POLICY TARGETS TO IMPROVE DIAGNOSIS AND TREATMENT OF HIGH CHOLESTEROL IDENTIFIED BY PEOPLE LIVING WITH HIGH CHOLESTEROL: RESULTS FROM A PATIENT-LED STUDY

Hall T[1], Johnson N[2], Vandigo J[3], Kelly D[2], Oehrlein EM[3]
[1]hearts4heart, East Perth, Western Australia, Australia; [2]Global Heart Hub, Galway, Connacht, Ireland; [3]Applied Patient Experience, LLC, Washington DC, USA
CORRESPONDING AUTHOR: Tanya Hall, Chief Executive Officer, hearts4heart -- tanya.hall@hearts4heart.org.au

BACKGROUND AND AIMS

- To reduce the burden of cardiovascular disease in Australia and New Zealand, a comprehensive approach leveraging innovative therapies and public policy is needed to support patient access to diagnosis and treatment.
- This study aimed to explore the experience of Australians living with high cholesterol, a leading cause of heart disease, to inform policymakers how to design and implement meaningful interventions to improve population health.

METHODS

- Semi-structured interviews were conducted among 19 people in Australia diagnosed with high cholesterol by a physician at least two years ago.
- Approximately half IPEC participants were required to have been hospitalised for a cardiac event (heart attack, unstable angina, ischemic stroke, peripheral artery disease) 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 (IORG = 0000635 and IRB Registration = 00000971) and deemed to have met the criteria for exemption from IRB oversight under 45 CFR 46.104(d)(2).

RESULTS

- Low levels of concern and complacency, both from the participants themselves and their care team, present a barrier to both understanding and care plan adherence, even among individuals who had experienced a cardiac event. [Table 1]
- Ensuring that the severity of a high cholesterol diagnosis is accurately conveyed, along with the development of supportive treatment plans and target goals provide opportunities to strengthen the clinical encounter. [Table 2]
- Education from multiple sources emerged as a key opportunity individuals identified to improve adherence, specifically among individuals who are newly diagnosed. Healthcare providers were the most frequently mentioned trusted source of information, but information from providers was frequently supplemented with additional sources, often those found online. Examples of education participants described as helpful included increased awareness of high cholesterol risks, medical and lifestyle treatment options, and the importance of care plan adherence and regular testing. [Table 3]

Table 1. Themes and illustrative Australian IPEC participant quotes on perceptions of severity and complacency

Individual Complacency	Perceived Provider Complacency
Q: How were you feeling emotionally after being diagnosed with high cholesterol?	Q: Could you describe the conversation(s) between you and your doctor after finding out you had high cholesterol?
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.	**Secondary prevention:** Over the whole thing, nobody talked to me about anything to do with weight loss or what I eat, or anything like that. I had... there was no conversations about anything like that. It's interesting because [husband's name] also, he had a triple bypass a year ago, so he had one done 8 months after I did. And the same thing for him, nobody talked about what... you shouldn't do this, what you should do and all that. Yeah, so there was no talk about what I should... other than exercise... again, exercise.

Table 2. Themes and illustrative Australian IPEC participant quotes related to opportunities for shared decision making during the clinical encounter

Not receiving information about the link between high cholesterol and heart disease at diagnosis	Not aware that lipid-lowering therapies need to be taken throughout their life.	Need for clearer communication and more targeted information regarding the risks of high cholesterol and the importance of maintaining treatment and lifestyle changes	Taking more responsibility and initiative regarding their care plan following a cardiac event
Q: Did you discuss the link between high cholesterol and heart disease?	Q: Were you aware that medicines for high cholesterol need to be taken throughout your life?	Q: When you think about the health care system, what do you think are signs of "good" quality care? And what do you think are signs of "bad" quality care?	Q: Have your feelings towards managing high cholesterol changed since the [cardiac event]? How so?
Primary prevention: Not in detail, no. Not that I can remember. I guess I just knew that it was a bad thing in terms of my health and that it can… I guess I just thought it was common knowledge that people knew that high cholesterol can lead to heart disease. So, I think he kind of knew that about me that he didn't need to explain that part I suppose. Yeah, he didn't link the two, the way he communicated he sort of assumed that I knew that I suppose, and I do.	**Secondary prevention:** [Healthcare provider name] said to me, "Oh, sorry, but you're going to have to go on medication." He didn't say for the rest of your life, but it turned out to be that.	**Primary prevention:** I think bad quality is doctors who are poor communicators, and who are sort of high-handed. I think they can be quite dismissive sometimes with patients, and I've experienced that and I don't really like that. So, I think that's poor quality care. I think it's about giving people enough information to make their own decisions without... You don't have to also give them War and Peace, you know, it doesn't have to be all of the information. I don't need to know all of the details. It's just having the right amount of information so I can make a choice, I think is important	**Secondary prevention:** Since then [cardiac event requiring hospitalisation], I've always made even more of a conscious effort to realize my age and realising my genetics, to not fry my food, to not… You know, to be aware.

Table 3. Themes and illustrative Australian IPEC participant quotes related to information types

HIGH CHOLESTEROL RISKS	TEST RESULT INTERPRETATION	MEDICAL AND LIFESTYLE TREATMENT OPTIONS	IMPORTANCE OF CARE PLAN ADHERENCE	SIDE EFFECTS
Q: Could you describe conversation(s) between you and your doctor after finding out you had high cholesterol. For example, did you discuss risks of high cholesterol?	Q: Who reviewed the lab results with you? Did the results make sense to you? Why or why not?	Q: Are there resources you wish existed, but you haven't been able to find?	Q: Did you doctor discuss potential health consequences of not staying on treatment?	Q: When you were prescribed medication, what was the conversation like between you and your doctor?
Primary prevention: I think the only questions I'd like, and I could go and Google it after we finish our meeting, is find out what the more macro about what can… bad health things can happen if you don't keep it under control. **Secondary prevention:** I think they should just be given information that it's treatable, it's manageable, and some clear information about increased risk if you don't do anything about it.	**Secondary prevention:** I had my angiogram and they said, "Oh, you're all fine and don't worry, it was minor," and then I've had one follow-up with a cardiologist, and I've got another one coming up in a couple of weeks, since November. So, it's two since November. But, yeah, really a whole lotta questions and not really a great deal of information coming the other way.	**Secondary prevention:** I would have liked to have walked… and this might sound old-fashioned, but I would have liked to have walked away with an email or a text message with a link to a video or even a good old brochure, a little pamphlet, in the pamphlet describing what high cholesterol can do, telling me what I should eat and what I shouldn't eat, telling me to regularly take the tablet at the same time every day.	**Secondary prevention:** I was of the opinion that I was just one of those people who had slightly elevated cholesterol and I was fine. But it turns out I was mistaken. If somebody asked my advice about cholesterol, I would tell them get it checked every 6 months and take it seriously, because this operation really, really hurts and I've got a scar right down my chest.	**Secondary prevention:** Well, my doctor's always explained the side effects to me. He is an amazing doctor, as I said, but sometimes I do my own research as well and doctors become really complacent. "I'll just give you a script and off you go," and you need to understand… I think every medication on the planet has a side effect and I think that you need to be aware of those side effects. I think public information is really important for side effects.

Table 4. IPEC Australian Participant Characteristics

Variable	n	(%)
Total (Australia)	19	38%
ASCVD event (n, %)		
Yes	7	37%
Age (mean, SD)	61.9	11.5
Age category (n, %)		
Less than 45	2	11%
45 to 64	8	42%
Over 65	9	47%
Sex (n, %)		
Female	4	21%
Weight category (n, %)		
Underweight	0	0%
Normal Weight	6	32%
Overweight	13	68%
Obese	0	0%
Rurality (n, %)		
Rural	1	5%
Suburban	18	95%
Urban	0	0%
Comorbid conditions (n, %)		
Diabetes	4	21%
High Blood Pressure	10	53%

CONCLUSION

- This study identified areas where Australians living with cardiovascular disease identify as targets for action to advance health outcomes by removing barriers to early diagnosis, treatment initiation, treatment adherence, and lifestyle change.
- Early diagnosis, supported by policies like the MBS Heart Health Check, is crucial to reducing the risk of cardiac-related events by allowing people time to engage with providers in developing and adhering to a care plan.
- There remains an unmet need in terms of what people with high cholesterol are looking for in terms of clinical interaction and information.
- These findings promote the engagement of people living with high cholesterol in policy-making decisions to enhance population health, including health technology discussions, and should be utilized to foster open dialogue between patients and policymakers.

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