



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

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BACKGROUND AND AIMS

- The European Society of Cardiology Guidelines on Cardiovascular Disease Prevention in Clinical Practice identifies the importance of aligning cardiovascular risk communication with an understanding of individual preferences.
- This research aimed to gain insights from people with high cholesterol about their priorities, knowledge of risks, and experiences within and outside the healthcare 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 (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

Across countries, participants described different levels of understanding regarding: (1) the association between high cholesterol and heart disease, (2) how treatment for their high cholesterol should be life-long following diagnosis, (3) the increased risk of cardiac events due to high cholesterol, and (4) other risk factors associated with cardiac events. [Table 2]

Participants described that only after experiencing an ASCVD event did they understand the risks due to high cholesterol. Participants also demonstrated varying knowledge about treatment options beyond oral, once-daily therapies. When asked about attributes of an "ideal" therapy, participants often described qualities of existing approved therapies (e.g., less frequent administration). [Figure 1]

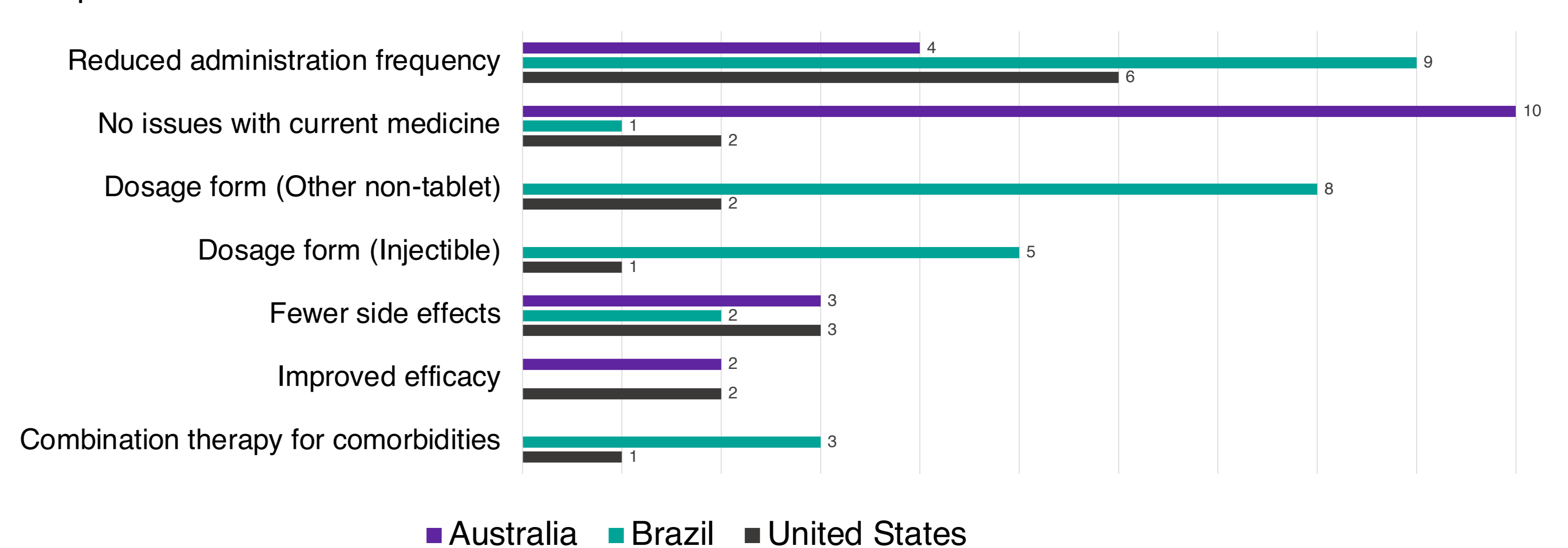
Table 1. IPEC Participant Characteristics

	Total	Australia	Brazil	United States
n (%)	50	19 38%	15 30%	16 32%
ASCVD event (n, %)				
Yes	22 44%	7 37%	7 47%	8 50%
No	28 56%	12 63%	8 53%	8 50%
Age (mean, SD)	54.7	61.9	48.3	51.2
Age Category (n, %)				
Less than 45	12 24%	2 11%	7 47%	3 19%
45 to 64	27 54%	8 42%	8 53%	11 69%
Over 65	11 22%	9 47%	0 0%	2 13%
Sex (n, %)				
Female	25 50%	4 21%	10 67%	11 69%
Male	25 50%	15 79%	5 33%	5 31%
Marital Status (n, %)				
Married	27 54%	9 47%	11 73%	7 44%
Never Married	14 28%	8 42%	2 13%	4 25%
Divorced	7 14%	1 5%	2 13%	4 25%
Widowed	2 4%	1 5%	0 0%	1 6%
Smoking (n, %)				
Never smoked	33 66%	10 53%	9 60%	14 88%
Current smoker	7 14%	3 16%	3 20%	1 6%
Ever Smoker	10 20%	6 32%	3 20%	1 6%
Weight (n, %)				
Underweight	0 0%	0 0%	0 0%	0 0%
Normal Weight	17 34%	6 32%	7 47%	4 25%
Overweight	24 48%	13 68%	5 33%	6 38%
Obese	9 18%	0 0%	3 20%	6 38%
Rurality (n, %)				
Rural	3 6%	1 5%	0 0%	2 13%
Suburban	32 64%	18 95%	5 33%	9 56%
Urban	15 30%	0 0%	10 67%	5 31%
Education (n, %)				
Some High School	4 8%	4 21%	0 0%	0 0%
High School	5 10%	1 5%	4 27%	0 0%
Some College	10 20%	1 5%	2 13%	7 44%
College Graduate or Above	31 62%	13 68%	9 60%	9 56%
ASCVD Event (n, %)				
Ischemic Stroke	5 10%	0 0%	2 13%	3 19%
Heart Attack	14 28%	4 21%	5 33%	5 31%
Peripheral Artery Disease	7 14%	3 16%	2 13%	2 13%
Unstable Angina	3 6%	0 0%	2 13%	1 6%
Comorbidity (n, %)				
Diabetes	20 40%	4 21%	10 67%	6 38%
High Blood Pressure	33 66%	10 53%	12 80%	11 69%

Table 2. Themes and illustrative IPEC participant quotes

<p>IPEC participants frequently described not receiving information about the link between high cholesterol and heart disease at diagnosis.</p> <p>Brazil (Primary prevention): The link, no. They've [healthcare provider] never mentioned it. I started taking the two drugs together. I don't know if it's related, but I started taking 20 mg of simvastatin and 25 mg of [metoprolol brand name]. At the same time I started taking the two together for arrhythmia and cholesterol.</p> <p>United States (Secondary prevention): Again, no, not there [at diagnosis]. And also, none of the information of how it affects me as a woman and having high cholesterol and potential heart disease as well and/or having a predisposition to it because of my mother having issues. So, none of that, none of those things were highlighted.</p>	<p>Slightly less than half of IPEC participants were not aware that lipid-lowering therapies need to be taken throughout their life.</p> <p>Australia (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. Yeah, I could tell it was serious, and I had to treat it seriously and I never missed a beat.</p> <p>United States (Secondary prevention): So, they didn't tell me that once I take it, I would have to take it for the rest of my life. And that is something that I would have liked to know because it might have lit a more fire to my ass to be like – because the time between that, I didn't start getting healthy until 42 or 43 because I'm 46 now. I don't want that on me because I just don't think it's good to be on any medication long-term if you can avoid it. So, they didn't explain that it's something I'd always have. And I would have liked more of a communication about that, even if it wasn't – yeah, you get 15 minutes.</p>	<p>Many IPEC participants expressed a need for clearer communication and more targeted information regarding the risks of high cholesterol and the importance of maintaining treatment and lifestyle changes.</p> <p>Australia (secondary prevention): As I said, the two heart attacks I've had, have been caused by almost external factors as far as I'm aware. It wasn't because I'm a heavy smoker, big drinker, or overweight. None of those obvious conditions for creating heart disease. I'm a bit neurotic, so I do walk a lot to burn off my energy. I'm not a couch potato.</p> <p>Brazil (secondary prevention): So I went to see a doctor, not a specialist, a general practitioner who I had been referred to by family members at the time. What he asked me was that in order to reduce it, I was in my early 40s, he said let's exercise, let's stop eating this, eat this, eat that and I didn't follow those rules. That's when these other consequences came because I continued to eat things I shouldn't have, I continued to be sedentary. I think it just increased over time.</p>	<p>Following their event, IPEC participants described taking more responsibility and initiative regarding their care plan. Many described significant improvements in their adherence to lifestyle changes</p> <p>Australia (Secondary prevention): Since then [cardiac event requiring hospitalization], I've always made even more of a conscious effort realizing my age, and realizing my genetics, to not fry my food, to not... You know, to be aware.</p> <p>Brazil (Secondary prevention): [Healthcare provider] said... we never got around to it, I never got around to taking any specific medication for cholesterol because the recommendation was diet, exercise and stopping smoking, stopping drinking alcohol. And when I was younger I didn't think much about it. Honestly, no. Things changed later, you know? When this tragedy really happened to me, let's say, that's when my life changed, but until then, I didn't pay much attention to the doctor.</p>
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Figure 1. Participant-identified ideal treatment attributes



CONCLUSION

This study finds varying levels of understanding related to the risks and therapies for hyperlipidemia across three countries. Findings from this work can help inform the development of resources and policies to ensure effective communication and understanding of high LDL cholesterol and its relationship to cardiovascular disease and other cardiovascular disease risk factors.

