INTERNATIONAL HYPERLIPIDEMIA PATIENT UNDERSTANDING OF CARDIOVASCULAR DISEASE RISK FACTORS AND THERAPEUTIC OPTIONS: RESULTS FROM A PATIENT-LED STUDY

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Purpose

- The European cardiovascular disease community is actively promoting a shift towards delivering more personalized cardiovascular care[1,2]
- This shift requires a reassessment of current clinical approaches, including approaches to shared decision-making.
- Shared decision-making should be grounded in factors impacting treatment adherence and oriented toward patient-relevant outcomes.
- The purpose of this research is to learn from people with hyperlipidemia about their experiences, priorities and needs inside and outside the health system

Methods

- Semi-structured interviews were conducted among 50 people in the US, Brazil, and Australia, who were diagnosed with high LDL-C by a physician at least two years ago.
- Half of the participants were required to have been hospitalized for an ASCVD event at least one year after their high LDL-C diagnosis.
- Interview transcripts were coded by two analysts using a grounded theory approach.
- The study protocol (Pro00074986) was submitted to Advarra and deemed to have met the criteria for exemption from IRB oversight under 45 CFR 46.104(d)(2).

Results

Participants in the Insights from People living with Elevated Cholesterol (IPEC) study described how healthcare providers can work with patients to personalize care through realistic, individualized care plans.

Table 1. IPEC Participant Characteristics

n (%)	50	100%
ASCVD event (n, %)		
Yes	22	44%
Age Category (n, %)		
Under 45	12	24%
45 to 65	27	54%
Over 65	11	22%
Sex (n, %)		
Female	25	50%
Rurality (n, %)		
Rural	3	6%
Suburban	32	64%
Urban	15	30%
Comorbidity (n, %)		
Diabetes	20	40%
High Blood Pressure	33	66%

Figure 1. Themes and illustrative quotes for how providers can personalize care with patients

Importance of conveying seriousness of diagnosis

Australia (primary prevention): I was a little surprised, but it didn't particularly worry me because as far as I'm concerned, my diet is reasonably okay. It's not excellent, but it's certainly not a bad diet. I don't have any takeaway food or anything like that. So I was a little bit surprised, but it didn't worry me because he said he would put me on the lowest dose of statins.

Importance of supportive, specific treatment plans and target goals

Brazil (secondary prevention): No, no. The only thing he said to me that I could understand was a scolding. That's what he told me, that if I didn't improve my diet, the medicine wouldn't work. That's what he told me. But I told him, I said, Doctor, I'm trying to improve my diet, it's not always that I can eat what's convenient, but as far as possible I'm trying. But I have never stopped taking my medication.

Importance of healthcare provider presence and availability

US (secondary prevention): I just felt like I was a number, you know? This is the medicine you need to take, follow up with your primary physician. And I did. I made appointments. They do labs once a year. I just felt like it was nothing that they were much concerned about. [. . .] And they just don't feel like they have time to – and they're not even listening. They're sitting there typing on their computer, or making notes, and not even listening to what you say.

Treatment attributes: Delivery mode or frequency

Pills or tablets - Brazil (primary prevention): For me, tablets, I don't like injections, I feel sick. I've had to take them, so the tablet is better for me. And even if it's every day, I find it easier. But if it was every week, it would also help.

Injections - Brazil (secondary prevention): [T] he injection goes straight into the vein and everything. [. . .] it would be great.

Less frequent - US (secondary prevention): I'm not opposed to shots. If I could just switch off or do a shot monthly or every month, I'd be probably more open to that just because it is a hassle.

Treatment benefits & patient-relevant outcomes

Improve lab values - Brazil (secondary prevention): I'd like to get as close to normal as possible, right? Even if it's with medication, right? I don't know, maintain normality. [. . .] that's what I'm aiming for.

Living longer & being there for loved ones - Brazil (secondary prevention): So I still want to be able to work a lot and make sure my 16-year-old daughter goes to college. And that's it. And to have a very good quality of life. With good health, being able to go out, travelling, having fun with the family. All of that.

Avoid ASCVD events -US (primary prevention): Avoiding serious complications like a heart attack again.

Reduced side effects - Australia (secondary prevention): I would like a medication without side effects, but I'm dreaming. I would like… I would like a cholesterol tablet that didn't cause you cramps. Yeah. I think more research needs to be perhaps done into it. I'm not sure. I mean, ideally, I'd love to be off all medication.

Conclusion

- This study identified topics patients want their HCP to include in shared decision-making. It can inform HCP efforts to deliver personalised cardiovascular care.
- Many health systems have structural barriers to effective shared decision-making, including the time HCPs have allotted to appointments, administrative burden, and access. Patient advocacy organisations and HCP organisations can partner to drive policy changes to overcome these barriers.

References

1. Backman WD, Levine SA, Wenger NK, Harold JG. Shared decision-making for older adults with cardiovascular disease. Clinical cardiology. 2020 Feb;43(2):196-204.
2. European Society of Cardiology. Guidelines for Patients - What patients need to know. https://www.escardio.org/Guidelines/guidelines-for-patients

Global Heart Hub's Insights from Patients living with Elevated Cholesterol (IPEC) study is a patient-led initiative made possible with the support of Novartis Pharma AG.