



Living with Elevated Lipoprotein(a) Levels: The Experiences of Patients and Caregivers

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Background: Elevated lipoprotein(a) (Lp[a]) is an inherited condition that increases cardiovascular disease (CVD) risk, independent of other factors, such as low-density lipoprotein C. Few attempts have been made to explore the life experiences of people with elevated Lp(a).

Objective: To explore the experiences of people living with or caring for a relative with elevated Lp(a).

Methods: Two multinational, virtual, interactive, moderated discussions of specific questions between people with elevated Lp(a) and relatives (caregivers), with experienced clinicians attending.

Results: Fifteen individuals with elevated Lp(a) and nine relatives took part in the virtual discussions. The most frequent reasons to measure Lp(a) levels were prior CVD events, eg, heart attacks, stroke, aortic valve diseases, or a family history of CVD events. Clinicians were often reluctant to measure Lp(a) levels as no effective treatment is available to people with elevated values. The most common interventions after confirmed elevated Lp(a) levels were lifestyle modifications and cholesterol-lowering medications to reduce overall CVD risk. A healthy lifestyle with diet and exercise was perceived as unsuccessful in managing overall CVD risk by 25% of people with elevated Lp(a) and 38% of relatives. Lifestyle advice was considered conflicting, unclear and inconsistent. Participants experienced elevated Lp(a) as an “invisible” disorder with very low awareness in the general population. Physicians’ advice was often too superficial to meet patients’ needs, putting insufficient emphasis on prevention and focusing on interventions after a CVD event.

Conclusion: Elevated Lp(a) was considered an “invisible” disorder with limited understanding among physicians and the general public. This reduces access to tests and shifts physician focus away from prevention towards reactive intervention.

Plain Language Summary: We report on the experiences living with high levels of lipoprotein a (Lp[a]) in the blood. This is a mostly inherited condition and is associated with an increased risk for heart attack, stroke, kidney failure and other cardiovascular events. Currently there is no medical treatment that directly lowers Lp(a) levels. People with high Lp(a) levels are advised to maintain a healthy diet and normal weight, avoid smoking, exercise regularly, and take cholesterol-reducing medication. While this lifestyle has no direct influence on Lp(a) levels, it helps lowering the overall cardiovascular risk. In the study, people with high Lp(a) and their relatives took part in an online discussion. Medical professionals attended but did not take an active part. Many participants struggled with managing their overall cardiovascular risk by a healthy lifestyle alone. The participants experienced lifestyle advice as conflicting, unclear and inconsistent and felt that their condition was an “invisible” disorder in their daily lives, which very few people around them, including medical professionals, knowing much about it. Physicians tended to treat patients after a harmful event rather than trying to help minimize the risk in the first place. Participants highlighted the need for trusted sources of information and for a greater awareness of Lp(a) among both the general public and healthcare professionals.

Keywords: lifestyle advice, cardiovascular risk, lipoprotein(a), qualitative study, patient experience

Introduction

Elevated lipoprotein(a) (Lp[a]) is an inherited condition that increases cardiovascular disease (CVD) risk, independent of other factors such as low-density lipoprotein C (LDL-C).¹ Prospective observational studies and genetic evidence support the association between elevated plasma Lp(a) levels and the risk of coronary heart disease (CHD) including myocardial infarction (MI).^{2–4} Elevated Lp(a) levels also independently increase the risk of peripheral artery disease⁵ and possibly renal failure.^{6,7}

Lp(a) concentration is measured in either nmol/L or mg/dL, with 100 nmol/L corresponding to approximately 40 mg/dL. Elevated Lp(a) levels, often defined as values above 100 or 125 nmol/L, are common in the general population. A study of over 400,000 individuals aged 37–73 years in the UK Biobank concluded that one in five had Lp(a) levels above 100 nmol/L and nine percent had levels above 175 nmol/L.⁸ This high prevalence has not translated into widespread awareness, however: large-scale quality-of-care surveys such as EUROASPIRE (European Action on Secondary and Primary Prevention by Intervention to Reduce Events) have so far paid little attention to Lp(a).⁹

There is consensus among guidelines on the utility of measuring Lp(a) levels at least once in a person's lifetime.^{10–13} Lp(a) levels are mainly genetically determined,¹⁴ and remain largely stable throughout life,¹⁵ although Lp(a) levels have been reported to be lower in premenopausal than in postmenopausal women.¹⁶ Measurements are considered valuable to identify individuals with elevated inherited Lp(a) plasma levels and familial risk for CVD, to assess risk more accurately, to implement lifestyle changes, and for management of CVD risk factors such as LDL-C, hypertension, or diabetes. But Lp(a) testing rates in the general population are low.¹⁷

It is difficult to target Lp(a) directly with interventions. Modification of other risk factors affects overall CVD risk but has no or only minor impact on Lp(a) levels.¹⁸ In people with elevated Lp(a) at elevated risk of CHD, large absolute decreases in Lp(a) levels would be necessary to achieve clinically meaningful risk reduction. Currently, no pharmacological therapies are available to achieve such reductions. Proprotein convertase subtilisin-kexin type 9 (PCSK9) inhibitors have been shown to reduce Lp(a) levels by up to 30%,¹⁹ but this is not considered sufficient for adequate risk reduction.²⁰ Moreover, the Lp(a)-lowering efficacy varies between patients, depending on the size of the particles, which is genetically determined.²¹ Statins slightly increase Lp(a) levels,²² but they reduce CVD risk through strong reductions in LDL-C levels.

Although elevated Lp(a) is typically an asymptomatic condition, living with the constant awareness of increased risk and with the need to adhere to lifestyle and drug regimens will have a significant impact on the lives of not only affected individuals but also their relatives and caregivers. Studies have shown reduced quality of life in patients with familial hypercholesterolemia²³ but there have been few attempts to explore the life experiences of people with elevated Lp(a), or on how views may be expressed in an international exchange between peers, rather than in structured, standardized interviews.

We report here the results of two multinational, virtual, interactive, moderated, structured discussions of specific questions between people with elevated Lp(a) levels or their relatives, with participation of a healthcare professional (HCP) in the patient roundtable discussion. The objective was to explore the similarities and differences between the two groups in their experiences of living with, or caring for a relative with elevated Lp(a).

Methods

Participants and Discussion Platform

The structured discussions took place in April 2023 on a virtual advisory board platform (Within3, Lakewood, OH, USA). The interactive tool and discussion format have been used previously in studies in other health conditions with similar objectives, as described in the literature.^{24–26} Participants were recruited through their clinicians and from patient advocacy groups. There were no formal inclusion or exclusion criteria. The goal was to include a mix of age groups, sex, ethnicity, and geographic origin, as well as characteristics, duration, and experiences of living with or caring for people with elevated Lp(a). All elevated Lp(a) levels had been formally confirmed. All participants were informed on the objectives of the research and provided written, informed consent to take part in the roundtable discussion. The study complies with the Declaration of Helsinki.

Participants viewed guiding questions and background presentations within the platform, which could be accessed from any connected device at any time which suited individual schedules and time zones. Responses and comments were visible to all participants, who could provide input at all stages of the discussions. Automated translation facilities enabled participants to interact in their native languages. An independent moderator had access to all responses and could provide clarification or ask for additional information where appropriate. Two representatives of the sponsor assisted with moderation and clarification if needed. One expert on internal medicine and lipid metabolism (EST) represented HCP perspectives and answered specific questions from the panelists. Neither the HCP nor the moderators provided answers to the closed and open questions which structured the discussions.

Discussion Topics and Analysis

Discussions focused on the experience of living with, or caring for someone with elevated CVD risk; treatment and management; views on the utility of measuring Lp(a); access to and use of information, and unmet needs. A combination of closed and open questions was included. Examples of the former are “How burdensome is living with your cardiovascular disease for your family on a scale of 1–10?” or “How successful (very, partially, not) do you feel a healthy lifestyle is in managing high Lp(a) levels?” Open questions concerned matters such as “In what ways does your cardiovascular disease impact your family’s life both physically and emotionally?” or “What challenges do dietary and exercise approaches to reducing Lp(a) levels involve for you?” The questions were used as a basis for discussions, not as a formal survey.

All data were analyzed descriptively. As this was a qualitative study, there was no a priori hypothesis. Closed question results are presented numerically.

Results

Fifteen individuals with elevated Lp(a) and nine relatives (caregivers) took part in the virtual roundtables. Patients came from China, Germany, Ireland, Italy, the Netherlands, Switzerland and the United Kingdom; relatives were from the same countries except Ireland and Italy. Over the roundtable period of two weeks, a total of 1657 posts were entered on the platforms. All participants were active in the discussions which were not driven by a specific subset of patients or relatives. The youngest participant was 15 years old; the oldest (an affected patient discussed by a relative) was 81 years.

Diagnosis and Interventions

The diagnosis of elevated Lp(a) was made equally frequently by cardiologists, vascular specialists, and endocrinologists/lipidologists. The most frequent reasons to measure Lp(a) levels were prior events, eg, heart attacks (patients) or a family history of CVD events (relatives; [Figure 1](#)). However, the time between an individual noticing symptoms and the measurement of Lp(a) levels could be up to several years.

Cardiologists were the most frequently consulted specialist HCPs (by 53% of patients; multiple mentions were possible), followed by internists or general practitioners (35%) and endocrinologists/lipidologists (29%).

The most common interventions after confirmed elevated Lp(a) levels were lifestyle modifications (changed diet and increased exercise) and cholesterol-lowering medications, including ezetimibe, statins and PCSK9 inhibitors ([Figure 2](#)). People with elevated Lp(a) tended to be more satisfied than the relatives, both with current management and with the perceived success of a healthy lifestyle in managing risk from elevated Lp(a) ([Figure 3](#)). A common comment was “I would be more satisfied if there were medicines available.” Most roundtable participants were aware that diet and exercise do not affect Lp(a) levels directly, yet, such adjustments were considered necessary for efficient management of other CVD risk.

However, 23% of people with elevated Lp(a) and 33% of relatives were very dissatisfied with current management; 25% and 38%, respectively, perceived a healthy lifestyle to be unsuccessful ([Figure 3](#)). The lack of immediate effects from changes in lifestyle made adherence difficult. Lifestyle advice was perceived as conflicting, unclear, and inconsistent. Panelists noted that dieticians’ views and recommendations change over time, as seen, eg, for eggs or healthy vs unhealthy fats.²⁷ Also, dietary needs change throughout people’s lives. It was also pointed out that an overemphasis on a healthy lifestyle can have adverse effects: patients with difficulties to adhere to recommendations may experience

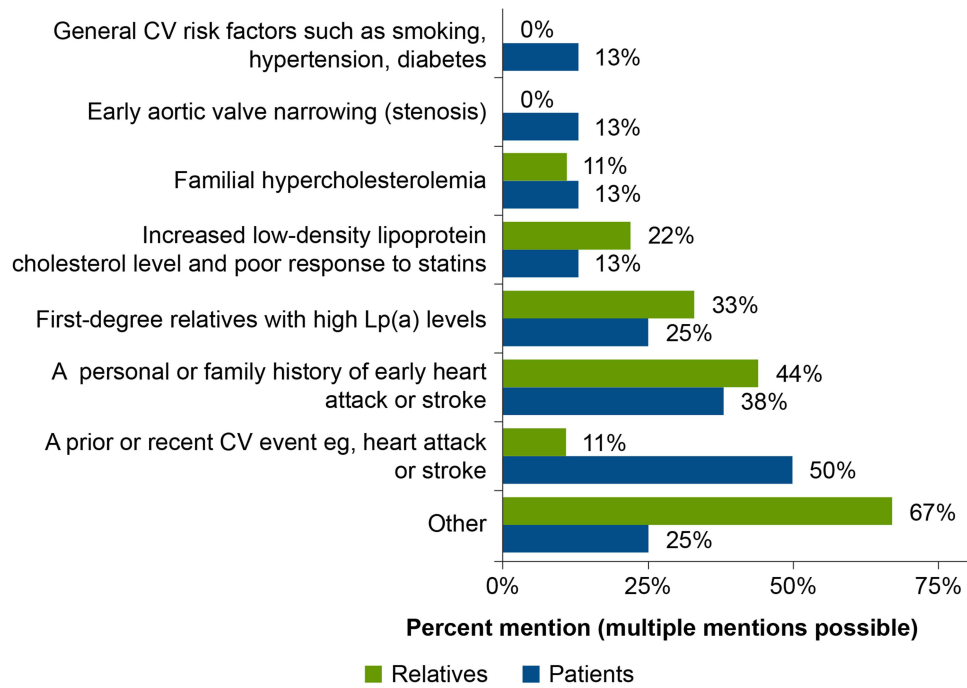


Figure 1 Participants' recall of reasons for clinicians to measure Lp(a) levels. Other includes: patient requested test; emergency coronary artery bypass graft; during hospitalization for CVD event; chest pains over many years.

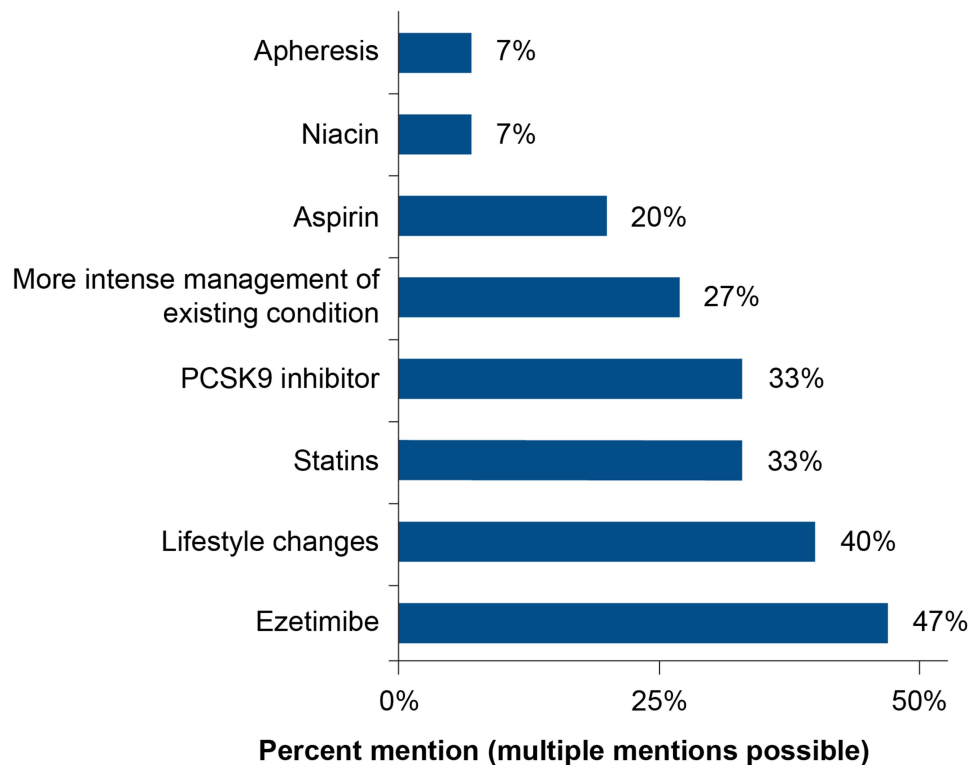


Figure 2 First interventions offered after diagnosis of elevated Lp(a).

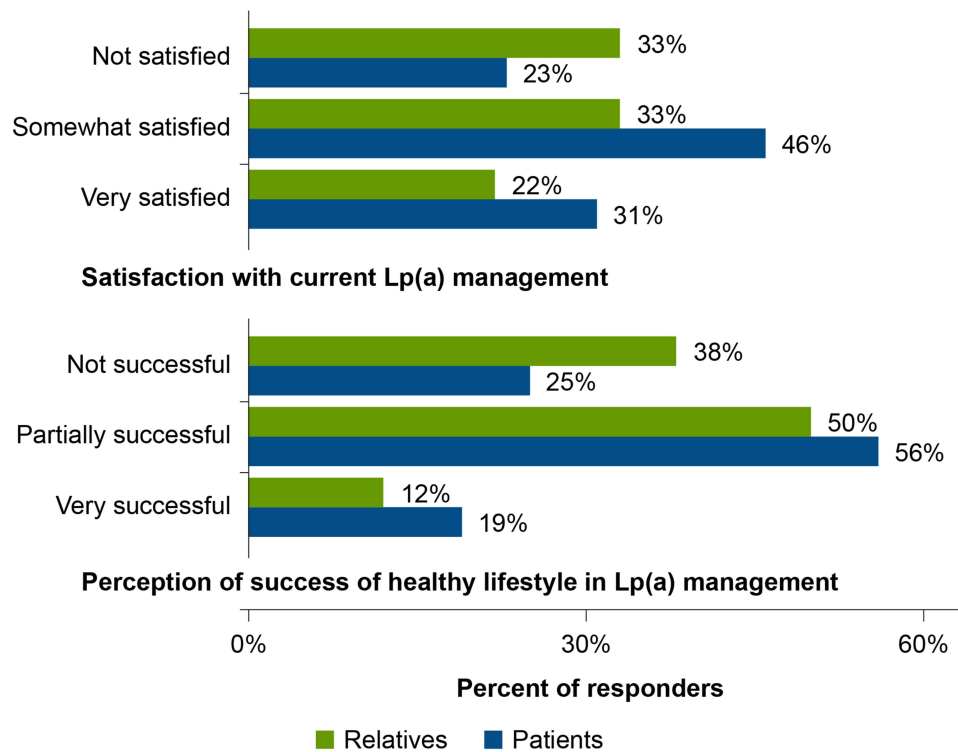


Figure 3 Patients' and relatives' satisfaction with current Lp(a) management (upper graph) and perception of the success of lifestyle changes in reducing CVD risk (bottom graph).

feelings of guilt, anxiety, and reduced emotional well-being. Extreme dieting may lead to malnourishment and over-exercising can have adverse physical consequences.

Lifestyle advice does not help active patients who have been following a healthy diet and exercised all their lives

Views on Lp(a) Measurement

The panelists were in favor of more general measurement of Lp(a) levels in risk groups; ideally Lp(a) should be included in standard lipid profiling. A negative test was reassuring, while elevated values could be an incentive to push overall risk targets further down and enable better risk management. Lp(a) as a single number was considered a simpler assessment than overall CVD risk, which is influenced by many factors including LDL-C. This advantage was noted despite a lack of a clear-cut correlation between specific Lp(a) values and CVD risk and associated need for intervention.

Repeated Lp(a) measurement was not considered valuable, except in children, in whom levels change with time. All roundtable participants agreed that the availability of an effective treatment would increase the motivation to check Lp(a) levels.

Access to Lp(a) measurement and treatment varied between countries and healthcare systems. Clinicians everywhere were often reluctant to measure Lp(a) levels since they would not be able to offer an effective treatment to people with elevated values. The five participants from China experienced that Lp(a) was only measured in inpatients, and many community medical institutions would not measure Lp(a) at all. In several countries people experienced a barrier of having to pay for measurements out of pocket unless referred by a clinician. A common concern which affected the motivation to have Lp(a) measured was that a diagnosis of elevated Lp(a) might increase the costs of arranging life or health insurance, or even mortgage rates.

Emotional Impact and Need for Support

For both patients and caregivers, the estimated burden of living with CVD varied widely (Figure 4). People with elevated Lp(a) and relatives alike often found the emotional burden and worries to be more important than possible physical signs.

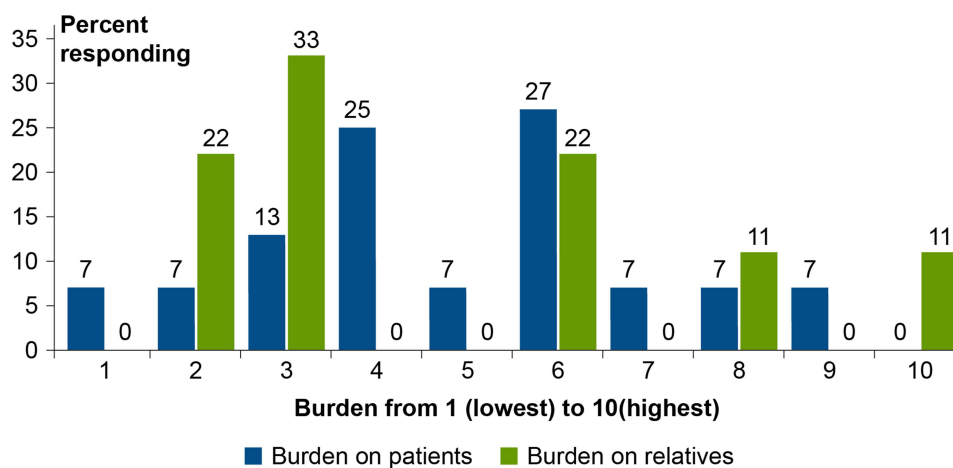


Figure 4 Burden of living with cardiovascular disease, as estimated by patients (blue bars) and relatives (green bars).

Patients with a history of a CVD event were powerfully affected by the experience and reported the greatest psychological burden. Parents diagnosed with elevated Lp(a) found it easier to accept and live with their own condition than with the knowledge that their children may be at increased risk.

It's like having an unbelievably patient sniper stalking you for years (patient)

None of the relatives and only 25% of the patients had known about Lp(a) before diagnosis. After diagnosis, patients and relatives were often relieved to find the cause of their experience. Before the confirmation of elevated Lp(a) levels, many patients with a history of a CVD event had partially blamed themselves for the situation, as CVD risk is frequently associated with lifestyle. Learning about the hereditary nature of elevated Lp(a) reduced feelings of guilt, although it raised worries about the effects on participants' family.

I'm grateful it has been confirmed as genetic because my initial reaction was "what did I do wrong?" when I was 23 and was told I had high cholesterol.

A common experience among the panelists was that elevated Lp(a) is very much an "invisible" disorder and that there is very low awareness of Lp(a) in the general population as well as among HCPs. "This is extraordinary considering that this lipid disorder may affect as many as 1 in 5 people." Even among people who had heard about Lp(a) the risk factor was often bundled with cholesterol in public consciousness without differentiation between them. Moreover, the erroneous belief remains widespread that a healthy lifestyle offers sufficient protection. The roundtable participants reported little understanding of their situation outside their close relatives and friends, mostly because of the lack of symptoms.

Most people including specialists who look at me acknowledge that I'm physically active and assume that I'm fine.

Although clinicians provided adequate medical support as far as possible, participants reported a general lack of emotional support. Typically, individuals with a CVD event receive greater emotional support than other people at risk. Relatives, in particular, often felt at a loss for support. The participants called for the provision of a core contact person ("coach") to contact easily in case of questions, doubts, or fear. Relatives also highlighted the need for a detailed, itemized "Carers Guide" to help in daily lives.

Information and Communication

Patients (75%) and relatives (88%) expressed "some" or "high" satisfaction with their interaction with HCPs. Insufficient quality of information and communication was the main reason for dissatisfaction. The roundtable participants reported that the confirmation of elevated Lp(a) levels had motivated information-seeking behavior, but only half of those

diagnosed received information about Lp(a) and genetics at diagnosis. Physicians often lacked the patience or available time to explain well.

Whenever we move and have to change general practitioner, I have to explain what Lp(a) is.

Physicians' advice was commonly experienced as too superficial and their knowledge of Lp(a) and how to measure levels was considered insufficient to meet patients' needs. In the panelists' view, cardiologists put too little emphasis on prevention, instead mainly managing people after a CVD event. This attitude was also linked to a reluctance to measure Lp(a) levels. Interdisciplinary communication between physicians was also often experienced as insufficient or lacking.

HCPs remained the main source of information to both groups of roundtable participants, followed by family and friends (Figure 5). Relatives were more active on social media, more engaged with patient organizations, and did more online searches than patients. Social media were used as a channel of support from friends and family. All panelists were highly concerned about the amount of nonsense, pseudo-science, and irresponsible speculation online.

The importance of patient organizations as resources of information and to combat online misinformation was emphasized. However, helpful organizations did not always have a prominent web presence and were sometimes difficult to find on the internet. In countries such as China, where patient organizations are less active or well known, some information needs were filled by chat groups including physicians. Panelists who were actively interacting with other patients or doing advocacy work reported that such activities helped to deal with the emotional aspects of their situation.

A summary of the most important needs expressed by patients and relatives, respectively, is given in Table 1.

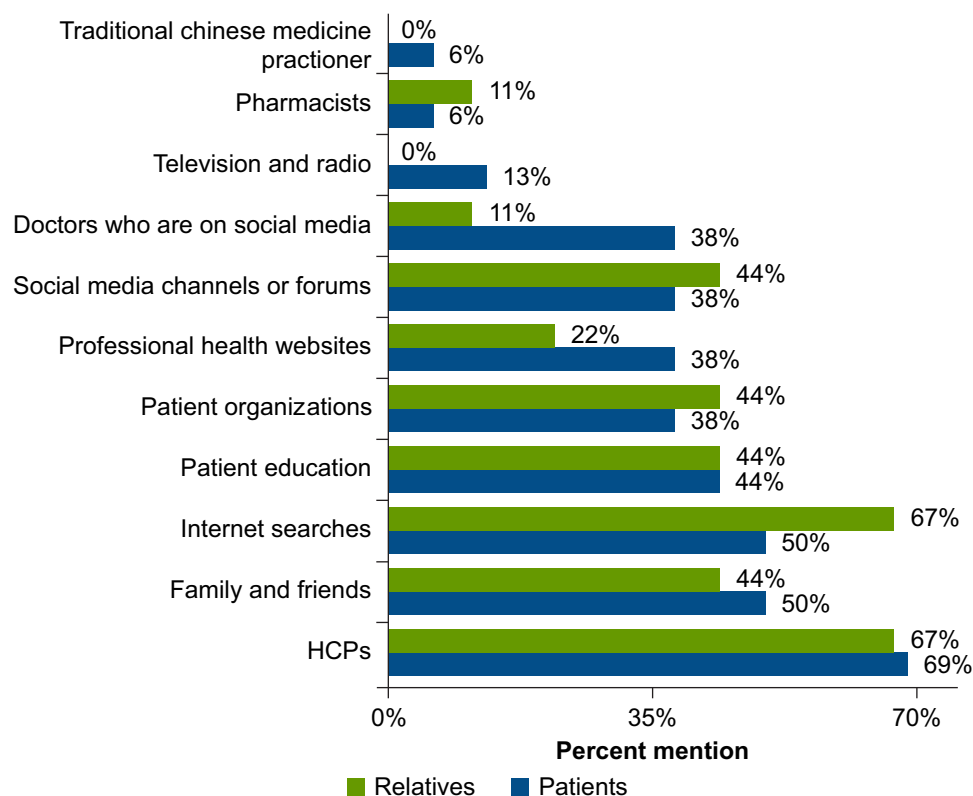


Figure 5 Key sources of information about Lp(a) ordered according to importance to patients.

Table 1 Main Needs to Help Living with Elevated Lp(a), Identified by Affected Individuals and Relatives, Respectively

| People with Elevated Lp(a) | Relatives |
|--|--|
| Detailed advice on lifestyle, in particular diet | Detailed, itemized “Carers Guide” for caregivers |
| Reliable experts who provide expert insights on, eg, social media | Reliable experts who provide expert insights on, eg, social media |
| Core contact person (“coach”) to contact easily in case of questions, doubts or fears | Core contact person (“coach”) to contact easily in case of questions, doubts or fears |
| Increasing awareness of Lp(a) in the general population and among HCPs | Increasing awareness of Lp(a) in the general population and among HCPs |
| Greater focus among HCPs on preventing CVD events instead of on treating patients after an event | Greater focus among HCPs on preventing CVD events instead of on treating patients after an event |
| Advice on interventions to reduce other CVD risk factors, in particular LDL-C to below “normal” levels | |
| More personalized support and advice | |
| Better information about gender differences and changes in Lp(a) at menopause in women | |
| Psychological support to help stick to the necessary lifestyle | |
| Greater acknowledgement by HCPs of the serious role of Lp(a) in CVD | |

Discussion

To live with elevated levels of a (currently) untreatable important CVD risk factor is bound to be associated with significant emotional and practical impact on the affected individual as well as their relatives. In this hypothesis-generating pilot study we attempted to tease out important life-experience aspects and unmet needs, through structured discussions among people with elevated Lp(a) and their relatives, respectively, with expert HCP attendance.

The perceived burden of illness varied greatly, which may reflect the heterogeneity in age, risk profile and healthcare system of the panelists. Nevertheless, there were a large number of common experiences and widespread agreement on needs between all participants. Information, emotional support, and recognition of elevated Lp(a) among physicians and the general public as an independent CVD risk factor were regarded as key topics.

The need for optimized communication between clinicians and patients has long been recognized,²⁸ and the responses from the panelists show this need to be acute for people with elevated Lp(a) levels. The panelists found information to be empowering, eg, patients often felt less guilty when informed about the hereditary nature of elevated Lp(a). However, improved communication would require greater awareness of the disorder among physicians, whose knowledge of Lp(a) was frequently considered insufficient.

Even with knowledgeable HCPs, information may be lacking. All roundtable participants wanted a clearer picture of how a specific Lp(a) value relates to risk and need for intervention. HCPs may struggle to help here due to the lack of knowledge of Lp(a) and the relation to CVD risk. Factors such as the use of several different units (nmol/L, mg/dL, and mg/L) complicate matters further. Without access to Lp(a)-reducing therapies physicians may not feel high priority to learn about the disorder, but the experiences of the panelists indicate that an HCP’s ability to inform affected individuals appropriately has great value, emotionally as well as motivationally.

The roundtable participants also experienced a very low awareness of elevated Lp(a) among the general public. Without symptoms, the condition of elevated Lp(a) is invisible, which limits understanding and support. Somewhat paradoxically, this meant that people with a healthy lifestyle were those least likely to receive support, as they did not conform to the prevailing image of a person at high CVD risk. The belief remains widespread that a healthy lifestyle offers sufficient protection from adverse CVD consequences. More activity is clearly needed to raise awareness of this

inherited condition. The roundtable participants argued that since elevated Lp(a) may affect up to 20% of the population, it should be recognized as a risk factor to the same degree as elevated cholesterol.

Panelists' views on the value of measuring Lp(a) echoed those of physicians: on the one hand, the lack of current treatment directed specifically at Lp(a) reduces the motivation to test for this biomarker. On the other hand confirming elevated Lp(a) levels increases awareness and can be an empowering motivation to increase efforts to control overall risk. Repeated measurement was not considered valuable, except for in children, in whom levels may change with time.²⁹ European and Canadian guidelines state that adults should have an Lp(a) measurement once in their lifetime,^{11,12} but access to Lp(a) measurement was suboptimal for most panelists. There appears to be little incentive for physicians to implement the recommendation without treatment options.

Support with lifestyle interventions ranked high on both patients' and relatives' lists of most important needs. Insufficient advice on diet and nutrition is the rule rather than the exception for people at elevated CVD risk,^{30,31} and clear and consistent communication would improve motivation, adherence, and prevention. Relatives also called for access to a detailed, itemized "Carers Guide" to help in daily lives. Such a valuable resource would require an interdisciplinary effort and may need to be adapted to different cultural contexts, but it would seem to be a tool worth exploring further.

These needs for reliable information also reflected the amount of nonsense, pseudo-science, and irresponsible speculation panelists encountered online. Some Chinese participants were helped by chat groups including physicians; participants from other countries found patient organizations very helpful in countering misinformation. A suggestion was to provide a single, credible contact person for advice. This would not necessarily be an expert physician, but the details and financial aspects remained unexplored.

When considering the way forward, lessons may be drawn from people with familial hypercholesterolemia, another heritable disorder which increases CVD risk. A recent Global Call to Action from the Global Familial Hypercholesterolemia Community was driven by the persistent unmet needs of those living with familial hypercholesterolemia.³² Patient- and family-centric perspectives on needs are similar in this population and in people with elevated Lp(a): prioritization of the condition as a global public-health concern, more support for education and advocacy efforts, funding for research, greater access to early diagnosis and family-based care.³³ Closer collaboration between patient organizations dedicated to familial hypercholesterolemia and elevated Lp(a) may provide valuable synergies.

The study has limitations. To enable a roundtable discussion, the number of participants was limited, which may produce biased impressions of the situation in individual countries. Further small-scale studies might be advised to focus on a more homogeneous population (eg age groups or gender). Several questions were structured, but the qualitative statements cannot be quantified. The scope for generalizations to wider populations is limited by the selection of participants in both groups, who represented engaged individuals, many of whom were in close contact with patient organizations and acted as advocates. In the discussion, participants' views may have been affected by comments from their peers on the platform. A further limitation was that this pilot project involved people with elevated Lp(a) and caregivers in discussions on separate occasions, without direct exchange between the groups. An important next step would be to use the same format for an inclusive roundtable with all stakeholders.

In summary, this interactive exchange provided important insights into the attitudes and experiences of people with elevated Lp(a) levels and relatives. The need to reduce overall CVD risk was found throughout the discussion, expressed in struggles with lifestyle interventions and the need for effective Lp(a)-targeting therapies. Even without such treatment, measuring Lp(a) was considered valuable, as it could empower, reduce feelings of guilt, and motivate actions to reduce overall CVD risk. In addition, both groups confirmed the clear need for increased awareness of Lp(a) among HCPs and the general public, and for improved and widely available trusted sources of information. The findings and their implications would need to be explored further in larger, systematic studies to improve the condition of people living with elevated Lp(a) and their relatives by various means, including possible new therapies. Among relevant topics might be specific terminology preferred by patients and the potential discrepancies between patient and physician perspectives on risk and therapies, as have been observed for other CV conditions.³⁴

Ethics Approval and Informed Consent

This was a non-interventional study. All methods were carried out in accordance with relevant guidelines and regulations. Approval of all experimental protocols by institutional and/or licensing committee was not sought as the project falls under Office for Human Research Protections (OHRP) Exempt Categories 45 CFR 46.101(B), ie, research involving the use of educational tests (cognitive, diagnostic, aptitude, achievement), survey procedures, interview procedures or observation of public behavior (<https://www.hhs.gov/ohrp/regulations-and-policy/regulations/45-cfr-46/common-rule-subpart-a-46104/index.html>). Further, members of the roundtable were informed of their involvement in research activities via the user agreement and privacy policy before participating in the virtual discussion. All participants provided informed consent to participate and to publish the outcomes of the discussion. Anonymity and adequate protection of participants' personal data was ensured. The virtual roundtable discussion was conducted on a secure website, with all information protected from external sources. All posts were anonymized for the purpose of publication. In this report, the use of "participant," "attendee," or "panelist" refer to the feedback provided without attribution to any named individual.

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Author Contributions

All authors made a significant contribution to the work reported, whether that is in the conception, study design, execution, acquisition of data, analysis and interpretation, or in all these areas; took part in drafting, revising or critically reviewing the article; gave final approval of the version to be published; have agreed on the journal to which the article has been submitted; and agree to be accountable for all aspects of the work.

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