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BACKGROUND

ALS Focus is a patient- and caregiver-led survey program measuring the needs, preferences, and experiences of people with ALS and caregivers (www.als.org/ALS-Focus; Parvanta et al., 2020). Given the critical role that caregivers play in the United States (AARP, 2020), ALS Focus recently fielded a Caregiver Needs survey to determine the top programs for ALS caregivers and their key concerns.

METHODS

The ALS Association developed the Caregiver Needs survey with input from current and past ALS caregivers, people with ALS, industry, and academic experts. The survey took place online (www.alsfocus.org) through a portal from Massachusetts General Hospital's (MGH) Neurological Clinical Research Institute (NCRI).

Dates: The ALS Focus Caregiver Needs survey took place from January to April 2021.

Measures: ALS caregivers self-reported their time spent providing care, programs or tools used and needed most, preparedness for changes in caregiving responsibilities, top concerns, and quality of life.

Sample: 324 current caregivers and 287 past caregivers of people with ALS (N = 611 total). Eligible participants were 18 years old or older and lived in the U.S.

RESULTS

FIGURE 1. NUMBER OF HOURS DEDICATED TO CAREGIVING AS REPORTED BY CURRENT AND PAST CAREGIVERS.

Most ALS caregiver respondents (68%) reported spending more than 30 hours per week providing care, and another 10% spent 11-20 hours per week on caregiving (Figure 1).

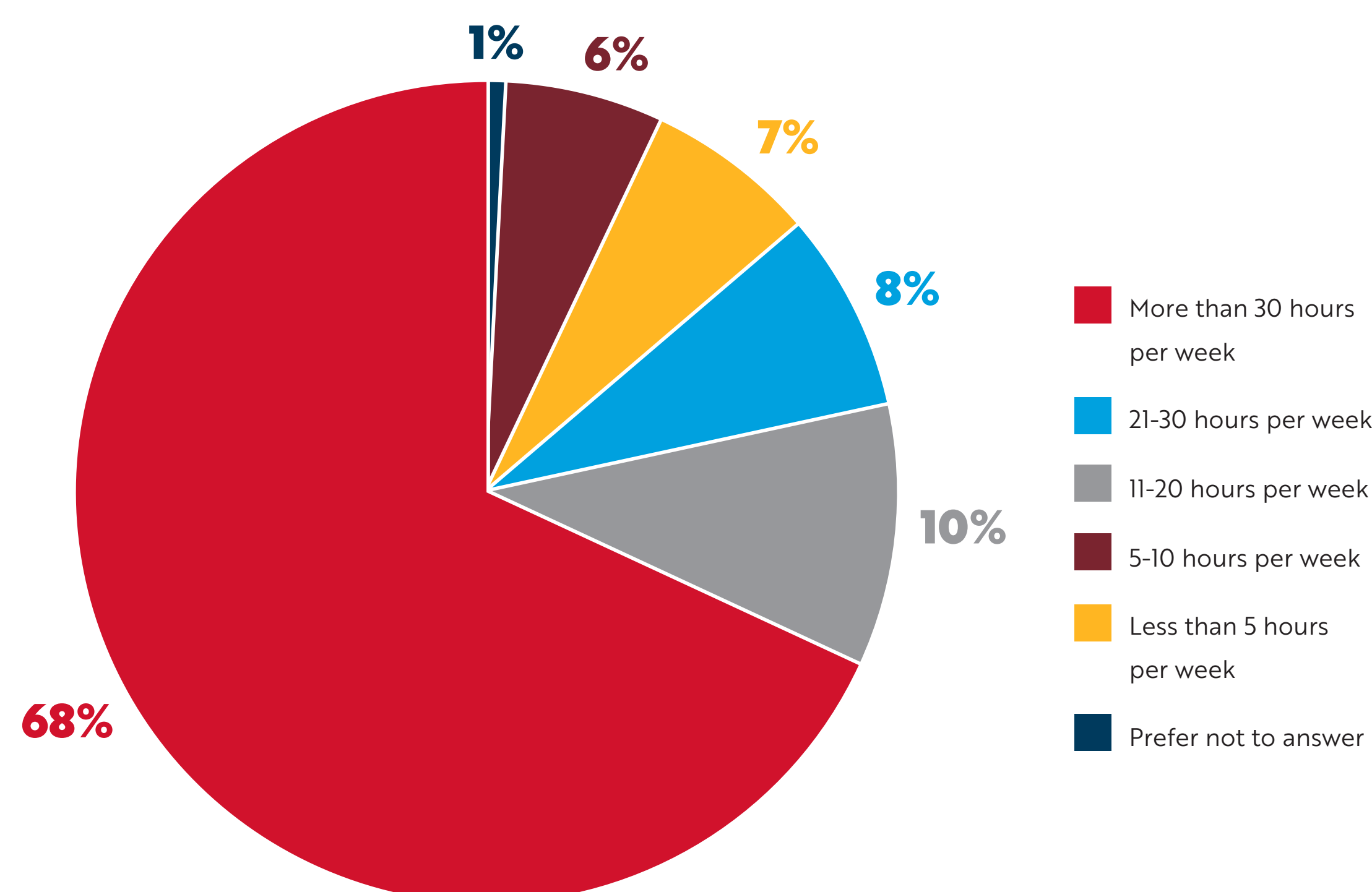


FIGURE 2. PROGRAMS MOST USED AND NEEDED BY ALS CAREGIVERS.

Out of a list of 24 support programs, ALS caregivers selected home visits from nurses and occupational or physical therapists as the most highly used (53%) and highly needed (49%) program. Fewer caregivers used trainings on general caregiving (34%), but these trainings ranked second (42%) in terms of mattering to caregivers in their roles.

The blue bars in Figure 2 show what percentage of caregivers used each program. The number next to each bar indicates the top 5 programs caregivers said they need.

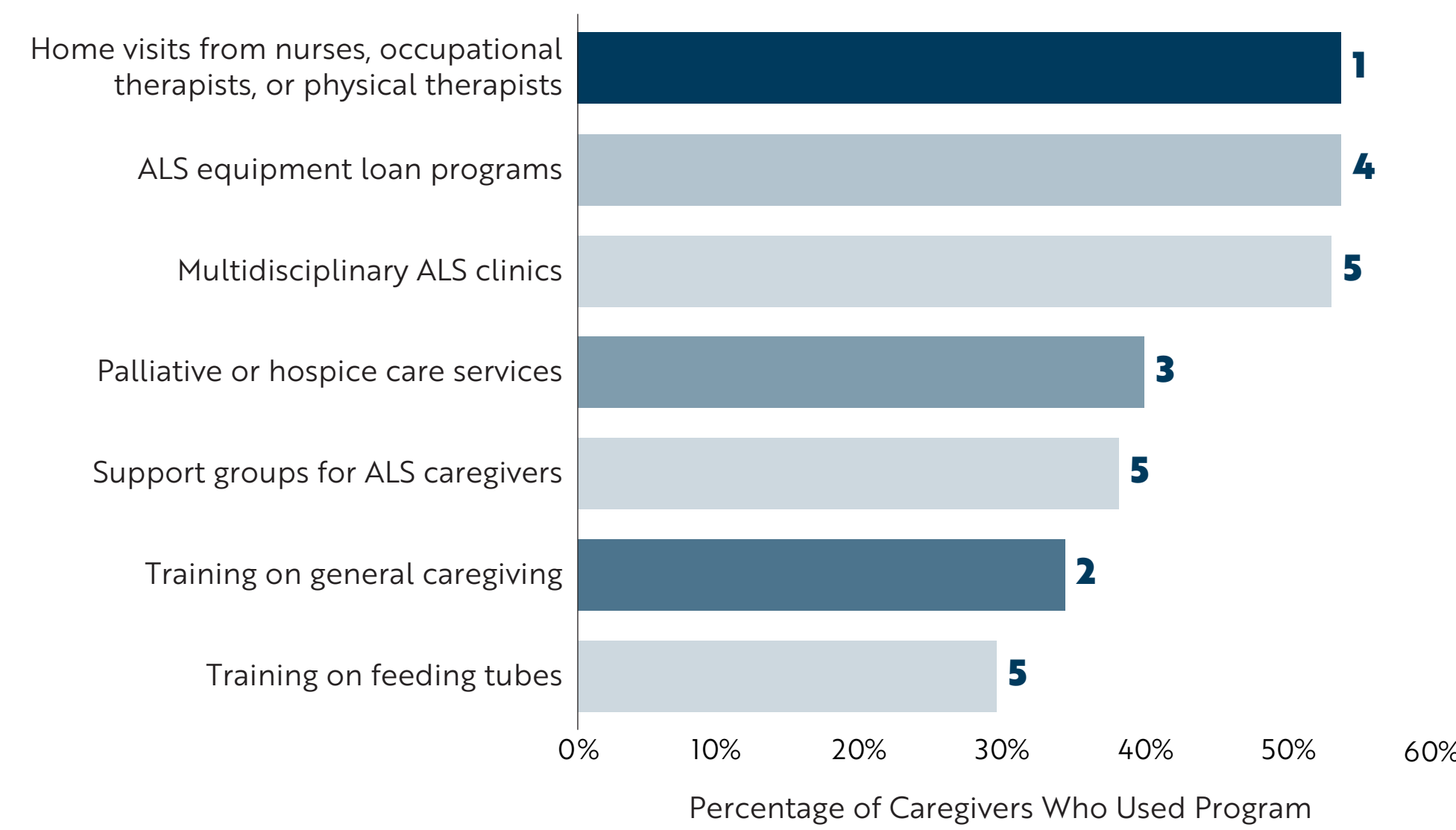


FIGURE 3. HOW PREPARED CAREGIVERS FEEL ABOUT TAKING ON NEW CAREGIVING RESPONSIBILITIES.

Just over half of current caregivers said they felt at least somewhat prepared for the coming changes in their responsibilities as ALS progresses. This result left nearly 46% who felt unprepared (Figure 3).

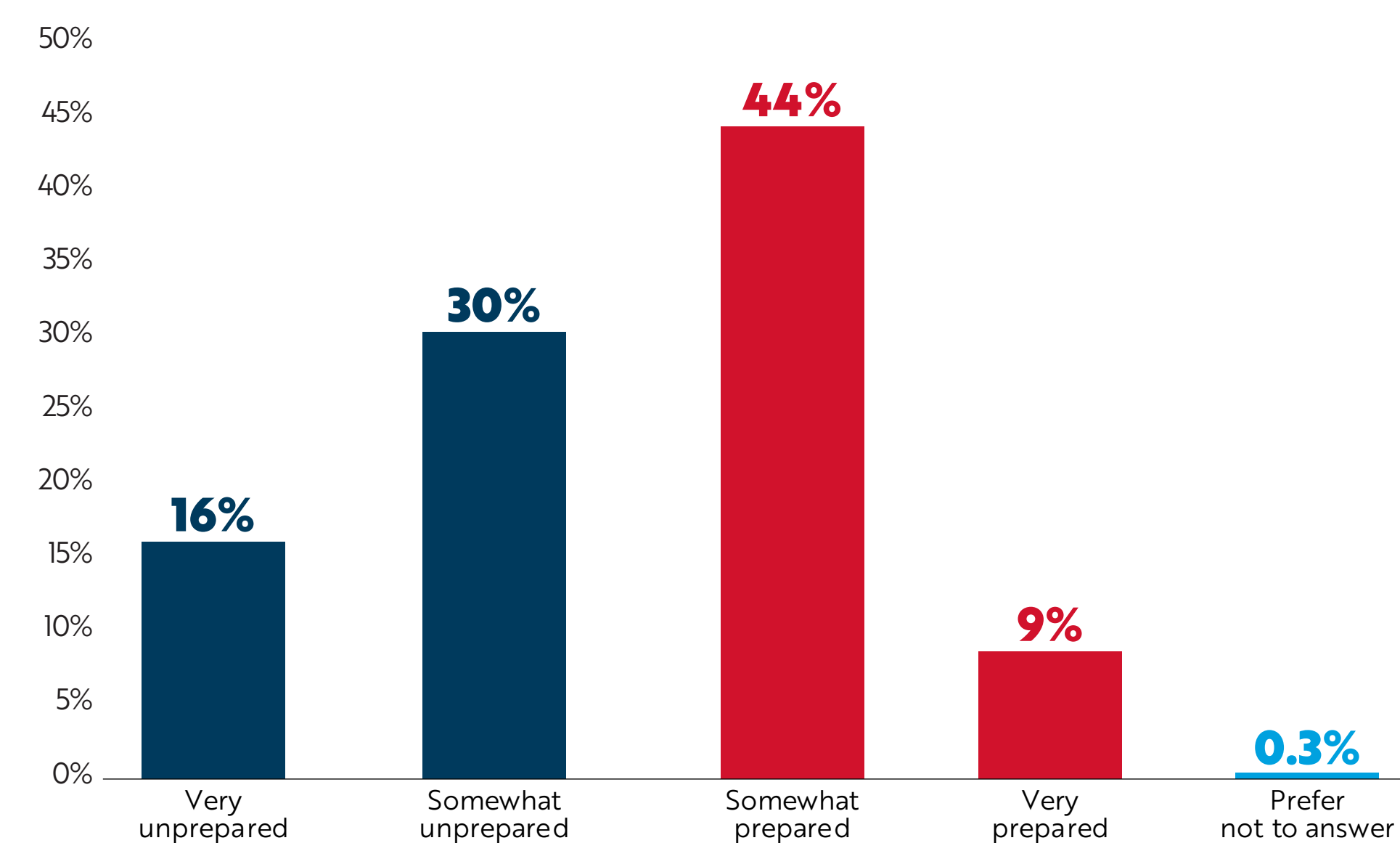


FIGURE 4. THE TOP FIVE MOST COMMON CONCERNS REPORTED BY CAREGIVERS.

ALS caregivers indicated their top 5 most common concerns from a list of 16 possible concerns adapted from Trail et al. (2004). The most common concern among caregivers (61%) was their family and loved ones' wellbeing (Figure 4).

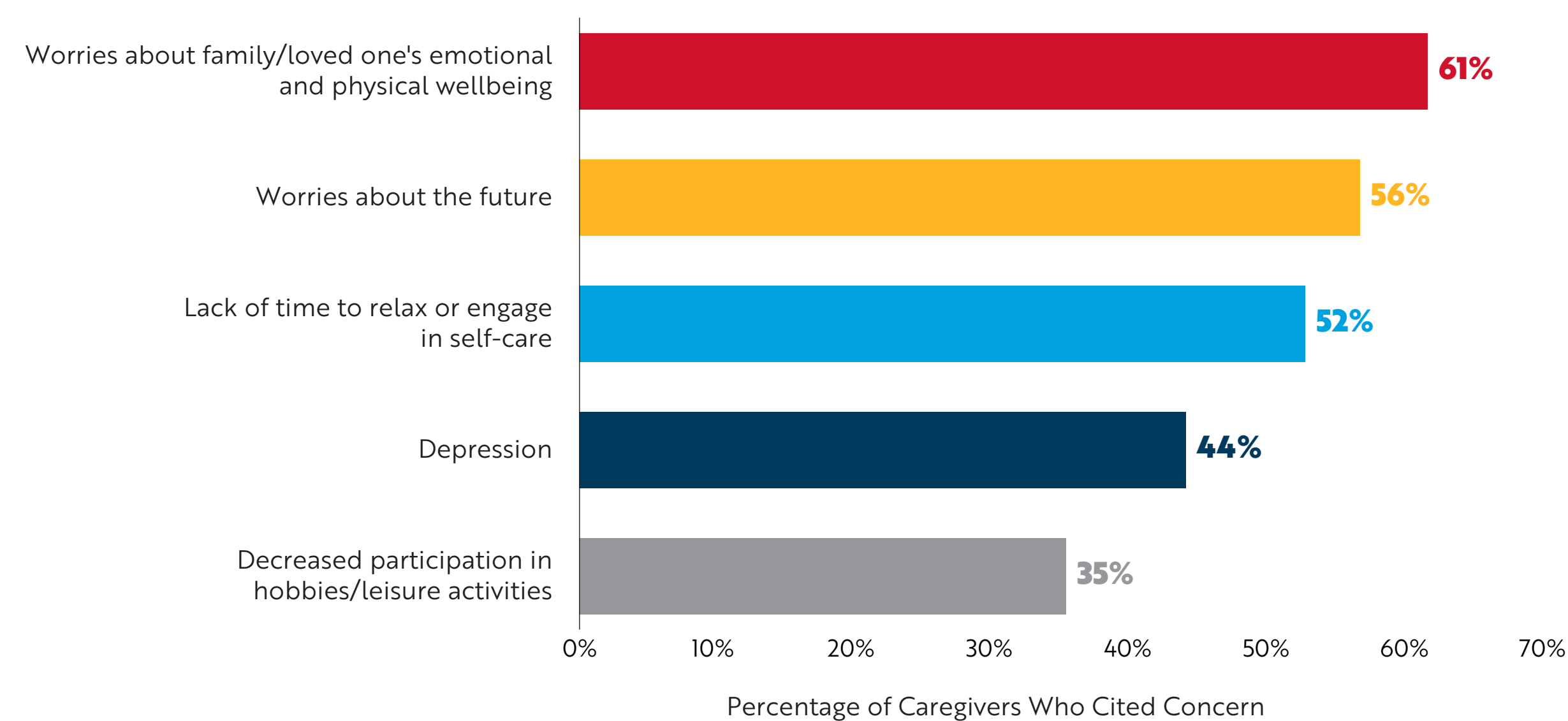
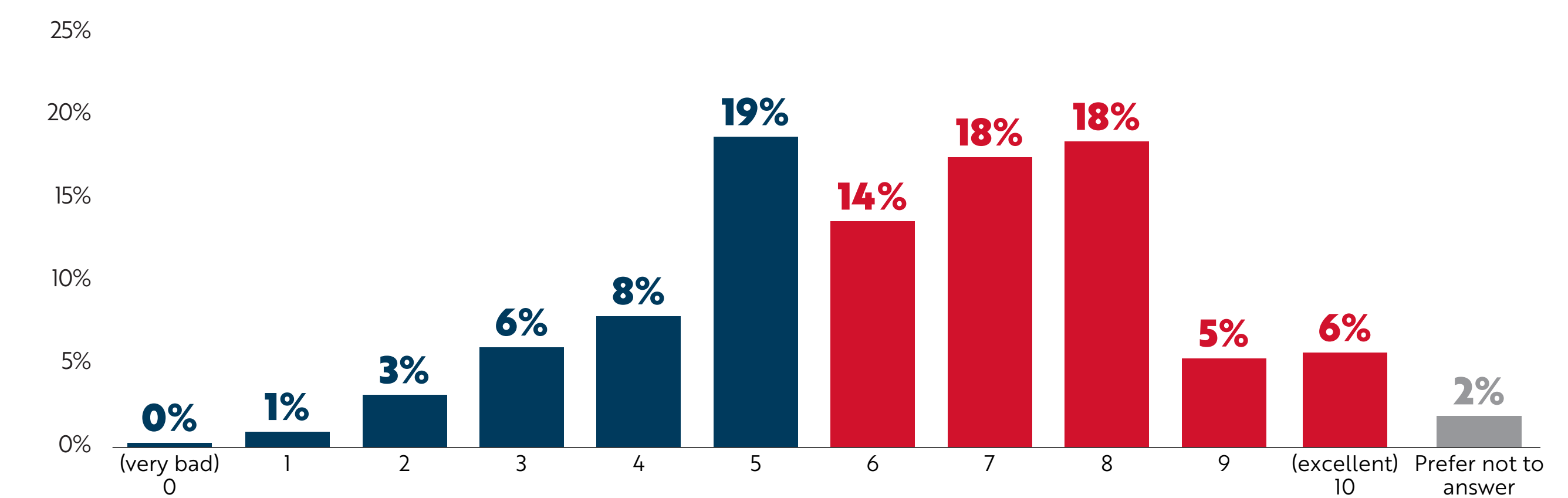


FIGURE 5. CURRENT CAREGIVERS' QUALITY OF LIFE RATING.

Based on a measure from Pagnini et al., (2010), current caregivers rated their overall quality of life on a scale from 0 (very bad) to 10 (excellent). Nearly two thirds (61%) rated their quality of life as a 6 or higher, leaving 37% who rated their quality of life on the lower or less positive side of the scale (Figure 5).



DISCUSSION

The ALS Focus Caregiver Needs survey systematically illuminated what ALS caregivers are going through and how to best support them going forward. Many caregivers feel unprepared for new changes as they provide ALS care. They are most concerned about their loved ones and deserve support to improve their own quality of life as they care for others. Home visits from healthcare professionals continue to be essential to ALS caregivers. Training on general caregiving should be made available and accessible to caregivers who need this service.

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