Understanding the Patient Experience with High Cholesterol in the United States: A Patient-community-led Qualitative Study

PCR201

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BACKGROUND

#1 Atherosclerotic cardiovascular disease (ASCVD) is the leading cause of mortality worldwide.[1]

Treatments and lifestyle modifications to lower LDL-C (low-density lipoprotein cholesterol), an important risk factor for ASCVD, are known to be effective.

≈80% of premature ASCVD events could be prevented.[2]

OBJECTIVES

We engaged people with high cholesterol in a hypothesis-generating, qualitative study to learn about:

- **The burden of managing high LDL-C**, including the impact on family members, work or student life, comorbidities, finances, and other life factors/social determinants of health.

- **Perspectives on current and future treatments** for high LDL-C, including meaningful treatment benefits.

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.

- This study was guided by a multidisciplinary Steering Committee.

- 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).

PARTICIPANT CHARACTERISTICS

	n	%
	16	100%
ASCVD event (n, %)		
Yes	8	50%
No	8	50%
Age (mean, SD)	51.2	10.1
Age Category (n, %)		
Less than 45	3	19%
45 to 64	11	69%
Over 65	2	13%
Sex (n, %)		
Female	11	69%
Male	5	31%
Marital Status (n, %)		
Married	7	44%
Never Married	4	25%
Divorced	4	25%
Widowed	1	6%
Smoking (n, %)		
Never smoked	14	88%
Current smoker	1	6%
Ever Smoker	1	6%
Weight (n, %)		
Underweight	0	0%
Normal Weight	4	25%
Overweight	6	38%
Obese	6	38%
Rurality (n, %)		
Rural	2	13%
Suburban	9	56%
Urban	5	31%
Education (n, %)		
Some High School	0	0%
High School	0	0%
Some College	7	44%
College Graduate or Above	9	56%
Event (n, %)		
Ischemic Stroke	3	19%
Heart Attack	5	31%

PATIENT-CENTERED RESEARCH IMPACTS

Living a long life
Participants expressed a desire to live as long as possible and desire to spend more time with family and friends

Avoiding ASCVD events
Secondary prevention participants and primary prevention participants familiar with the link between high LDL-C and heart disease described their desire to avoid an ASCVD event.

Improvements in lab values
Participants described feeling satisfied when their adherence to lifestyle change and/or medicines translated into improvements in their lab values

DIAGNOSIS JOURNEY AND BARRIERS TO MANAGING HIGH CHOLESTEROL

Participant pathways to diagnosis

7	5	4

■ Wellness Check ■ Visit for Comorbidity ■ Visit for Signs and Symptoms
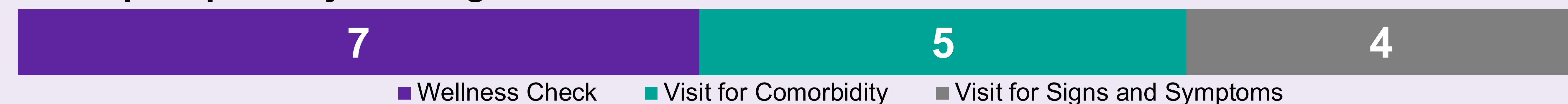
In most instances, high LDL-C was diagnosed as part of an annual wellness visit or a visit for another condition, such as diabetes. However, some people did not access health system services until signs and symptoms associated with ASCVD or a symptomatic co-occurring condition were experienced.

Medicines prescribed at diagnosis

10	5	1	1

■ Statin ■ None ■ Colesevlam ■ Fibrate

Lack of awareness & understanding of cardiac risks associated with high LDL-C
In general, there is a lack of awareness regarding the seriousness of elevated LDL-C upon diagnosis. In our US sample, one in three participants did not receive a medicine upon diagnosis. There are many ASCVD risk factors. Most patients are familiar with several, but not all. This leads to inconsistent adoption of evidence-based lifestyle changes.

Management of comorbidities may be prioritized over managing high LDL-C and allows less time to discuss LDL-C.
Symptomatic comorbidities are often the primary focus of HCPs and patients until after an ASCVD event.

Life factors, including career and family obligations, can make lifestyle changes more challenging.
Many participants described how their work schedules, travel, and family events or obligations got in the way of lifestyle changes to manage their LDL-C. Family support and proactively building lifestyle changes into daily routines made it easier to be adherent.

Out-of-pocket costs for medicines and healthcare
Several participants described accumulating medical debt due to insurance cost-sharing for ASCVD-related hospitalizations or the costs of medicines while they were uninsured because they were unable to work.
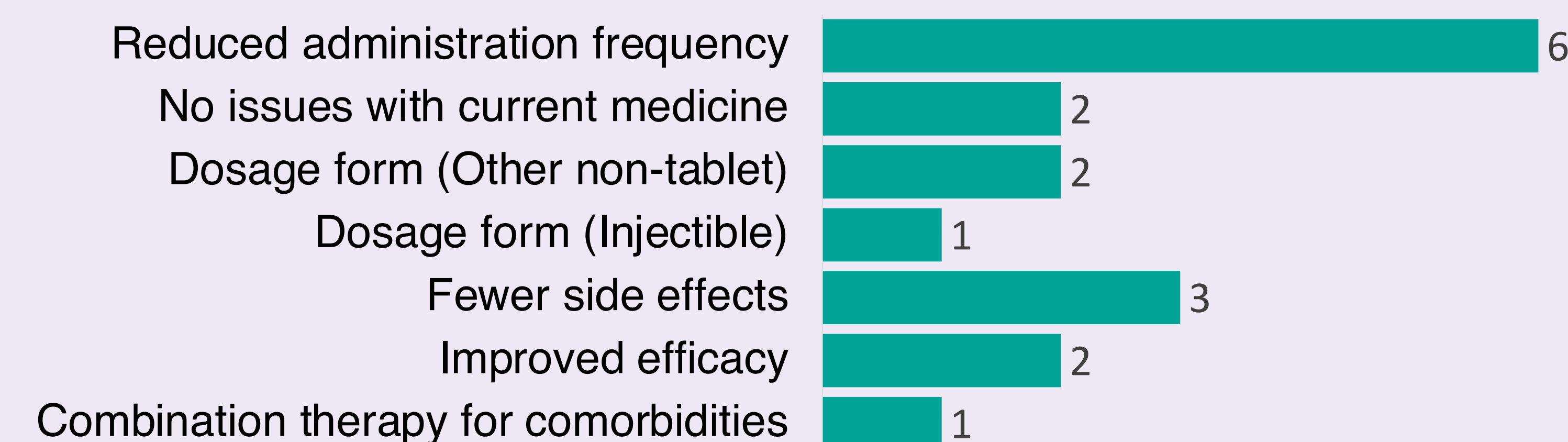
Lack of in-network providers, HCP engagement, and provider availability
Participants shared that providers not being available (e.g., not in their network, booked far into the future, or geographically distant) created barriers to adherence. Additionally, among patients who were able to access providers, many described a lack of engagement in their healthcare encounters.

Several participants described that HCPs did not address their concerns and perceived bias due to their age, sex, or race.
"I was disregarded and told I was a hypochondriac and told to go home and that it was just me coughing, that it was just me overweight. Just being a woman, I think is sometimes even greater of a disregard than being a person of color. Having both, yeah, you're completely disregarded. You're completely silenced to even simplest complaint, just even to complain. You don't have a voice. You shouldn't have a voice a lot of times in healthcare."

IDEAL TREATMENT ATTRIBUTES

Attribute	Count
Reduced administration frequency	6
No issues with current medicine	2
Dosage form (Other non-tablet)	2
Dosage form (Injectible)	1
Fewer side effects	3
Improved efficacy	2
Combination therapy for comorbidities	1

The most commonly described attribute of an ideal treatment did not require daily administration (n=6). Participants described desiring weekly, monthly, and quarterly dosing regimens. They also described their ideal treatment as having minimal side effects or being provided in a specific dosage form, such as an injection or patch.

"Its effects would be measurable, and it would be quick, whatever it would be, to have it happen. Side effects would be minimal. Something that you could do or take or have done that you would feel the difference immediately"

IMPLICATIONS FOR HEALTH ECONOMICS AND OUTCOMES RESEARCH

- This study highlights that elements of care that people with high cholesterol value may be overlooked in claims-based analyses.

- Outcomes traditionally assessed in clinical research (reduction in lab values, survival, ASCVD events) are relevant to patients

- Economists should consider including career impacts and family spillover effects in economic evaluations

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Insights from Patients living with Elevated Cholesterol

References: (1) World Health Organisation (WHO). Cardiovascular diseases – Overview. Accessed April 29, 2024. https://www.who.int/health-topics/cardiovascular-diseases (2) World Health Organisation (WHO) Europe. Cardiovascular diseases – Overview. Accessed April 29, 2024. https://www.who.int/europe/health-topics/cancer/cardiovascular-disease