study involving interviews with 27 hypercholesterolaemic outpatients and 21 physicians.
Setting: 21 centres in Paris, Bordeaux and Lille.
Methods: Semi-structured interviews were conducted by a sociologist with the aid of two interview guides focusing on hypercholesterolaemia. Interviews were recorded and subsequently transcribed, and qualitative analysis was performed to identify emerging themes.
Results: Six main themes emerged: understanding hypercholesterolaemia — a ‘virtual’ disease; understanding cardiovascular risk — a vague concept; lifestyle measures; long-term effects of medication; medical language difficulties; and patients’ expectations and needs. Patients and physicians disagreed over the terms used to describe hypercholesterolaemia and cardiovascular risk, and the complexities of medical language. In contrast, patients and physicians agreed on the difficulties associated with implementing lifestyle changes and adhering to long-term treatment.
Conclusions: The differences in perception and experience between physicians and patients indicate that physician–patient communication is sub-optimal and highlights the need to improve educational material for cardiovascular disease prevention. This analysis helps to identify appropriate educational objectives and methods for patients at risk of cardiovascular disease, and develop a structured educational programme.
Keywords: cardiovascular diseases; patients; perception; patient education; antilipemic agents.

Introduction
HYPERCHOLESTEROLAEMIA is a major risk factor for cardiovascular disease and many studies show that control of elevated cholesterol reduces the occurrence of cardiovascular events. For treatment to be successful, patients are required to make long-lasting changes to their lifestyle and nutrition, and may be required to take long-term lipid-lowering medication. Patients find it difficult to maintain their prescribed treatment over time; extensive clinical studies have demonstrated differences between prescribed recommendations and the patient’s lifestyle, indicating poor adherence to lifestyle changes. Faced with this problem, health professionals are increasingly concerned about the value of the educational messages they give and their effect on patients at risk of cardiovascular disease.

Understanding differences in patients’ and physicians’ perceptions and experience of hypercholesterolaemia will aid the development of appropriate educational strategies. This will have clinical benefits for the treatment of the disorder and for patient compliance with therapy, thereby improving prevention of cardiovascular disease. Hence, the purpose of this study was to explore the perceptions, experience, educational needs, and barriers to learning encountered by hypercholesterolaemic patients. This was achieved via parallel qualitative studies conducted with patients and physicians.

Method
This was a qualitative study using semi-structured interviews conducted with patients and physicians in France between June and July 2000 in Paris, Bordeaux and Lille.

Participants
Patients. Twenty-seven patients with high cholesterol levels treated for primary or secondary prevention of cardiovascular disease were recruited by consulting specialists and general practitioners (GPs). In order to represent the larger numbers of patients requiring primary prevention in the population as a whole, a ratio of 2:1 primary:secondary prevention patients was chosen. All patients were over 18 years old but were otherwise not selected according to age. Patients were recruited according to the following criteria to represent additional risk factors and co-morbidities.

Primary prevention:
- adults >18 years with primary hypercholesterolaemia (Type IIA or IIB),
low-density lipoprotein cholesterol (LDL-C) >5.68 mmol/l before treatment or >4.13 mmol/l in association with other cardiovascular risk factors (diabetes, smoking >10 cigarettes per day, high blood pressure [≥140/90 mmHg], obesity with body mass index [BMI] >30 kg/m², family history of coronary heart disease).

Secondary prevention:
- adults >18 years of age, with a history of myocardial infarction, stroke or peripheral vascular disease,
- LDL-C >2.58 mmol/l.

Physicians. Physicians surveyed were selected at random from a telephone directory. They were selected if they regularly treated hypercholesterolaemic patients, and all were primary care physicians. The 21 physicians that participated in the survey were selected to represent the specialisations that treat hypercholesterolaemia, namely general physicians, cardiologists and endocrinologists. None were involved in the treatment of a patient who participated in the study.

Interviews
Interviews were conducted with the aid of two interview guides, one for patients and one for physicians. These were devised and validated by a group of three expert consultants in cardiovascular prevention and were based on the Health Belief Model. The patient- and physician-specific guides included 24 and 16 questions, respectively, and covered the same themes, which focused on hypercholesterolaemia (Table 1). The respondent was free to lead the conversation and open the discussion on each theme.

The interviews were performed by a sociologist who had been provided with extensive information on the existence of cardiovascular risk factors in the patients participating in the study. The average length of the interviews was 90 minutes. The interviews were recorded and subsequently transcribed. All patients and physicians gave their informed consent to participate in the study, which was carried out according to local ethical regulations.

Analysis
The interviews were analysed manually using the analysis of content method. The transcribed interviews were read, line by line, to reveal emerging themes, which were then encoded. The codes for each interview were compared across the responses to identify broader categories, linking together individual themes. Particular attention was paid to the choice of emerging themes in order to closely represent the responses provided by study participants. The analysis was performed initially by the interviewer; however, a second member of the medical team read all the interviews independently to ensure authenticity and concordance of emerging themes. Given that the aim of this study was to identify the perceptions of patients at high cardiovascular risk rather than measure parameters that could be analysed statistically, the data are not presented numerically. The patients’ and physicians’ responses are presented in thematic groups to illustrate the key subject areas that emerged from the study.

Results
Respondents
The patients interviewed were aged 31–71 years (mean age of 64 years), from various socioprofessional and educational backgrounds, and representing a number of co-morbidities and risk factors (Table 2). Of the 30 patients contacted, three patients did not respond because they were on holiday.

The characteristics of the primary care physicians that participated in the survey are presented in Table 2. Three physicians did not respond and the reasons given were: lack of time, not treating enough dyslipidaemic patients and not being interested in the study.

Emerging themes
Analysis of 70 hours of recording identified 28 emerging themes. These have been grouped into six categories presented in Table 3.

Understanding hypercholesterolaemia: a ‘virtual’ disease
As a result of the absence of symptoms linked to high cholesterol levels, hypercholesterolaemic patients do not feel ill or realise that their levels may have changed:

‘Six months ago a blood test for cholesterol was fine and now [my] cholesterol level is high. Why has this happened so quickly?’ (Patient 4, primary prevention.)

When the term ‘disease’ is mentioned, it is described by patients as a ‘mute disease’, ‘special’, or ‘a benign disease’. However, some physicians did not agree with this concept of disease and did not wish to express hypercholesterolaemia in these terms:

‘You must tell them that they are not sick, because when you tell people they are sick, there is a pejorative..."
Understanding cardiovascular risk: a vague concept

Patients have a poor understanding of the concept of cardiovascular risk factors as explained by most physicians. As a result of the often asymptomatic expression of hypercholesterolaemia and its transitory appearance, the associated risk is perceived by the patient as unstable, unpredictable and abstract.

Patients compared the risk of hypercholesterolaemia to ‘Russian roulette’ and ‘drunk driving’, and described the risk as an ‘impalpable risk, revealed only twice a year by the blood test’.

Moreover, patients do not perceive cardiovascular risk factors as a disease and have little appreciation of the consequences of cardiovascular disease risk:

‘Is it more localised in the heart or in the whole system, I don’t know?’ (Patient 4, primary prevention.)

Indeed, some patients treated for secondary prevention of cardiovascular disease do not associate hypercholesterolaemia with cardiovascular disorders:

‘I don’t have cholesterol any more, I’m not worried … I don’t know whether the cholesterol is the cause of my illness — peripheral vascular disease of the lower members first of all and coronary problems?’ (Patient 10, secondary prevention.)

The surveys also revealed that although physicians provided reassurance to the patients, their explanation of the consequences of high cholesterol lacked precision and detail:

‘The [cholesterol] figures don’t mean a thing, they aren’t worried when it’s high. Because they are being treated for their infarction or their heart failure, they think they are doing something for their cholesterol.’ (Patient 12, secondary prevention.)
Table 3. Main themes revealed by the analysis of interviews.

<table>
<thead>
<tr>
<th>Category</th>
<th>Emerging themes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Understanding hypercholesterolaemia</td>
<td>A ‘virtual’ disease</td>
</tr>
<tr>
<td></td>
<td>Existence and consciousness of a health problem</td>
</tr>
<tr>
<td></td>
<td>Origin/cause</td>
</tr>
<tr>
<td></td>
<td>Cholesterol level</td>
</tr>
<tr>
<td></td>
<td>Good and bad cholesterol</td>
</tr>
<tr>
<td></td>
<td>Physical and psychological feelings and concerns</td>
</tr>
<tr>
<td></td>
<td>Lifestyle to apply</td>
</tr>
<tr>
<td></td>
<td>Possibility of cure</td>
</tr>
<tr>
<td>Understanding cardiovascular risk</td>
<td>Knowledge of other risk factors</td>
</tr>
<tr>
<td></td>
<td>Priority given to risk factors</td>
</tr>
<tr>
<td></td>
<td>Affected organs</td>
</tr>
<tr>
<td></td>
<td>Effect on health</td>
</tr>
<tr>
<td></td>
<td>Awareness of cardiovascular risk</td>
</tr>
<tr>
<td>Lifestyle measures</td>
<td>Change in lifestyle</td>
</tr>
<tr>
<td></td>
<td>Change of family and professional life and leisure</td>
</tr>
<tr>
<td></td>
<td>Attitude adopted</td>
</tr>
<tr>
<td></td>
<td>Difficulty in changing</td>
</tr>
<tr>
<td></td>
<td>Satisfaction with measures</td>
</tr>
<tr>
<td>Effect of medication</td>
<td>Treatment taken for high cholesterol</td>
</tr>
<tr>
<td></td>
<td>Duration of treatment</td>
</tr>
<tr>
<td></td>
<td>Satisfaction with treatment</td>
</tr>
<tr>
<td></td>
<td>Treatment of associated risk factors</td>
</tr>
<tr>
<td></td>
<td>Possible consequences</td>
</tr>
<tr>
<td>Medical language difficulties</td>
<td>Importance of the physician’s speciality in monitoring high cholesterol</td>
</tr>
<tr>
<td></td>
<td>Consultation procedure</td>
</tr>
<tr>
<td></td>
<td>Understanding information</td>
</tr>
<tr>
<td></td>
<td>Sharing information</td>
</tr>
<tr>
<td>Patient expectations and needs</td>
<td>Further information about cholesterol and its consequences</td>
</tr>
<tr>
<td></td>
<td>Help sought from physicians or family and friends</td>
</tr>
</tbody>
</table>

*Lifestyle measures: difficult to put into practice*

The difficulty of implementing lifestyle recommendations is appreciated by both patients and physicians. Indeed, one patient stated that lifestyle changes required ‘huge efforts’. For patients, dietary changes appear to be the most restrictive:

‘After my excesses, I have to start again to live with the prohibitions.’ (Patient 21, primary prevention.)

Patients are required to manage their diet to avoid a series of ‘forbidden foods’. They reported receiving contradictory medical advice regarding what they should and should not eat:

‘One time peanuts are forbidden, then at another time they are allowed.’ (Patient 15, primary prevention.)

Physicians sometimes underestimated the restrictions imposed by lifestyle changes or dismissed these as unimportant, whereas other physicians were not convinced of the effectiveness of diet and tended not to insist on it:

‘I try to explain things kindly, telling them that they have to change their lifestyle, that’s all.’ (Doctor H, GP)

‘Diets don’t change the cholesterol much, so it’s logical not to overload it.’ (Doctor L, GP)

*Effect of medication: questions on long-term use*

Patients and physicians are generally satisfied with lipid-lowering treatment. It is considered ‘not too restrictive’ by some patients, although others want to be more clearly informed about the risks of non-compliance:

‘Generally speaking, I’m satisfied with my treatment, but there is a lack of information about the risks involved with this benign disease.’ (Patient 7, primary prevention.)

Compared with following a modified diet, patients find the medication easy to use. However, some patients express concerns about potential side effects of therapy, and these may lead to patients modifying their treatment regimen:

‘They systematically bring down the cholesterol. It’s brutal … At the moment I’m tired and I tend to blame it on this very strong medication.’ (Patient 2, secondary prevention.)

‘I have certain principles concerning the medication. I avoid taking it at least once a week, on Sunday for example. The body needs to rest … the medication is all
the more effective then.’ (Patient 14, primary prevention.) Moreover, despite their initial satisfaction, some physicians report a difficulty in accepting even a modest side-effect profile for long-term preventative medication and are reluctant to prescribe high doses of these medications:

‘I’m satisfied with the treatments, there are not many problems, but of course we would like to have medication without side effects; because in prevention, side effects are hard to accept.’ (Doctor K, cardiologist.)

‘It’s in the mentality, in primary prevention it’s difficult to use high doses of medication … we are still afraid of high doses …’ (Doctor J, cardiologist.)

Medical language difficulties: complexity and a source of confusion
Patients and physicians are not always at ease with the terminology used in the field of dyslipidaemia. Physicians report problems in describing the condition and its treatment to patients. This is reflected in the patients’ responses, which reveal that they often have difficulty in understanding the explanations given by physicians. Furthermore, the physician’s explanation is also influenced by his own scientific belief. For example, the concept of ‘good cholesterol’ (high-density lipoprotein cholesterol [HDL-C]) is a source of confusion for both patient and physician:

‘That’s what I have never understood; they talk about good and bad cholesterol and I always have the bad one.’ (Patient 1, primary prevention.)

‘I don’t know either what the exact role of HDL-C is in limiting the risk factors. I don’t go into too much detail with the patients.’ (Doctor K, cardiologist.)

Although, for reasons of simplicity, the physician uses the terms ‘good’ or ‘bad’ for cholesterol and ‘forbidden’ or ‘allowed’ for foods, it is difficult to give accurate explanations in this all-or-nothing context. In the same way, the concept of life-long treatment is difficult for the physician to explain:

‘When they ask me: “Doctor, will I have to take this medication all my life?” I am very cynical; I tell them that eternity is not our affair because we all die one day, so just as long as possible …’ (Doctor D, endocrinologist.)

Patients’ expectations and needs: evolution over time
Physicians report that patients ask very few questions about their high cholesterol levels. In contrast, Table 4 presents many questions that patients have asked their physicians, illustrating a lack of concordance between the patients’ requests and the answers given by their physicians. In addition to requests for diet or medication details, patients need to be supported in maintaining long-term management of their condition by encouragement and feedback from the physician:

‘It would be good to be able to check it like diabetics do … a little drop of blood. Perhaps that would stimulate some people.’ (Patient 4, primary prevention.)

Patients report that, depending upon the answers they receive from their physician, they may look for help outside medical consultation, for example, from family and friends or in the print media:

‘These bits of information, I’ve found them here and there, by searching, looking at documentation, magazines.’ (Patient 4, primary prevention.)

When the patient initially presents with hypercholesterolaemia, there is considerable discussion of the condition between the patient and physician. Physicians estimate that this initial visit lasts between 15–30 minutes; however, both physicians and patients acknowledge that there is less discussion in subsequent consultations:

‘Apart from the blood tests, nothing else happens.’ (Patient 17, primary prevention.)

‘There comes a time when I no longer bother them: take your medication. It’s better to go on to other things.’ (Doctor B, GP)

Discussion
There are a number of studies that consider patients’ or care-givers’ perceptions of cardiovascular prevention separately; however, our study is the first qualitative study to examine both points of view.

Summary of main findings
Differences between patients’ and physicians’ perceptions of hypercholesterolaemia were evident. Physicians take a more rigid, scientific approach to the diagnosis and treatment of hypercholesterolaemia, while patient perceptions are based on subjective and emotional experiences; these differences may account for the observed discrepancies. However, this study also highlights the inadequacy of physicians’ replies to patients’ questions. The results reveal that physicians face difficulties in explaining therapeutic recommendations, and this is a contributory factor in poor patient understanding of hypercholesterolaemia and its treatment.

Strengths and limitations of this study
This is the first qualitative study to examine both patients’ and physicians’ perception and experience of hypercholesterolaemia simultaneously, enabling agreements and discrepancies between physicians and patients to be identified. However, given cross-country differences in culture and healthcare provision in France, these results may not easily be extrapolated to other countries. This is a qualitative study, and as such may have benefited from some form of validation of responses. Furthermore, it is acknowledged that physician behaviour may be influenced more by quantitative, scientific data, rather than such qualitative assessments.

Comparison with existing literature
Our results are consistent with a previous study that also observed differences between patients’ and physicians’
perceptions. Murray et al observe that patients’ perception of cardiovascular risk is based essentially on cultural and social influences, while the health professional approaches the concept of risk according to an epidemiological and physio-pathological basis.

A lack of patient–physician understanding is apparent in our study, such that patients do not comprehend the nature of their condition. Patients felt that the idea of risk and risk factors was abstract and they did not make the link between high cholesterol and cardiovascular disease. Medical terminology may act as an obstacle to patient learning, as illustrated by misunderstandings about the importance of LDL-C and HDL-C. This is also the case in other medical fields; for example, diabetology, in which terms such as ‘retinopathy’ or ‘neuropathy’, may be poorly understood by patients. Also, in common with diabetes, our study physicians acknowledged difficulty in explaining certain aspects of a patient’s condition and treatment, and patients found these explanations difficult to understand.

In the present study, the lack of clarity in explaining hypercholesterolaemia may contribute to patients’ interest in the health press and their search for help outside medical consultation. The results of work done by Caggiula and Watson show that information obtained from associated sources, such as television or the print media, is strongly related to the level of compliance. Indeed, patients and physicians spoke of a weariness in their therapeutic relationship over time in our study. Major clinical trials with statins confirm this; a gradual reduction in the number of patients complying with treatment was observed with long-term treatment, irrespective of whether patients were receiving active drug or placebo therapy. A link between an effective patient–physician relationship and adherence to treatment of cardiovascular risk factors has been demonstrated previously, illustrating the need to reinforce the therapeutic relationship over time through an educational procedure that actively involves both patient and physician.

The finding that lifestyle modification is a difficult subject for both the physician and patient confirms previous studies in cardiovascular disease and type 2 diabetes. The nutritional aspect is a difficult subject for both the physician, who is sceptical with respect to its efficacy, and the patient, who lacks customised information. The physician’s confidence in the success of lifestyle measures depends, among other things, on his knowledge of the methods used to implement them, the benefits resulting from their application, and the perception of his own efficacy in this preventive field.

In contrast to lifestyle changes, patients find it easier to take medication than to modify their diet, an observation that was also made in a secondary prevention qualitative study. However, the modest adverse effects associated with lipid-lowering medication are a source of concern for patients and physicians in this study and previous investigations. The withdrawal of cerivastatin from the market, since completion of this study, illustrates the basis of these fears. Moreover, the present study extends these findings to primary prevention patients and focuses on hypercholesterolaemia and its central role as a risk factor of cardiovascular disorders.

**Implications for future research or clinical practice**

An improvement in cardiovascular prevention must be based on the analysis of perception of all risk factors, including hypercholesterolaemia. This study highlights the need for improved training and appropriate educational tools for...
physicians involved in cardiovascular disease prevention. The use of qualitative methods advances the understanding of knowledge in the field of cardiovascular disease. A further study is planned, which aims to organise and quantify the results of this qualitative analysis, before designing an educational programme suitable for patients at cardiovascular risk. To account for cultural differences, similar studies should be performed in other countries to form the basis of educational programmes specific to that population.

References

Acknowledgements
This study was performed under the aegis of the Société Française d’Atherosclérose and ARCOL (French Society for Atherosclerosis and ARCOL) in partnership with the Comité Français d’Éducation pour la Santé (French Committee for Health Education), with the support of Edusante, Nour et AstraZeneca pharmaceutica.