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BACKGROUND

ALS Focus is a survey program led by people with ALS and ALS caregivers to measure the needs, preferences, and experiences of ALS-affected individuals in the United States through ongoing surveys covering an array of topics (www.alsfocus.org). The ALS Focus Mobility Survey centered on access to affordable and high-quality mobility equipment, which supports engagement in the world as one lives with ALS or provides ALS care. This survey built on and was informed by previous mobility research with people with ALS [1, 2].

METHODS

The ALS Association developed the Mobility Survey with input from people with ALS, caregivers, industry, and academic experts. This survey took place online through a portal from Massachusetts General Hospital's (MGH) Neurological Clinical Research Institute (NCRI).

Survey Dates: The ALS Focus Mobility Survey took place from October to December 2021.

Measures: Survey questions asked about mobility devices used outside the home, including power wheelchairs, portable ramps, and rollators. Participants reported which devices they/the person with ALS used, how they accessed those devices, what standard or advanced features their devices include as indicators of quality, whether the devices met their mobility needs, and if they started using the devices on time.

Analytic Sample: 233 people with ALS and 119 current ALS caregivers (N=352 total). Eligible participants were 18 years old or older and lived in the U.S.

RESULTS

In this sample, 53% (n=186) reported current use of a power wheelchair, 27% (n=95) a portable ramp, and 28% (n=99) a rollator.

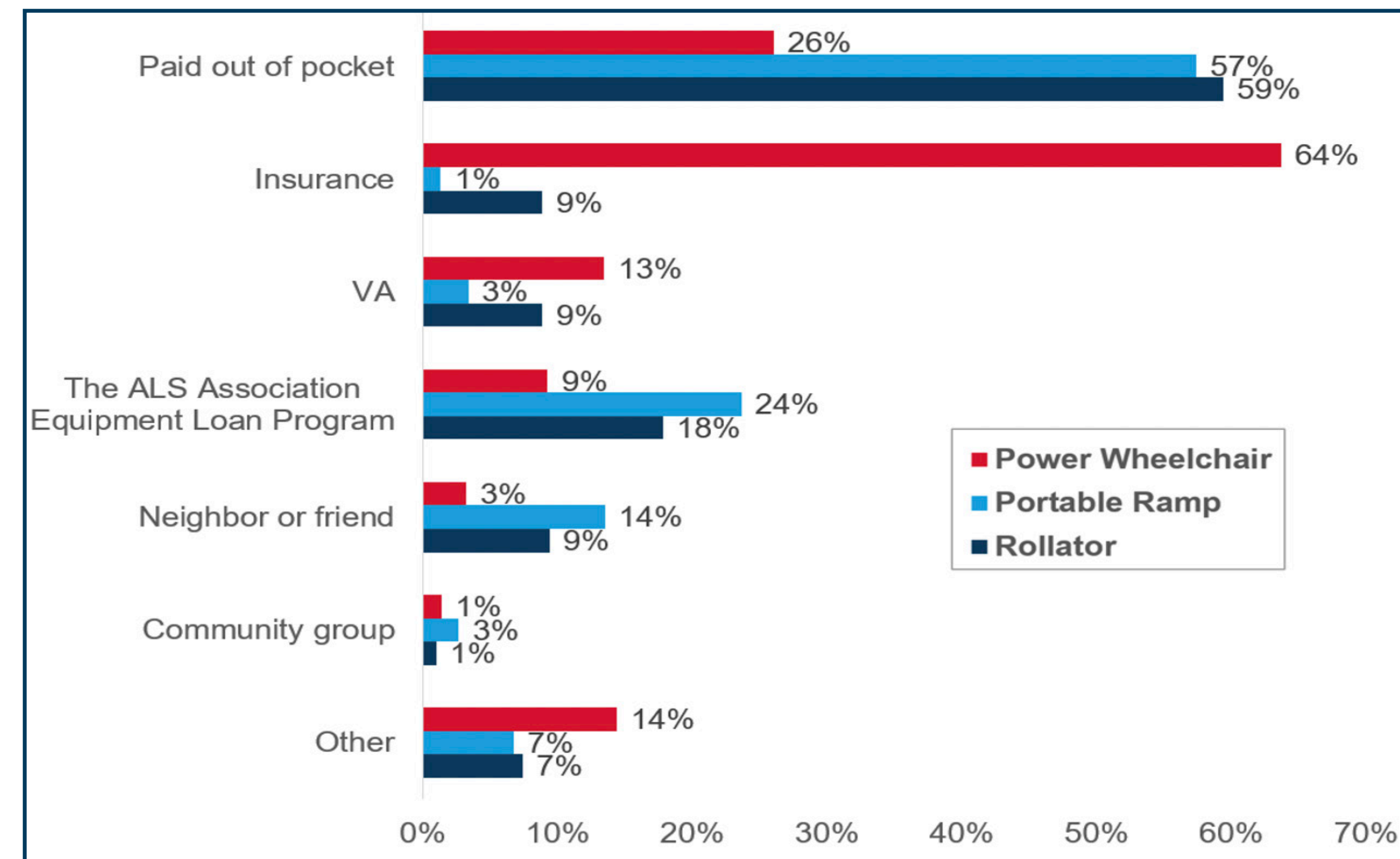
FIGURE 1. REASONS FOR NOT USING MOBILITY EQUIPMENT

- Delayed delivery of power wheelchair
- Difficult to operate power wheelchair
- Malfunctioning power wheelchair
- Emotionally unprepared to start using a power wheelchair
- Never heard of a portable ramp
- Did not know how to get a portable ramp
- Did not know where to use a portable ramp
- Physically unable to use a rollator

** Of those who did not currently use a power wheelchair, portable ramp, or rollator, 50-65% said they did not need the equipment*

Of those who did not currently use a power wheelchair, portable ramp, or rollator, 50-65% said they did not need the equipment. Open-ended responses revealed a variety of other reasons that people did not currently use these devices besides not needing them. Figure 1 summarizes these factors.

FIGURE 2. ALS MOBILITY EQUIPMENT SOURCES OF ACCESS



Participants were asked which sources paid for or provided their current or past mobility equipment, and they could select all applicable sources.

As shown in Figure 2, most said insurance at least partially covered the power wheelchair (64%, n=137), and a quarter (26%, n=56) paid at least some of the cost out of pocket. Notable proportions of participants reported receiving a portable ramp (24%, n=35) or a rollator (18%, n=36) through The ALS Association Equipment Loan Program. Still, over half reported paying out of pocket for a portable ramp (57%, n=85) or rollator (59%, n=120).

FIGURE 3. POWER WHEELCHAIR QUALITY AND COVERAGE

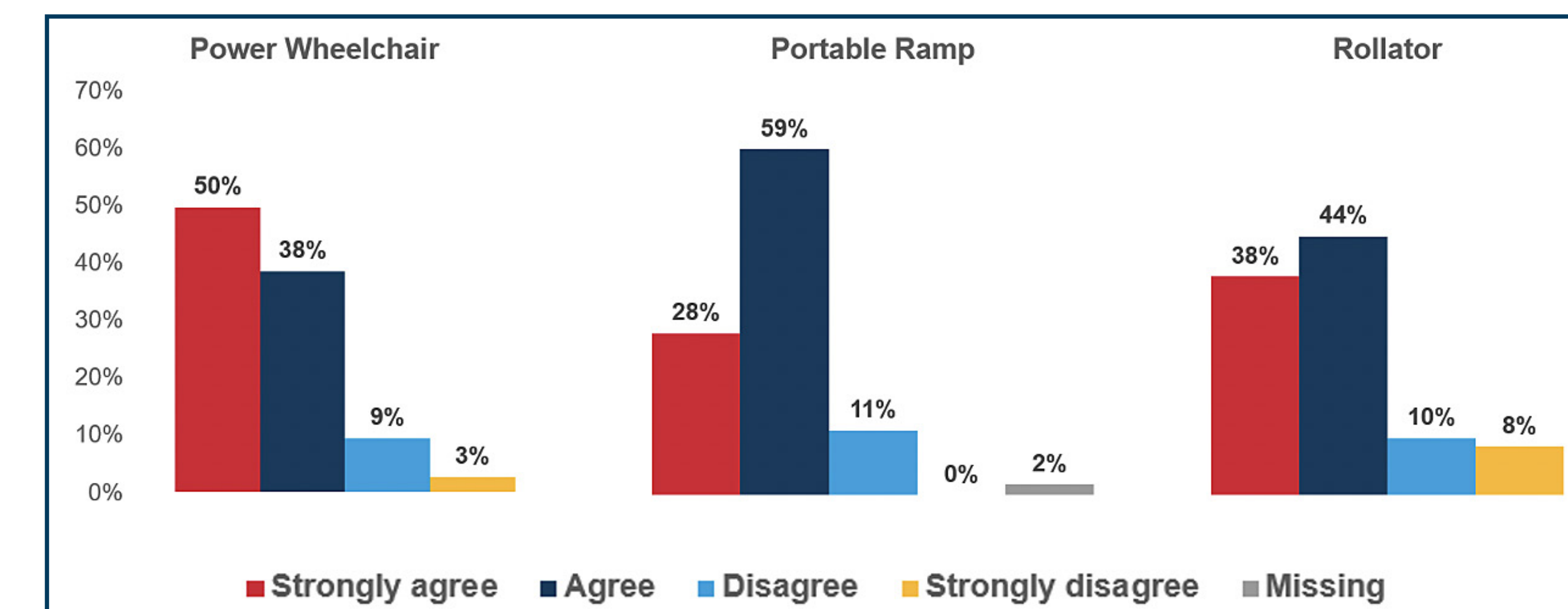
Power wheelchair option	Quality coding	Has option (N=186)	Insurance refused to cover option (N=186)
Standard joystick	Standard	93%	<1%
Captain seat	Standard	48%	1%
Tilt-in-space	Advanced	84%	1%
Power elevating leg rests or foot platform	Advanced	88%	3%
Electronic seat elevation	Advanced	80%	47%
Alternative drive controls	Advanced	41%	4%

Participants were asked what options their power wheelchair included (e.g., electronic seat elevation), which the study team coded as 'standard' or 'advanced' quality. Figure 3 shows access to each of these options. Most participants (92%, n=172) said their wheelchair or the wheelchair of the person they care for had at least one advanced option. The survey also asked if insurance refused to cover any of these options. Rarely did insurance refuse to cover any option according to responses, except in the case of electronic seat elevation, where nearly half (47%, n=87) said insurance refused to cover this option.

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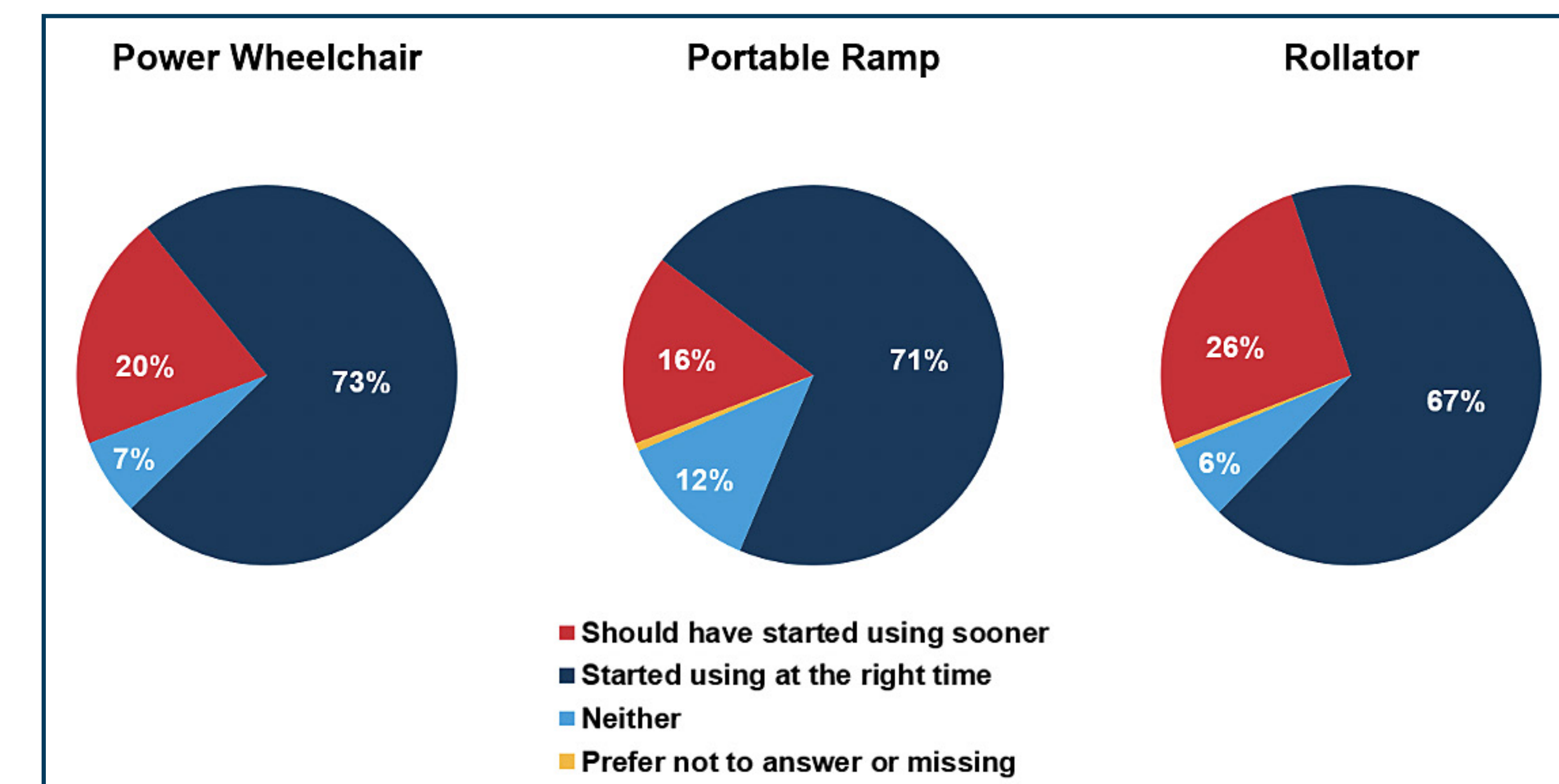
FIGURE 4. PERCEPTIONS ON WHETHER EQUIPMENT MEETS CURRENT MOBILITY NEEDS



Note. Only participants with ALS were asked this question.

For each type of equipment, participants with ALS were asked how much they agreed or disagreed with the statement: "My [equipment type] meets my current mobility needs." As shown in Figure 4, anywhere from 11% (n=6) to 18% (n=13) of participants with ALS disagreed that their equipment met their needs. Disagreement was most pronounced for rollators, suggesting that these devices fell short of meeting ALS mobility needs.

FIGURE 5. PERCEPTIONS ON WHETHER EQUIPMENT USE STARTED ON TIME



Participants were asked for their opinion on the timing of when they or the person they care for started using each type of mobility equipment. Figure 5 shows that 16% (n=24) to 26% (n=52) thought they/the person with ALS should have started using their power wheelchair, portable ramp, or rollator sooner.

DISCUSSION

The ALS Focus Mobility Survey quantified key directions to support access to mobility equipment so that people with ALS and caregivers may engage with the world in the way they want. Advocacy for affordable seat elevation on power wheelchairs, which allows people with ALS to interact with others at eye level, is warranted. Having mobility equipment before it is needed, rather than after, could also prevent injuries or hindered access to clinics and other spaces outside the home. Greater reach of equipment loan programs and insurance coverage would facilitate these positive health and quality of life outcomes for people with ALS.

REFERENCES

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