

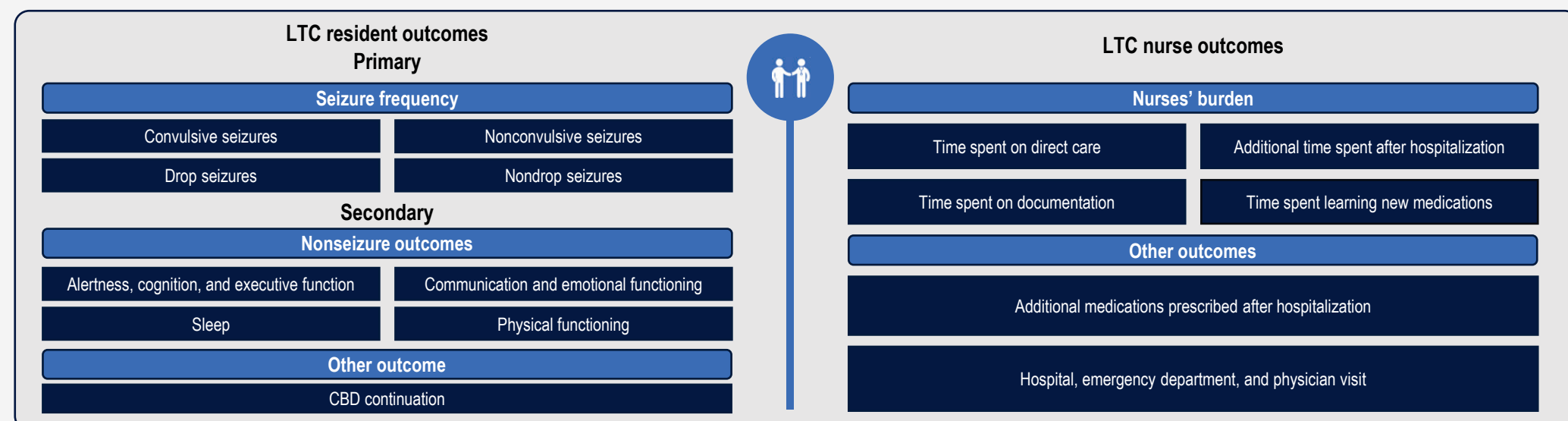
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Introduction

- Lennox-Gastaut syndrome (LGS), Dravet syndrome (DS), and tuberous sclerosis complex (TSC) are rare developmental and epileptic encephalopathies with onset in infancy or early childhood¹
- Epileptic seizures are associated with a significant burden of care, high healthcare utilization rates, and reduced health-related quality of life for both patients and caregivers.^{2,3} Prevalence of epilepsy is high in long-term care (LTC) and group home residents⁴⁻⁶
- Epidiolex®, a plant-derived highly purified pharmaceutical formulation of cannabidiol (CBD; 100 mg/mL oral solution), is approved for the treatment of seizures associated with LGS, DS, and TSC in patients ≥1 year of age and has demonstrated real-world effectiveness in both seizure and nonseizure outcomes in outpatient settings⁷⁻⁹
- The real-world effectiveness of CBD among residents with epilepsy in LTC settings, such as a community independent-living arrangement/group home or intermediate care facility (ICF), has not been studied from the perspective of experienced caregivers (nurses), despite the high prevalence of epilepsy in these settings
- The **BE**havior, **CO**gnition, and **MO**re with Epidiolex® in the Long-Term Care Setting (BECOME-LTC) survey evaluated nurses' perspectives on the outcomes associated with CBD treatment in LTC settings

Objective

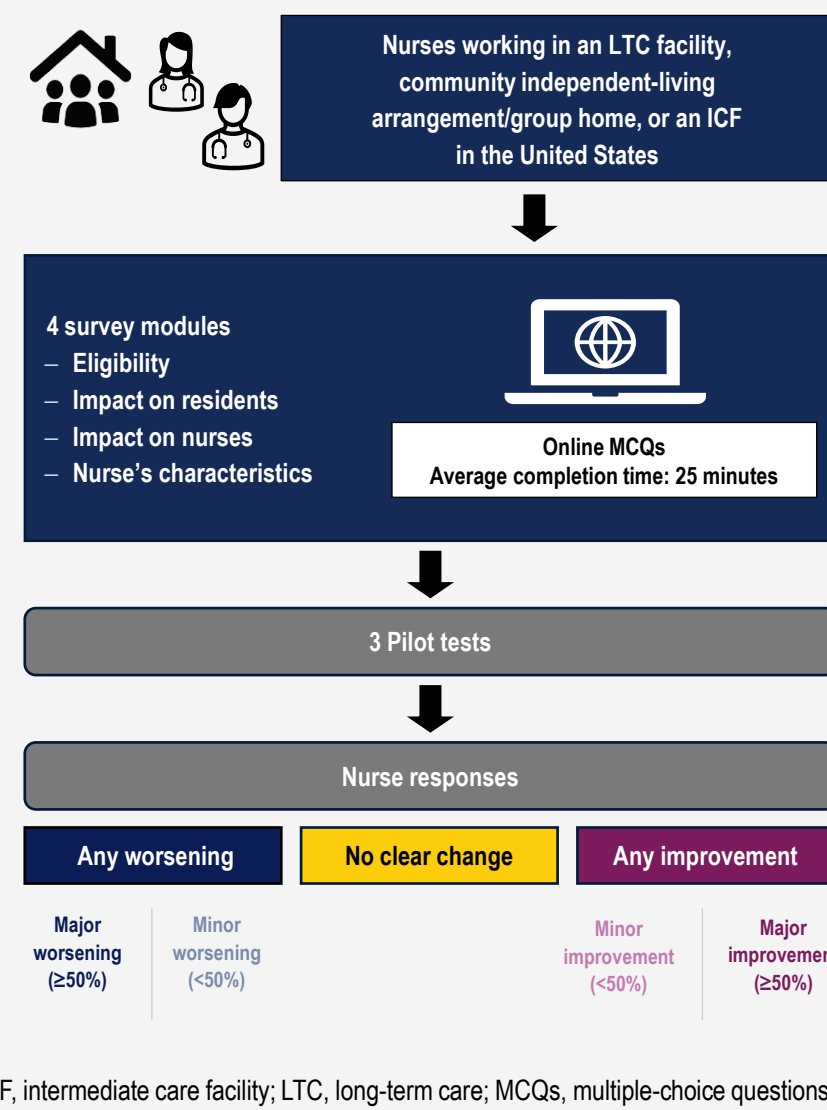
- To evaluate nurse-reported changes in seizure frequency and nonseizure outcomes among residents in an LTC setting before and after initiation of CBD treatment (**Figure 1**)

Figure 1. Study outcomes

CBD, cannabidiol; LTC, long-term care.

Methods

- Nurses actively working in LTC facilities, including community independent-living arrangements/group homes or ICFs in the United States, who are actively treating ≥1 patient (with CBD for ≥3 months) with a seizure-related disorder were included
 - The primary source of recruitment was through nurses affiliated with the Developmental Disabilities Nurses Association (DDNA), and additional nurses were recruited through a survey vendor, Sago
- Nurses completed an online, multiple-choice survey and ranked their impression of change in outcomes using a symmetrical Likert scale (from worsening to improvement) based on the most recent residents treated with CBD (Epidiolex®; **Figure 2**)
- For each outcome, nurses could choose 1 of 6 responses: Major improvement (≥50%); Minor improvement (<50%); No change; Minor worsening (<50%); Major worsening (≥50%); Don't know
- The study outcomes were measured as proportion of nurses who observed improvements or saw a decrease in hospital, emergency department (ED), and physician visits, as well as the impact on nurse's time due to seizure or hospitalization among the LTC residents

Figure 2. Study design

ICF, intermediate care facility; LTC, long-term care; MCQs, multiple-choice questions.

Results

Nurse, resident, and facility characteristics

Table 1. Nurse (respondent) characteristics

	Total respondents (N=102)
Age, years, n (%)	
22–34	13 (13)
35–44	42 (41)
45–54	26 (25)
≥55	21 (21)
Sex, n (%)	
Female	87 (85)
Male	9 (9)
Prefer not to say	6 (6)
Education, n (%)	
CNA, LPN, or associate's degree (eg, AA, AS)	24 (24)
BSN degree	50 (49)
Advanced degree	23 (23)
Other	5 (5)
Occupation, n (%)	
Nurse	95 (93)
Nurse consultant	6 (6)
Qualified developmental disability professionals	1 (1)
Years of experience, n (%)	
1–5	11 (11)
6–10	22 (22)
>10	69 (68)
Years at current facility, n (%)	
<1	4 (4)
1–5	41 (40)
6–10	25 (25)
>10	32 (31)
Recruitment cohort, n (%)	
DDNA	67 (66)
Sago	35 (34)

AA, associate of arts; AS, associate of science; BSN, bachelor of science in nursing; CNA, certified nursing assistant; DDNA, Developmental Disabilities Nurses Association; LPN, licensed practical nurse.

Table 2. Resident characteristics reported by nurses

	Total respondents (N=102)
Age, years, n (%)	
≤20	16 (16)
21–35	41 (40)
36–50	26 (25)
>50	19 (19)
Sex, n (%)	
Female	36 (35)
Male	64 (63)
Prefer not to say	2 (2)
Race*, n (%)	
American Indian or Alaska native	3 (3)
Asian	3 (3)
Black or African American	12 (12)
White	80 (78)
Other/prefer not to answer	8 (8)
IDD diagnosis, n (%)	
No	23 (23)
Yes	79 (77)
Condition*, n (%)	
DS	8 (8)
LGS	37 (36)
TSC	2 (2)
Other refractory epilepsy condition	35 (34)
None of the above/uncertain*	25 (25)

*Multiple options could be selected, so counts and percentages may not sum up to 100%.

*Includes seizure disorders other than DS, LGS, TSC, or a refractory epilepsy condition, which was not available as a terminology in the choices displayed in the survey and nurses reported these as "None of the above/uncertain." DS, Dravet syndrome; IDD, intellectual or developmental disability; LGS, Lennox-Gastaut syndrome; TSC, tuberous sclerosis complex.

- A total of 102 nurses who treated a resident with CBD for ≥3 months completed the survey (**Table 1**)
- As reported by nurses, 84% of residents were aged ≥20 years; 46% had LGS, DS, or TSC (**Table 2**)
- Community independent-living arrangement/group home was the most common type of residence facility (reported by 42% of nurses), followed by LTC facility (29%), ICF (19%), and others (10%)
- More than half of nurses (58%) worked in a facility with >50 residents, while 52% worked in a facility with ≤10 nurses

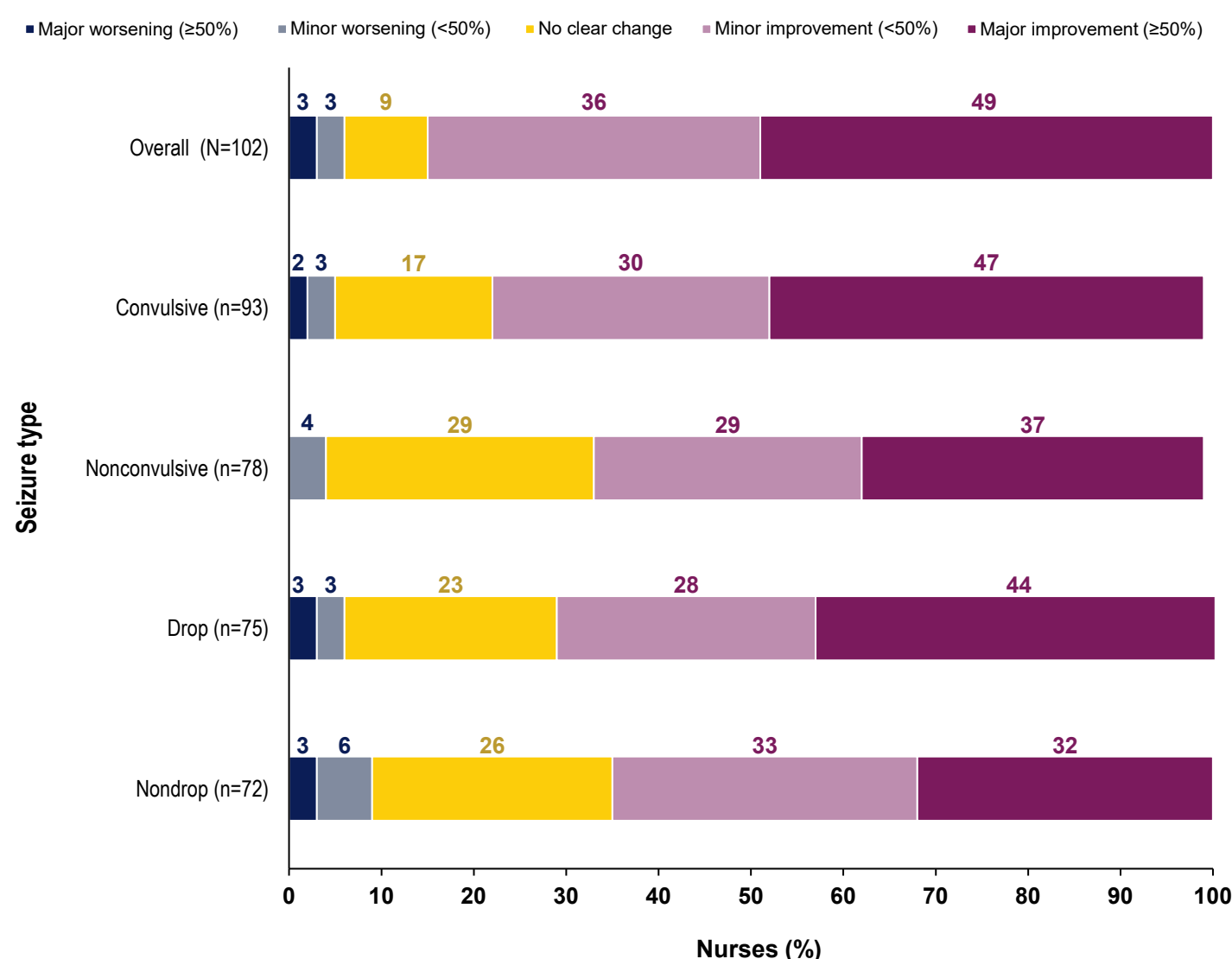
CBD continuation

- A majority (98% [100/102]) of nurses would advocate for the continued use of CBD
- The most common reasons for advocating to continue the use of CBD as reported by nurses were reduced seizure frequency (83%), reduced seizure severity (81%), improved social functioning (39%), improved sleep (37%), and increased alertness (37%)

Conclusions

- In this analysis, 85% of nurses reported reduction in seizure frequency and 38–75% reported improvements in nonseizure outcomes among residents with LGS, DS, TSC, and other refractory epilepsy conditions receiving CBD treatment in LTC settings
- According to nurses, the use of CBD among residents in LTC settings reduced hospitalizations, ED visits, and nurses' burden of direct and indirect care time for residents
- These survey results suggest the benefits of CBD treatment in residents with epilepsy in LTC facilities and group homes and support further evaluation of CBD in these settings

LTC resident outcomes: Seizure frequency

Figure 3. Nurse-reported changes^a in seizure frequency after CBD treatment^a"Changes" refers to any worsening (major [≥50%] or minor [<50%] increase) or any improvement (major [≥50%] or minor [<50%] decrease) in seizure frequency. CBD, cannabidiol.

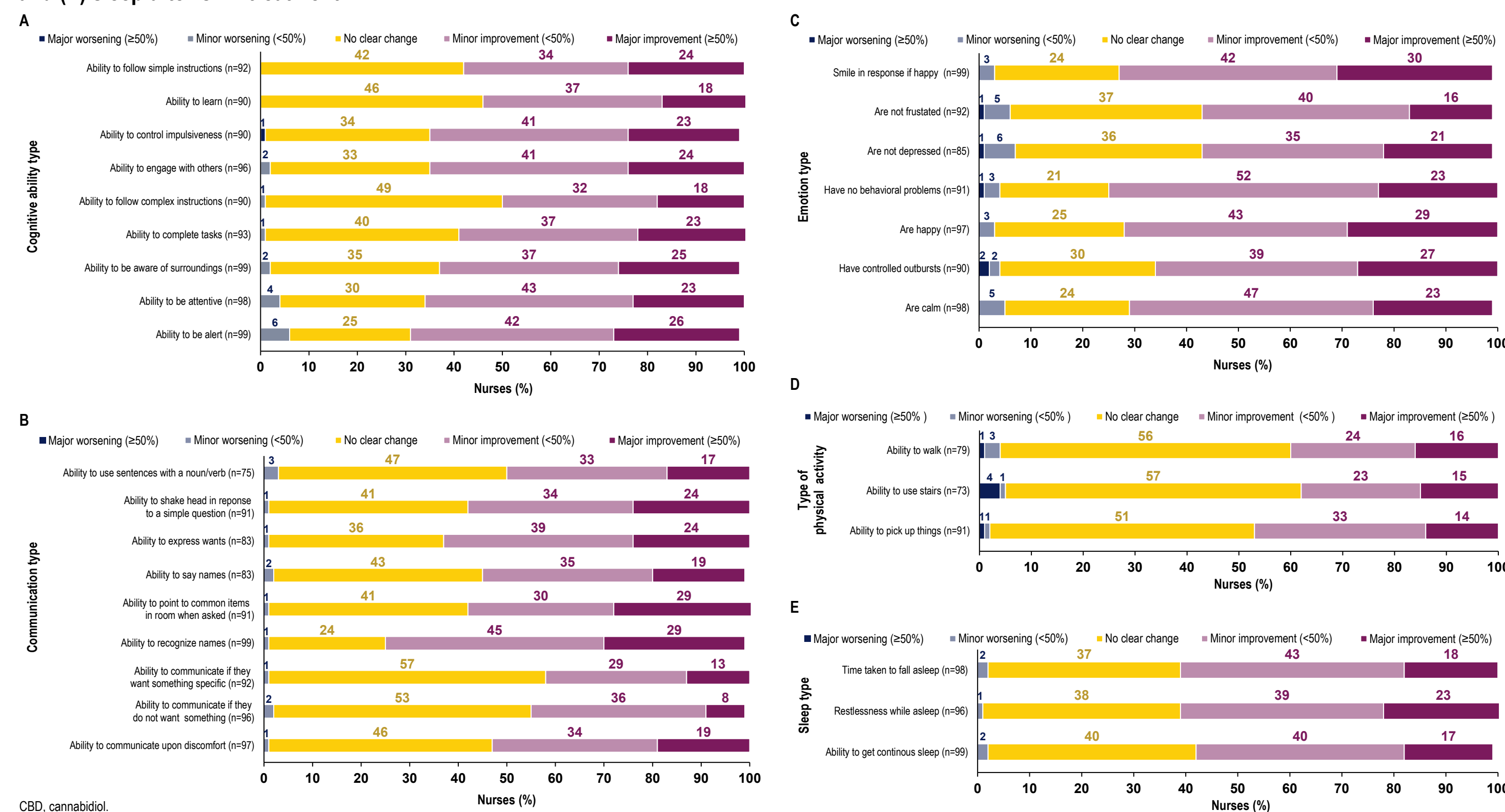
- Reduction in overall seizure frequency after CBD initiation was reported by 85% of nurses; 9% reported no change and 6% reported worsening (**Figure 3**)
- After CBD initiation, improvements were observed across seizure types, with 77% of nurses reporting reduction in convulsive seizures, 72% in drop seizures, 66% in nonconvulsive seizures, and 65% in nondrop seizures
 - Across seizure types, no change in seizure frequency was reported by ≤29% of nurses and worsening by ≤9%

LTC nurse outcomes

Nurses' burden

- Nurses reported that seizures and hospitalizations increase their burden of care
 - 67% reported having to provide ≥30 minutes of documentation, and 85% reported having to provide ≥30 minutes of direct care after a seizure
 - 26% of nurses spent ≥30 minutes learning new medications, and 69% spent ≥1 hour at the hospital after a resident hospitalization

LTC resident outcomes: Nonseizure outcomes

Figure 4. Nurse-reported changes in nonseizure outcomes of (A) cognitive ability, (B) communication ability, (C) emotional ability, (D) physical ability, and (E) sleep after CBD treatment

- After CBD initiation, improvements were reported in nonseizure outcomes, with 50–68% of nurses reporting improvements in cognitive abilities (**Figure 4A**), 42–74% in ability to communicate (**Figure 4B**), 56–75% in emotional functioning (**Figure 4C**), 38–47% in physical functioning (**Figure 4D**), and 57–62% in sleep (**Figure 4E**)

Resident hospitalizations, ED visits, and physician visits

- After CBD initiation, 79% of nurses reported a reduction in hospitalizations, 78% noted fewer ED visits, and 59% observed a decrease in physician visits

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