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Appendix

TABLE E-1 Brief Description of the International Classification of Functioning, Disability and Health (ICF) Framework and Questionnaires Used at Long-Term Assessment*

International Classification of Functioning, Disability and Health (ICF)[15]
The ICF was established by the World Health Organization in 2001 as a framework for measuring health and disability multidimensionally. Impairments of body structure and function are portrayed in the context of abilities or limitations in activities that an individual performs, how an individual participates as a member of society, and the influence of environmental factors.
Diener Satisfaction with Life Scale (SWLS)[32]
The SWLS assesses global life satisfaction via a 5-item questionnaire using a 7-point Likert scale response, ranging from strongly disagree to strongly agree. Summary scores range from 5 (low satisfaction) to 35 (high satisfaction).
Abbreviated World Health Organization Quality of Life scale (WHOQOL-BREF)[31]
The WHOQOL-BREF, derived from the WHOQOL-100, is a 26-item questionnaire that contains 2 items to address overall quality of life and general health, and 24 items that divide into 4 subdomains: physical health, psychological health, social relationship, and environmental health. A higher score denotes a higher perceived quality of life.
Modified Brief Pain Inventory (BPI)[33]
The modified BPI assesses the extent to which pain has interfered with 12 activities (e.g., mood, sleep) within the past week. A response of "0" means that pain did not interfere with the activity, and a response of "10" indicates that pain completely interfered with the activity. Responses across the 12 activities are averaged for a summary score ranging from 0 to 10.
Frequency of Participation Questionnaire[30]
The FPQ was developed for children with disabilities and is made up of 14 items. Questions assess the frequency of extracurricular activities (e.g., eating outside of the home), with 6 response options ranging from "never" to "more than once per week." A higher score denotes higher participation.
Functional Mobility Scale (FMS)[29]
The FMS was developed for children with cerebral palsy to describe their use or nonuse of different assistive devices in traveling short (5 m), medium (50 m), or long (500 m) distances. There are 6 choices, ranging from "independent on all surfaces" to "uses wheelchair, stroller, or buggy."
Gillette Functional Assessment Questionnaire (FAQ)[27,28]
The FAQ walking scale is a parent-reported tool developed for children with motor impairments. The 10-point ordinal scale ranges from 1 (nonambulatory) to 10 (walks, runs, climbs on all terrains independently). Use of orthoses or assistive devices to perform such tasks is permissible. Additionally, there are 22 advanced FAQ skills (e.g., running, stepping, kicking, riding a bike) that the parent ranks using a 4-point ordinal scale ranging from 1 ("easy") to 4 ("can't do at all/too young for activity").
Caregiver Priorities and Child Health Index of Life with Disabilities (CPCHILD) comfort component[34]
The comfort component of the CPCHILD questionnaire was developed for children with cerebral palsy to describe their health status and well-being. It asks about pain or discomfort experienced by the child in the past 2 weeks during 7 activities of daily living (e.g., while lying down/sleeping). Responses range from "none of the time" to "every day." If pain was a concern, an intensity rating is selected, including "mild," "moderate," or "severe." It is then converted to a standardized score, with 100 indicating no pain.
Self-Report Leeds Assessment of Neuropathic Symptoms and Signs (S-LANSS) pain scale[35]
The S-LANSS was developed to assess whether the type of pain being experienced is related to neuropathy. Seven questions ask about the sensation, color, and response to touch of painful areas. A score of ≥12 suggests that the pain is predominantly of neuropathic origin.

*Only the Gillette Functional Assessment Questionnaire was also administered at the baseline and short-term visits.

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TABLE E-2 Treatments Received Prior to and After the Qualifying Baseline Gait Analysis*

	Total		Per Limb				Total		Per Limb		
Prior Treatment	Non-DFEO + PTA	DFEO + PTA	Non-DFEO + PTA	DFEO + PTA	Factor	Post Treatment	Non-DFEO + PTA	DFEO + PTA	Non-DFEO + PTA	DFEO + PTA	Factor
Botulinum injection†	27	91	0.90	2.68	0.34	Botulinum injection†	101	73	3.37	2.15	1.57
Gastrocnemius - soleus complex lengthening	22	23	0.73	0.68	1.08	Foot and ankle soft tissue	20	14	0.67	0.41	1.62
Hamstring lengthening	19	33	0.63	0.97	0.65	Implant removal‡	16	91	0.53	2.68	0.20
Femoral derotational osteotomy	13	23	0.43	0.68	0.64	Foot and ankle osteotomies	14	38	0.47	1.12	0.42
Adductor lengthening	11	22	0.37	0.65	0.57	Hamstring lengthening	15	5	0.50	0.15	3.33
Foot and ankle osteotomies	11	17	0.37	0.50	0.73	Gastrocnemius-soleus complex lengthening	13	12	0.43	0.35	1.23
Foot and ankle soft tissue	12	31	0.40	0.91	0.44	Tibial derotational osteotomy	13	21	0.43	0.62	0.70
Implant removal‡	9	20	0.30	0.59	0.51	Neural other§	13	2	0.43	0.06	7.2
Selective dorsal rhizotomy	8	11	0.27	0.32	0.82	Femoral derotational osteotomy	10	17	0.33	0.50	0.67
Rectus transfer	8	11	0.27	0.32	0.82	Rectus transfer	8	11	0.27	0.32	0.82
Tibial derotational osteotomy	8	15	0.27	0.44	0.60	Soft tissue, other	7	12	0.23	0.35	0.66
Psoas lengthening	6	15	0.20	0.44	0.45	Adductor lengthening	6	7	0.20	0.21	0.97
Osteotomy, other	3		0.10			Psoas lengthening	4	12	0.13	0.35	0.38
Soft tissue, combination	3	2	0.10	0.06	1.70	Spine	4		0.13		
Soft tissue, other	3	9	0.10	0.26	0.38	Osteotomy, other	3	3	0.10	0.09	1.13
Intrathecal baclofen	2	8	0.07	0.24	0.28	Leg length	2	6	0.07	0.18	0.38
Exploratory	1		0.03			Intrathecal baclofen	2	1	0.07	0.03	2.27

Spine	1	1	0.03	0.03	1.13	Soft tissue, combination	2		0.07		
Neural, other§		9		0.26		Osteotomy, other	1		0.03		
Cast long		4		0.12		Cast, long	1		0.03		
Leg length		2		0.06		Exploratory	1	1	0.03	0.03	1.13
Soft tissue, unknown		1		0.03		Selective dorsal rhizotomy	1		0.03		
						DFEO		34		1.00	
						Patellar advancement#		35		1.03	
Total	167	348	5.6	10.2	0.54	Total	257	395	8.6	11.6	0.74

*N = 34 in the DFEO + PTA group and n = 30 in the non-DFEO + PTA group (including participants who only answered questionnaires). Data are ordered according to the greatest frequency of treatments received per limb in the non-DFEO + PTA group for the listed epoch. Factor reflects treatment frequency of non-DFEO + PTA relative to DFEO + PTA participants. †Counted per muscle group and per event (for example, injections to both medial and lateral hamstrings were counted as 2 injections). ‡Counted per each implant removed (Example 1: if a tibial and femoral plate were removed on the same day, that would be counted as 2 implant removals. Example 2: if a tension band was removed in a surgical event separate from a tibial screw and femoral implant, these would be counted as 3 implant removals. Example 3: if a proximal tibial implant was removed following DFEO + PTA and a distal tibial implant was removed following tibial derotational osteotomy, that would be counted as 2 implant removals). §Phenol injections, with the exception of a single instance of a baclofen test dose. #One individual underwent patellar advancement revision.

TABLE E-3 Demographics and Select Variables at Baseline for the Qualifying Individuals in the DFEO + PTA Group Who Did Not Participate in the Study (N = 53)*

Demographics	
Age at gait analysis† *(yr)*	13.4 (4.2) [10.6-21.5]
GMFCS level‡ *(no.[%])*	
I	5 (9%)
II	18 (34%)
III	25 (47%)
IV	5 (9%)
FAQ walking level†	8 (3) [2-10]
Gait	
Knee flexion at contact§ *(°)*	47.2 ± 13.7 [24.4-85.4]
Minimum knee flexion§ *(°)*	41.1 ± 15.0 [19.4-87.3]
GDI§	60 ± 11 [43-85]
Velocity§ *(nondimensional)*	0.26 ± 0.12 [0.04-0.55]
O_2 consumption#§ *(nondimensional, % of speed-matched typically developing reference)*	378 ± 185 [169-1,095]
Physical examination	
Knee flexion contracture† *(°)*	15 (10) [10-40]
Extensor lag**† *(°)*	20 (20) [0-60]
Patella alta** *(no. [%])*	46 (98%)

*Did not participate for various reasons, as shown in Figure 1. One random limb was selected for analysis. †The values are given as the median, with the width of the interquartile range in parentheses and the range in brackets. ‡GMFCS level assigned retrospectively for 85% of the individuals who qualified but did not participate (Fig. E-1). §The values are given as the mean and the standard deviation, with the range in brackets. #Missing data (28%). **Missing data (13%).

TABLE E-4 Manual Muscle Testing Scores at Baseline and Long-Term Assessment*

	Baseline	Long-Term
Hip flexion		
DFEO + PTA	4 (2) [2-5]	4 (2) [2-5]
Non-DFEO + PTA	4 (0) [2-5]	4 (1) [2-5]
Hip extension, knee 0°		
DFEO + PTA	3 (2) [1-5]	3 (2) [1-5]
Non-DFEO + PTA	3 (2) [1-4]	3 (2) [1-5]
Hip extension, knee 90°		
DFEO + PTA	2 (1) [1-4]	2 (1) [1-5]
Non-DFEO + PTA	3 (1) [0-3]	2 (1) [1-5]
Hip abduction		
DFEO + PTA	3 (1) [1-5]	3 (2) [1-5]
Non-DFEO + PTA	3 (1) [1-4]	3 (2) [1-5]
Hip adduction		
DFEO + PTA	3 (2.25) [1-5]	3 (3) [2-5]
Non-DFEO + PTA	4 (2) [2-5]	3 (2.25) [2-5]
Knee flexion		
DFEO + PTA	3 (1) [1-5]	3 (1) [2-5]
Non-DFEO + PTA	4 (1) [2-4]	3 (1) [2-5]
Knee extension		
DFEO + PTA	3 (2) [2-5]	5 (2) [3-5]
Non-DFEO + PTA	4 (1) [2-5]	4 (2) [3-5]
Plantar flexion		
DFEO + PTA	2 (1) [0-4]	2 (0) [0-5]
Non-DFEO + PTA	2 (1.5) [0-4]	2 (0) [2-5]
Dorsiflexion		
DFEO + PTA	3 (2) [0-5]	4 (3) [1-5]
Non-DFEO + PTA	4 (1) [1-4]	4 (2) [2-5]

*Ranging from 0 (no contraction felt) to 5 (typically developing strength). The values are given as the median, with the width of the interquartile range in parentheses and the range in brackets.

TABLE E-5 Modified Brief Pain Inventory (BPI) Screening Question at Long-Term Assessment: "Has the Patient Had Pain Other Than These Everyday Kinds of Pain Today?"

	DFEO + PTA	Non-DFEO + PTA	P Value
Yes *(no. [%])*	10 (30%)	13 (45%)	0.296
No *(no. [%])*	23 (70%)	16 (55%)	

TABLE E-6 Modified BPI at Long-Term Assessment: Pain Interference Over the Past Week*

	DFEO + PTA	Non-DFEO + PTA	P Value
Average interference score	0.9 (2.6)	1.2 (3.2)	0.601
General activity	1 (3) [0-8]	1.5 (4) [0-9]	0.504
Mood	1 (3.25) [0-8]	1.5 (3) [0-7]	0.414
Mobility	2 (5) [0-10]	2 (5) [0-9]	0.949
School/work	0 (3.25) [0-8]	1 (4) [0-9]	0.717
Relations with others	0 (2) [0-6]	0 (2) [0-6]	0.682
Sleep	1 (4) [0-7]	1 (5) [0-8]	0.539
Enjoyment of life	0 (2.25) [0-8]	1 (3) [0-9]	0.693
Self-care	0 (2.25) [0-7]	1 (3) [0-9]	0.412
Recreational activities	0 (4.25) [0-8]	1 (3) [0-6]	0.936
Social activities	0 (2.25) [0-8]	0 (3) [0-7]	0.856
Communication with others	0 (0) [0-8]	0 (2) [0-7]	0.154
Learning new information	0 (0) [0-7]	0 (1) [0-7]	0.599

*Modifications adapted from Tyler et al.[33], including the addition of "Communication with others" and "Learning new information." Score of 10 = pain completely interferes. The values are given as the median, with the width of the interquartile range in parentheses and the range in brackets.

TABLE E-7 Pain Medication(s) at Long-Term Assessment*

	DFEO + PTA	Non-DFEO + PTA	P Value
Taking pain medications?			0.384
Yes *(no. [%])*	6 (18%)	8 (27%)	
No *(no. [%])*	28 (82%)	22 (73%)	
Duration	>1 yr	>1 yr	0.592
Frequency	1×/day and >1×/day	2-4×/wk	0.592

*Adjacent categories were combined to meet the minimum expected count for statistical analysis (for duration, 2 categories were formed: <1 year and >1 year; and for frequency, 2 categories were formed: once a day or more, and less than once a day).

TABLE E-8. Participants Scoring ≥12 on the Self-Report Leeds Assessment of Neuropathic Symptoms and Signs (S-LANSS) at Long-Term Assessment*

	DFEO + PTA	Non-DFEO + PTA	P Value
Yes *(no. [%])*	3 (9%)	4 (14%)	0.695
No *(no. [%])*	29 (91%)	24 (86%)	

*Score of ≥12 suggests that pain is predominantly of neuropathic origin.

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TABLE E-9 CPCHILD Comfort Domain Quantifying Pain at Long-Term Assessment

	DFEO + PTA			Non-DFEO + PTA			P Value for Standardized Score
	Frequency	Intensity	Standardized Score*	Frequency	Intensity	Standardized Score*	
Activity							
Eating/drinking	Never	Mild	100 (0) [71-100]	Never	Moderate	100 (0) [14-100]	0.190
Toileting	Never	Mild	100 (14) [29-100]	Never	Mild	100 (29) [29-100]	0.403
Dressing	Never	Mild	100 (29) [29-100]	Never	Mild	100 (29) [29-100]	0.206
Transfer	Never	Mild	100 (14) [14-100]	Never	Mild	79 (43) [0-100]	0.025†
Sitting	Never	Mild	100 (18) [14-100]	Never	Mild	79 (43) [0-100]	0.016†
Lying down	Never	Mild	100 (29) [0-100]	Never	Mild	93 (57) [0-100]	0.437
Sleeping	Never	Mild	100 (29) [14-100]	Never	Mild	100 (29) [0-100]	0.750
Average	Never	Mild	100 (14) [29-100]	Never	Mild	100 (29) [0-100]	0.447

*Standardized score of 100 = no pain. The mode is given for frequency and intensity. Standardized scores are given as the median with the width of the interquartile range in parentheses and the range in brackets. †Significant difference between the DFEO + PTA and non-DFEO + PTA groups ($p < 0.05$).

TABLE E-10 Completion of Questionnaires

	DFEO + PTA	Non-DFEO + PTA	P Value
WHOQOL-BREF			
Did someone help you fill out this form? *(no. [%])*			0.312
Yes	12 (35%)	15 (50%)	
No	22 (65%)	15 (30%)	
Gillette FAQ			
What is your relationship to the patient? *(no. [%])*			0.114
Self	26 (76%)	17 (57%)	
Other	8 (24%)	13 (43%)	
Modified BPI			
What is your relationship to the patient? *(no. [%])*			0.020*
Self	26 (79%)	15 (50%)	
Other	7 (21%)	15 (50%)	

*Significant difference ($p < 0.05$).

TABLE E-11 Summary of the Americans with Disability Act (ADA) of 1990, Including Changes Made by the ADA Amendments Act of 2008

The Americans with Disabilities Act of 1990[49]
The primary purposes of this act of the U.S. Congress were to eliminate discrimination against individuals with disabilities. The act addresses the needs of people with disabilities by granting them equal opportunities for employment, public services, public accommodations, and telecommunications. For example, buses, rail vehicles, and buildings (e.g., universities, hospitals, shopping centers, workplace) are required to be wheelchair-accessible. Employers cannot discriminate on the basis of disability.

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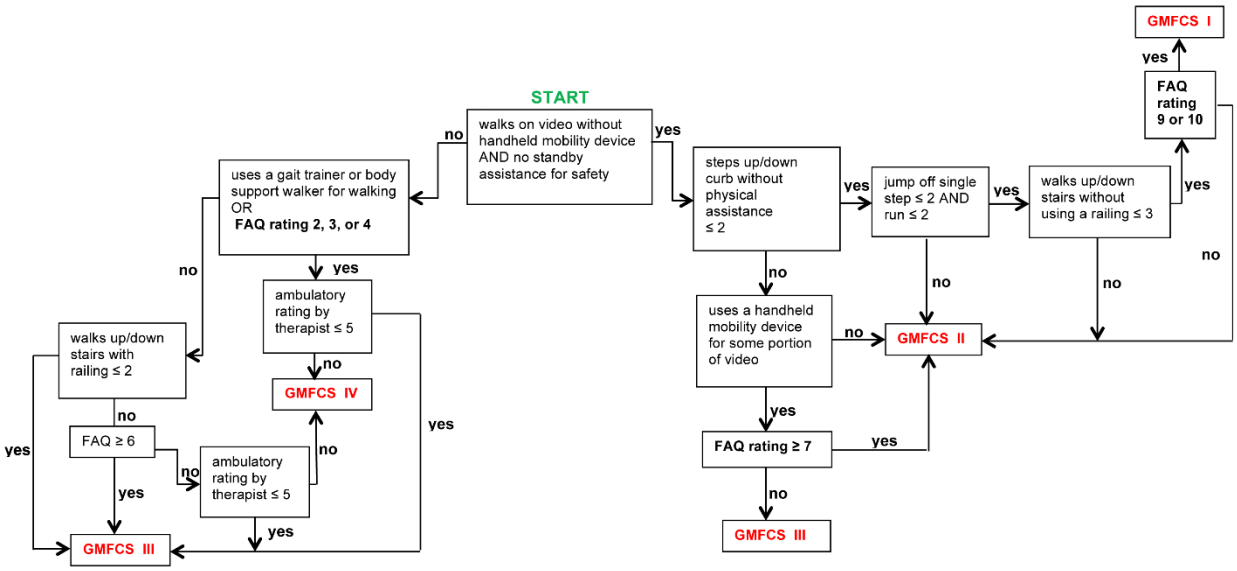
Fig. E-1



Decision tree was based on FAQ walking level[27], FAQ-22 skills[28], video, and ambulatory rating by therapist using a modified Hoffer scale. FAQ: FAQ walking level; FAQ-22 skill level difficulty: 1=easy, 2=a little hard, 3=very hard, 4=can't do; ambulatory rating by therapist ≤5: household or community ambulation. The algorithm was tested on 500 patients (not in the study) who had a GMFCS level previously assigned. Overall accuracy was 87%, and accuracy for GMFCS I-IV individuals was 86%, 90%, 87%, and 87%, respectively. Misclassification by more than one GMFCS level was 0.2%. When only a Yes/No was available for difficulty rating of an FAQ-22 skill, level 3 was assumed. When no FAQ data were available, we assumed individuals could not perform any FAQ-22 skills and an FAQ walking level 4 was assumed. When ambulatory rating by a therapist was not available, an FMS rating ≥2 for household distances was used as a surrogate.

Flowchart of retrospective Gross Motor Function Classification System (GMFCS) level assignment made on the basis of video assessment, Gillette Functional Assessment Questionnaire (FAQ) walking level, and/or ambulatory rating by a physical therapist.

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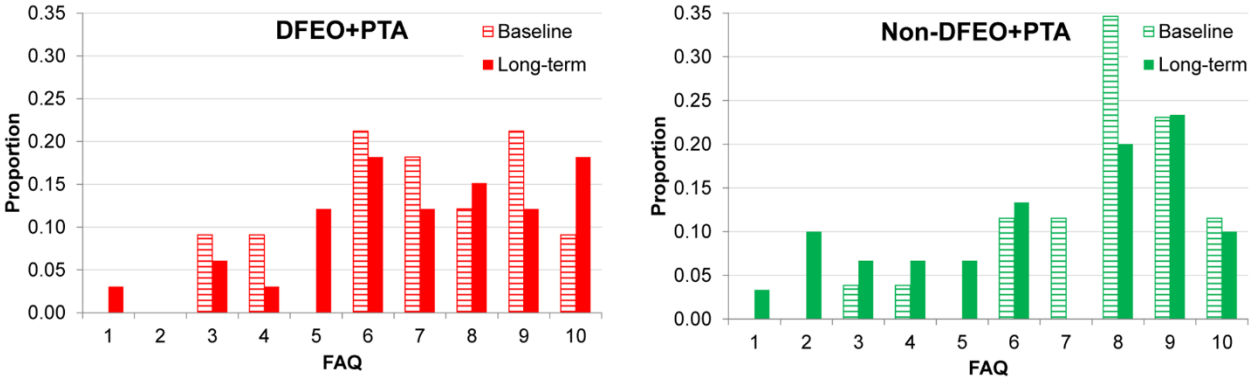
Fig. E-2



Baseline and long-term Gillette Functional Assessment Questionnaire (FAQ) walking level for all 64 participants (including those who only answered online questionnaires at long term). A larger value indicates better walking function[27].

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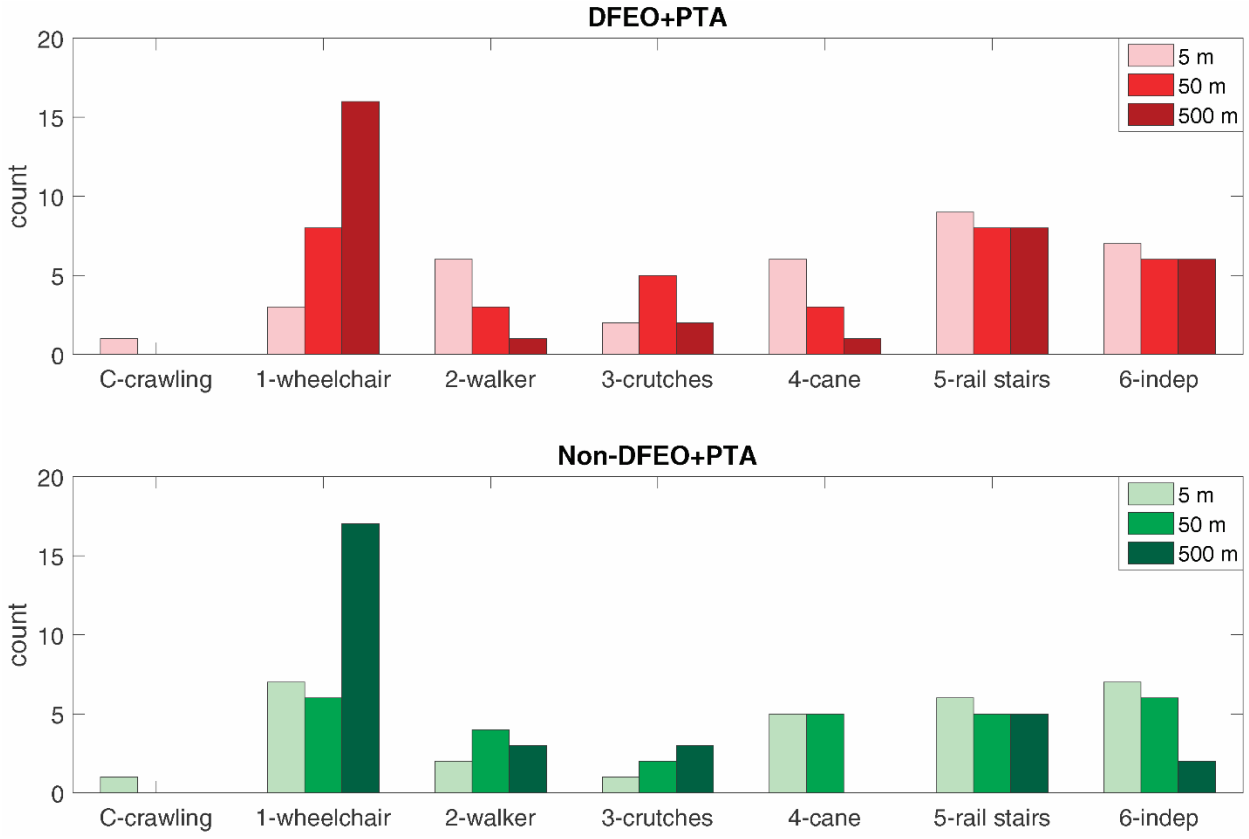
Fig. E-3



Classification of mobility using the Functional Mobility Scale (FMS)[29] for DFEO + PTA and non-DFEO + PTA participants at long term. Indep = independent.