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BACKGROUND

Paying for care is a burden for people living with ALS in the United States (US). Even when someone has health insurance coverage, they must obtain authorization for the care they seek. Health care providers submit prior authorization requests to a person's health insurance plan to pay for care, services, treatments, or equipment before the person receives it. Claims are submitted after care, services, treatments, or equipment have been delivered. Health care providers are responsible for establishing medical necessity when submitting prior authorization requests and claims to reimburse the cost of ALS care. When a health insurance plan denies a prior authorization request or claim, the burden falls on the person with ALS to appeal. Measuring the experiences of people with ALS and caregivers as they seek to cover the cost of ALS care can help guide advocacy efforts for expanding ALS insurance coverage in the US. The ALS Focus™ (www.ALSFocus.org) Insurance and Payment for ALS Care Survey captured these experiences.

METHODS

The ALS Association developed the Insurance and Payment for ALS Care Survey with input from people with ALS, caregivers, industry, government, and academic experts.

Measures: Survey questions asked people with ALS and current caregivers about experiences submitting prior authorizations and claims to health plans, and the impact of denials and the subsequent appeals process on health and quality of life outcomes. A **prior authorization** was defined as a request to a person's health insurance plan to pay for care, services, treatments, or equipment before receiving it. A **claim** was defined as a request to a person's health insurance plan to pay for care, services, treatments, or equipment after receiving it.

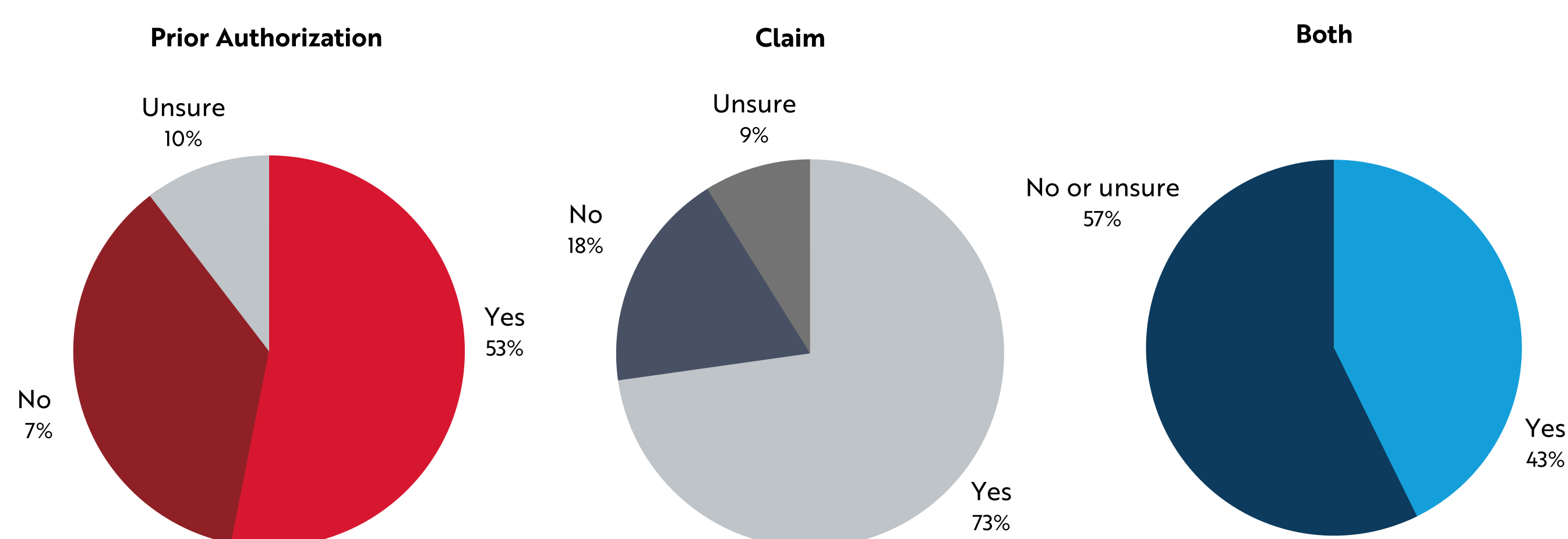
Data: Self-reported data were collected through the ALS Focus online survey platform from November 28 to December 16, 2022.

Analytic sample: This analysis is based on 192 survey responses from people with ALS (n=163), proxies (n=2), and current caregivers (n=27). Eligible participants were 18 years old or older and lived in the US.

RESULTS

All people with ALS reflected in this survey reported having at least one health insurance plan to cover the cost of ALS care. Most (80%) used Medicare, 28% used an employer-sponsored plan, 15% had private insurance, and 11% received care through the VA. For the 154 participants who used Medicare, 57% (n=109) had fee-for-service, 32% (n=61) had Medicare Part D, 22% (n=43) had Medicare Advantage, and 21% (n=41) had a Medicare Supplement/Medigap plan.

FIGURE 1. INSURANCE SUBMISSION EXPERIENCE AMONG PEOPLE WITH ALS AND THEIR CAREGIVERS



Note: One respondent did not answer the question about submitting a claim.

Figure 1 shows more than half of participants (53%, n=102) reported that prior authorization had been requested for ALS care, either their own or the person they cared for. Furthermore, 73% (n=139) had experienced a claim being submitted for ALS care. Over 40% (n=82) had experienced both prior authorization and claim submissions.

FIGURE 2: DIFFICULTY OF THE SUBMISSION PROCESS

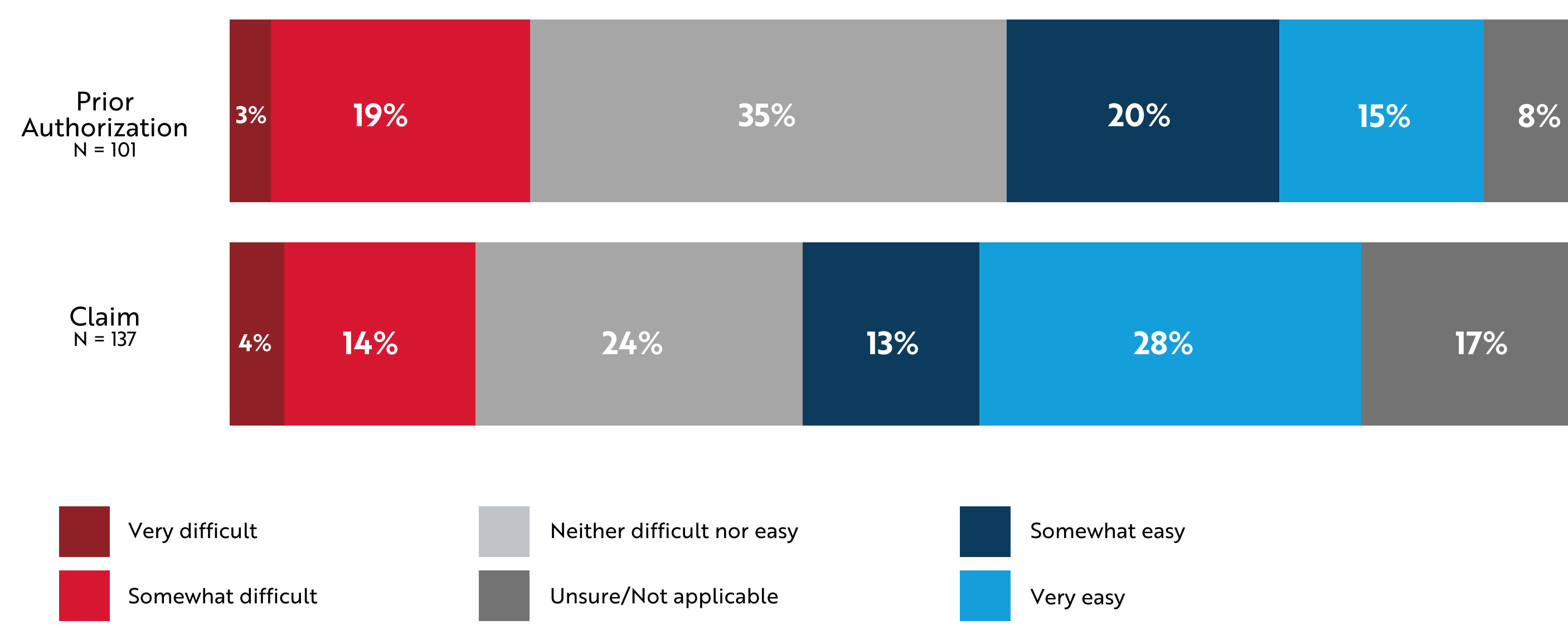
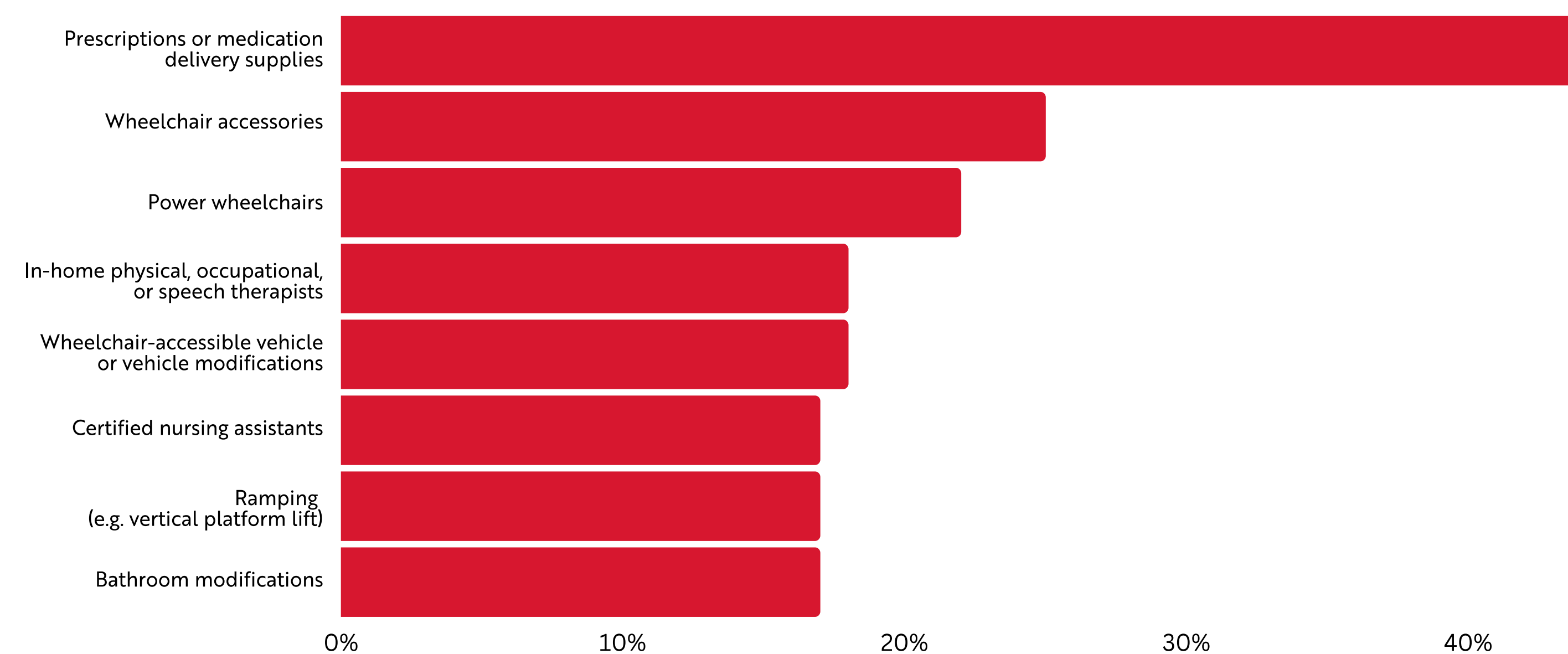


Figure 2 shows more than a third of participants perceived the prior authorization or claim submission process to be somewhat or very easy (35% and 41%, respectively). Approximately one in five described submissions as somewhat or very difficult (22% and 18%, respectively). Most participants indicated that nurses, doctors, other medical staff members, or a durable medical equipment company representative assisted with submissions.

FIGURE 3: MOST DENIED ALS CARE OR SERVICES



Note: There are two missing participants on all 48 response options; N=60.

Of the participants who reported prior authorization or claim submissions (N=192), approximately one in three had been denied (n=62). Figure 3 shows that, across 48 types of care, prescription or medication delivery supplies were denied most often (45%, n=27). Wheelchair accessories and power wheelchairs were the next most common denials (25%, n=15 and 22%, n=13, respectively). Open-ended responses frequently mentioned denials for power wheelchair enhancements and/or modifications (e.g., eye gaze, ability drive). In-home care delivered by physical therapists, occupational therapists, speech therapists, and certified nursing assistants was the fourth most common denial (18%, n=11).

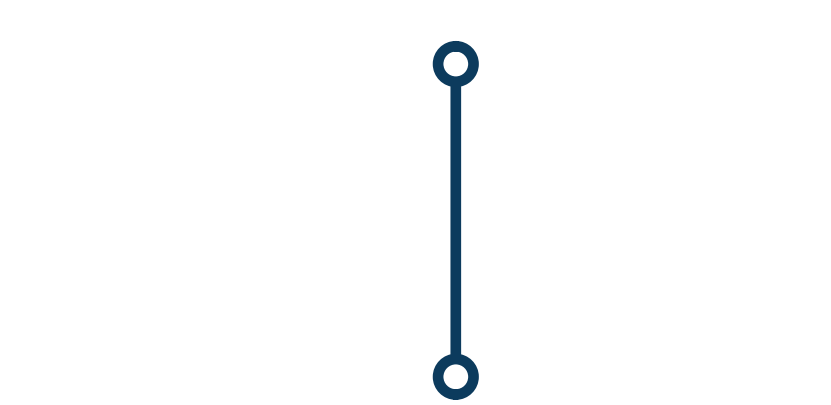
FIGURE 4: INSURANCE APPEAL JOURNEY

62 out of 192 participants surveyed had been denied prior authorization or payment for a claim.

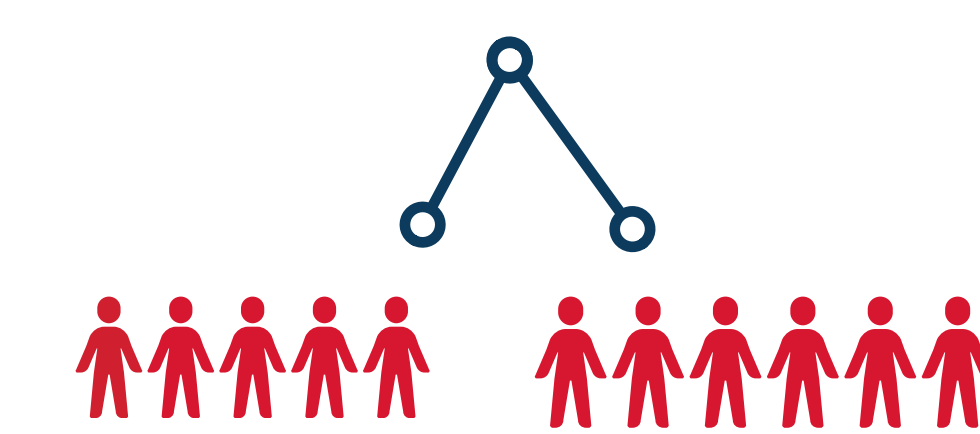
34 people appealed prior authorization

67% appealed up to 3 times

61% waited up to 6 months



11 denied full authorization

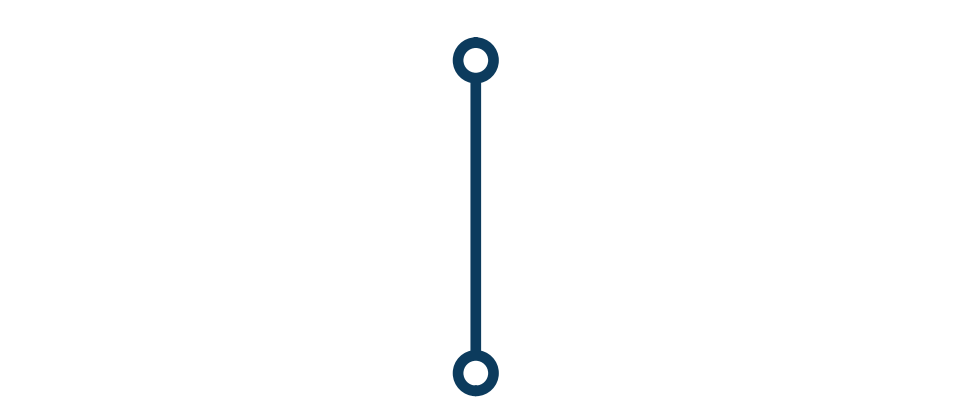


5 paid out of pocket **6 didn't obtain care**

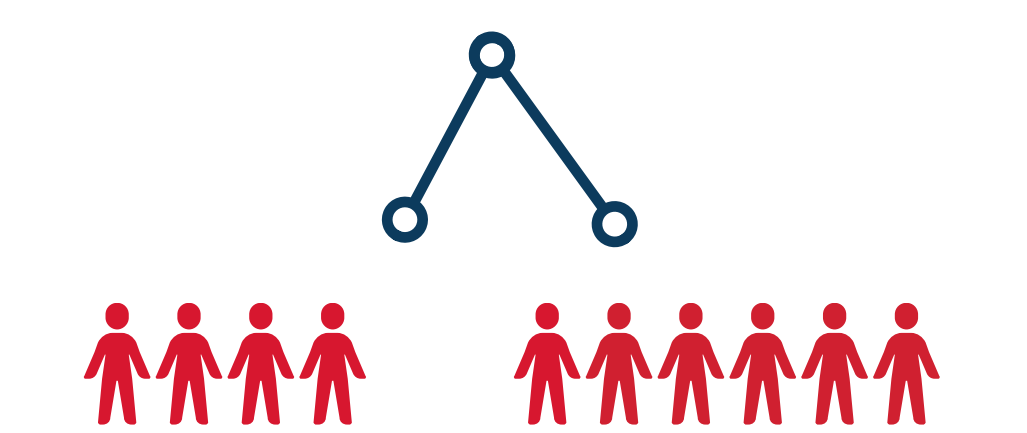
26 people appealed a claim

62% appealed up to 3 times

62% waited up to 6 months



10 denied full payment



4 paid out of pocket **6 stopped receiving care**

As illustrated in Figure 4, following a denial, 67% of those denied prior authorization and 47% of those denied a claim appealed the insurer's decision (n=34 and n=26, respectively). Most had to appeal up to three times and wait up to 6 months for a resolution. Subsequently, people received at least a partial denial of payment about a third of the time. For those denied full authorization or payment, they either had to pay out of pocket or not obtain/discontinue the care.

DISCUSSION

Findings from the ALS Focus Insurance and Payment for ALS Care Survey demonstrate the substantial burden that denied and delayed coverage of essential care places on people with ALS. The results reveal an urgent need for comprehensive coverage of the array of ALS care and services. This ALS Focus survey data informed development of an ALS Association Resource Guide, which aims to empower the ALS community to educate and persuade health plans in the US to cover ALS care early and often.

We would like to acknowledge the ALS Focus Patient and Caregiver Advisory Committee (PCAC), Steering Committee, and industry partners for their valuable contributions to the ALS Focus Insurance and Payment for ALS Care Survey and the ALS Focus program.