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CLINICAL GUIDANCE

Multidisciplinary collaborative consensus statement on the barriers and solutions to care access, patient and caregiver support, and clinical capacity and capability for patients with spasticity

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Abstract

Background: There is evidence that patients with spasticity are not receiving adequate care. Identifying the unmet needs of patients with spasticity is essential to develop services and treatment strategies to better support this population This is an effort to identify challenges related to treatment of spasticity and provide the springboard for the implementation of identified solutions.

Objective: To identify the main barriers to spasticity care and identify potential solutions.

Design: Delphi process.

Setting: Expert panel.

Participants: A total of 35 participants with diverse experience and knowledge related to spasticity care were invited and 29 attended an in-person 2022 Spasticity Summit hosted by the American Academy of Physical Medicine and Rehabilitation.

Methods: The expert panel participated in a presummit survey to identify the main potential barriers to spasticity care. During the in-person meeting the panel initially worked in small groups and then as whole to reach consensus through the Delphi process. The panel also completed a postsummit survey.

Results: Several barriers to spasticity care and potentials solutions were identified. Consensus was reached for the top three barriers and potential solutions (>50% and >75%, respectively). Top barriers included the need for a document listing all the challenges related to access of care for spasticity, increased caregiver and community awareness of spasticity, and education of clinicians regarding patient needs. Top solutions to barriers included increasing the number of providers who treat spasticity, enhancing patient and caregiver education, and developing and publishing a consensus guidance statement.

Conclusions: Consensus was achieved on the top three barriers to spasticity care and potential solutions. The purpose of this analysis is to pave the way for further development of solutions to improve the care of patients with spasticity.

INTRODUCTION

Spasticity is a major disabling disorder that affects mobility and causes serious complications such as pain, joint limitation, and muscular contractions, significantly affecting the individual's functionality and quality of life.[1,2] Therapeutic interventions include physical and occupational therapy and interventional treatments, such as intrathecal baclofen (ITB), phenol injections, and botulinum neurotoxin (BoNT).[3] Physiatrists specializing in spasticity management comprise the majority of spasticity providers and often work with a team of rehabilitation, orthopedic, psychological, and social health care providers.[4] According to the Association of

Academic Physiatrists, many areas in the United States currently have a shortage of physiatrists and rehabilitation services, which represents one of the greatest unmet needs in spasticity care.[5]

The burden of spasticity is significant, and research to identify the unmet needs of patients is essential to develop services and treatment strategies to better support this population.[6] Access to adequate care is one of the main challenges facing patients with spasticity.[6,7] When spasticity is left untreated, complications in the affected muscles are compounded due to reduced mobility and disuse, and delayed spasticity care can lead to incomplete patient recovery.[6] In the United States, many individuals do not live in areas where hospitals and clinics offer treatment for spasticity, most notably in nonurban and highly Hispanic communities.[8] Barriers to access may also include financial burdens for patients, which can preclude potential treatment options.[6]

Patient and caregiver support is also a fundamental component of high-quality spasticity care.[9] Caring for individuals with spasticity can be challenging and stressful, and caregivers often struggle to aid with activities of daily living, such as personal hygiene and dressing.[7] Spasticity often causes decreased mood and social interactions for individuals, which affects family relationships and increases caregiver burden.[10] Fears of inadequate care and financial concerns can also negatively affect the well-being of caregivers and their patients.[9]

Clinic capacity and capability are vital considerations for the quality of spasticity care. Difficulties in diagnosing and managing spasticity can reduce the quality of care and delay necessary referral and treatment.[6] Recent studies report that despite a 21%–35% prevalence of spasticity in nursing homes, only 13% of those individuals had a diagnosis or spasticity-related condition recorded in their medical records.[7] Lack of physicians able to provide BoNT injections is a significant contributor to delayed care.[6] An international survey of patients living with spasticity reported that about half (53%) of respondents reported receiving their first BoNT injection within a year of developing spasticity, approximately a quarter (23%) received BoNT treatment within 1–3 years, and 23% waited more than 3 years after their symptoms developed to receive treatment.[11] The survey also indicated several issues with patient access to treatment, including costs of treatment and access to experienced injectors.[11]

There is a lack of information on the barriers to improve access to care for individuals with spasticity. Comprehensive documentation of the growing impact of spasticity is required to enact the change needed to identify and overcome barriers to proper care.[10,12] The American Academy of Physical Medicine and Rehabilitation (AAPM&R) has recognized the gap in the care for patients with spasticity and convened a group to develop an evidence-based consensus statement to identify the U.S. health care's high-priority barriers related to spasticity care and identify potential solutions to those barriers. In contrast to clinical practice guidelines, which are based on high-level evidence, consensus statements utilize an explicit methodology and reflect experts' opinions to identify areas of agreement and disagreement.[13] Consensus statements have produced significant advances in care, especially in situations where evidence is limited, but improvement in health care quality is necessary.[13]

To address this crucial issue in health care, the AAPM&R convened a Spasticity Summit to go through the process of developing a consensus statement that would define and document the U.S. health care's high-priority challenges related to spasticity and provide the springboard for the implementation of identified solutions over the next 3–5 years to improve spasticity care.

METHODS

Summit strategy overview

AAPM&R organized a summit focused on spasticity, inviting national stakeholders to foster collaboration and exchange ideas. Two co-chairs were appointed by the Executive Committee of AAPM&R's Board of Governors to lead this effort. The co-chairs started by brainstorming a list of all the potential stakeholders who could be invited. The list included individuals and organizations who are invested in finding new ways to improve the quality of life for individuals with spasticity, such as medical professionals, disability advocates, government officials, researchers, industry representatives, insurers, and people with spasticity. The co-chairs then narrowed down the list by considering factors such as the stakeholder's level of interest in spasticity, their influence locally and nationally, and their ability to contribute to the summit in-person. The co-chairs understood the list of invitees may need to be flexible as the list of stakeholders could change leading up to the day of the summit; therefore, they were prepared for organizations to change the individuals attending on their behalf and understood that not all stakeholders may be represented in this first summit. These stakeholders were invited to participate in the AAPM&R Spasticity Summit workshop to discuss the barriers and potential solutions for improved care and support for those with spasticity. A list of the stakeholders who attended the summit and their expertise is included in Table 1. The process was divided into several parts. The Delphi process for gaining consensus was utilized as the methodology for this consensus statement.[14] The Delphi technique employs sequential questionnaires answered anonymously by participants with relevant expertise.[14] After each

TABLE 1 AAPM&R spasticity summit attendees and organizations represented.

Spasticity summit speakers and moderators	
Christina Kwasnica, MD, FAAPMR	Spasticity Summit co-chair Medical Director, Neurorehabilitation Barrow Neurological Institute
Atul Patel, MD, MHSA, FAAPMR, AAPM&R Treasurer	Spasticity Summit co-chair Physician and Vice President, Kansas City Bone & Joint Clinic
Steven Flanagan, MD, FAAPMR, AAPM&R President	Chair of Rehabilitation Medicine at NYU School of Medicine Rusk Rehabilitation at NYU Langone Health
Doug Diefenbach	Spasticity Summit Facilitator Principal Consultants in Association Philanthropy (CAP)

Spasticity summit attendees and organizations (in alphabetical order)	
John Baratta, MD, MBA, FAAPMR	UNC Chapel Hill School of Medicine Clinical Assistant Professor, Department of Physical Medicine and Rehabilitation Representing the American Academy of Physical Medicine and Rehabilitation (AAPM&R)
Sonja Boone, MD, FACP	Blue Cross Blue Shield Association Executive Director, Medical Policy Services
Joseph Burris, MD, FAAPMR	Professor and Chair of Physical Medicine and Rehabilitation Encompass Health Chair in Physical Medicine and Rehabilitation University of Missouri School of Medicine University of Missouri Health Care Medical Director Rusk Rehabilitation Hospital, an affiliation of Encompass Health and MU Health Care, representing AAPM&R
Susan Connors	Chief Executive Officer Brain Injury Association of America
Jennifer Crocker, MD, FAAPMR	Director, Integrated Spasticity Management Ipsen Biopharmaceuticals
Monica de Abadal, MD	Senior Vice President, Head of Medical Affairs, North America Ipsen Biopharmaceuticals
Alfred Gellhorn, MD	Director, Statistics and Innovation GlaxoSmithKline Pharmaceuticals Representing PM&R Journal
Steve Gnatz, MD, MHA, FAAPMR	Chief Medical Officer Medrina Representing AAPM&R
Richard Harvey, MD, FAAPMR	Clinical Chair, Brain Innovation Center Shirley Ryan AbilityLab Representing AAPM&R
Michael Hast, PhD	Director, Scientific Strategy Merz Therapeutics
Kimberly Heckert, MD, FAAPMR	Director, Spasticity Management Fellowship, Clinical Associate Professor Thomas Jefferson University, The Sidney Kimmel Medical College Department of Rehabilitation Medicine Representing AAPM&R
Helen Hoenig, MD	Rehabilitation Physician at the Department of Veterans Affairs Professor of Medicine and Senior Fellow of the Center for the Study of Aging and Human Development Duke University Representing American Geriatrics Society
Chip Mitros	US Strategic Sales Group, Targeted Drug Delivery Medtronic
Jose Naranjo	Vice President, Marketing Merz Therapeutics
Kevin O'Brien	President, North America Merz Therapeutics
Linda Page	Chief Scientist, Targeted Drug Delivery Medtronic
Richard Shields, PT, PhD, FAPTA	Gary L Soderberg Endowed Professor in Physical Therapy and Rehab Science; Chair and Department Executive Officer, Department of Physician Therapy and Rehabilitation Science Lucille and Roy Carver College of Medicine, The University of Iowa Representing American Physical Therapy Association
Divya Singhal, MD, FAAN	Service Chief, Spinal Cord Injury Neurorehab Service US Department of Veteran Affairs Representing American Academy of Neurology
Monica Verduzco-Gutierrez, MD, FAAPMR	Professor and Chair, Department of Rehabilitation Medicine UTHealth San Antonio Representing AAPM&R
Alex Vosooney, MD	Lead Physician Allina Health West St. Paul Clinic Representing American Academy of Family Physicians
Christopher Watters	Vice President, Franchise Head, Neuroscience Business Unit Ipsen Biopharmaceuticals

Note: Individuals provided written consent to have their names and organizations listed.

questionnaire, the participants are made aware of the group response; however, anonymity during the voting process ensures that the responses of others do not influence participants.[14] The Delphi process has often been used to reach consensus around many topics in medicine, such as education, development of clinical guidelines, and prioritization of research topics.[14]

Pre-summit survey

Prior to the summit, a literature review was completed to identify three central barriers related to spasticity care and corresponding issues for each area. The top three barriers identified were access to care, patient and caregiver support, and clinical capacity and capabilities. Summit attendees were surveyed to rank the corresponding issues for each area based on their knowledge and experience from most important (1) to least important (6). Attendees could also add new corresponding issues as write-ins. These corresponding issues served as the foundation for the summit discussion.

Breakout discussion sessions nos. 1 and 2: Barriers to spasticity care and solutions

Using the presummit survey results, attendees participated in two breakout sessions with a facilitator, a note taker, and approximately 10 attendees. Preassigned group assignments ensured a balanced representation of attendees from clinical experts, patient advocates, and industry and payor representatives. The two co-chairs of the summit and one expert methodologist floated between groups to ensure that breakouts stayed focused on the goals of the summit.

In the first breakout session, each group was assigned one of the three barriers to spasticity care identified during the presummit survey: access to care; patient and caregiver support; and clinical capacity and capabilities. The focus of these sessions was to reach consensus on the top corresponding issues identified from the presummit survey in each of the corresponding area.

In the second breakout session, each group went back to their assigned group pertaining to one of the three areas of barriers to spasticity care. They were tasked to identify up to five actionable solutions that, if implemented, would have the most significant impact on spasticity care. The work from this breakout session informed consensus process to prioritize solutions with the full group.

Full group discussion: Solutions to spasticity care barriers

Summit attendees then participated in a full group consensus process. Attendees heard the actionable solutions per key barrier area of access to care, patient and caregiver support and clinical capacity, and capability from the second breakout session. These solutions were displayed on flipcharts. Using stickers, attendees had nine votes to place on solutions they deemed of most importance to address. More than one vote could be given to a solution. The voting was designed to show attendee affiliation to identify trends among those with similar roles and points of view as follows: (1) clinicians and health care providers, (2) patient advocates, and (3) industry and payor representatives.

Post-summit consensus survey

After the conclusion of the summit, the attendees were again surveyed about their perception of the importance of key issues discussed during the summit. The questionnaire was designed to determine if attendees agreed with the rank order of the solutions reached at the summit. Attendees were able to add write-in responses as suggestions.

Data analysis

Presummit survey data were summarized by ranking the relative importance of each barrier using weighted averages. These were calculated by multiplication of each component by a factor reflecting its importance (most important [1] to least important [6]), which was then summed and divided by the number of data points. Lower weighted averages indicate the highest importance. Ranking of the perceived relative importance of future priorities was performed using overall counts of each future priority identified by participants.

RESULTS

Pre-summit survey: Barriers to spasticity care

The summit was attended by 29 of the 35 invited guests. 27 of the 29 participants completed the presummit survey in full, and two participants only partially completed the survey. Survey results showed that there is a lack of information on the barriers to improve access to care for individuals with spasticity. Comprehensive documentation of the growing impact of spasticity is required to enact the change needed to identify and overcome barriers to proper care, including improving patient and caregiver support and increasing caregiver and community awareness of spasticity as a diagnosis; and education of physicians regarding patient needs. This gave us information on the presummit beliefs of participants.

Breakout group no. 1 consensus: Barriers to spasticity care

The results of breakout session no. 1 are detailed in Table 2. Within the barrier area of Access to Care, documentation of the access to care challenge remained the no. 1 ranked priority barrier among the group. Interestingly, the consensus from the group voted for the write-in of "need for guidelines for the standard of care" as the no. 2 priority barrier, replacing improving geographic provider coverage. Ensuring incentives for a favorable regulatory and business environment remained priority no. 3 among attendees in the breakout group. The participants emphasized that the barrier area of access to care is a growing problem that could be addressed using existing databases or patient registries to provide evidence of care quality and help define outcomes, such as functionality. In addition, group members suggested Relative Value Scale Update Committee advocacy could aid in increasing reimbursement for complex spasticity management, especially with ITB therapy, and insurance plans could perform cost/savings analysis to demonstrate the lowered overall cost of care with ITB.

Within the barrier area of Patient and Caregiver Support, increased caregiver and community awareness remained the no. 1 ranked priority barrier among the group. Improving patient capability to follow care plans also remained the no. 2 priority. However, greater access to physical support was included as an addition to the no. 2 ranked priority. The breakout group consensus was that improved access to physical support was essential to improving care plan adherence for individuals with spasticity and should include ramps, transportation, patient aids, and nurses. In addition, the participants highlighted the importance of developing high-quality patient and caregiver educational materials about spasticity and available treatments. Finally, improving financial support, optimizing mental and emotional health, and empowering patients and caregivers with community and social advocacy groups were essential to overcome this barrier.

For the barrier area of Clinical Capacity and Capabilities, the education of clinicians regarding patient needs remained the no. 1 priority barrier. However, the no. 2 priority barrier from the presummit survey, improvement of diagnosis, was replaced with an attendee write-in to articulate the standard of care and employ protocol spasticity treatment guidelines. Finally, ensuring an environment of incentives to encourage providers to enter the field of spasticity management remained priority no. 3 among breakout group attendees. The participants reviewed the need for standardized care guidelines and clinician education. Also, a Stratified Center of Excellence was proposed to be beneficial for routing patients to appropriate care, depending upon the capabilities and treatment offerings at different locations. Lastly, financial incentives and a favorable regulatory and business environment were strongly emphasized by attendees to improve providers' quality of life and reduce workforce issues.

TABLE 2 Presummit survey: weighted average ranking of barriers.

Access to care	Weighted average
Document the access challenge	13.6
Improve geographic provider coverage	16.0
Ensure an environment of incentives	18.0
Increase access for uninsured/underinsured	20.0
Increase access for underserved	21.8
Patient and caregiver support	**Weighted average**
Increase caregiver/community awareness	12.2
Improve patient ability to follow care plan	12.7
Greater access to physical support	14.3
Improve support for untrained patients/caregivers	16.3
Equip patients/caregivers for advocacy	20.0
Optimize mental/emotional health	22.3
Clinical capacity and capabilities	**Weighted average**
Educate clinicians regarding patient needs	11.7
Improve diagnosis	14.5
Ensure an environment of incentives	17.3
Improve treatment options	17.3
Increase case follow-up incidence	18.3
Clarify professionals' roles	19.3

Note: Lower numerical weighted averages represent higher priority rankings.

Breakout group no. 2 consensus: Solutions to spasticity care barriers

The top solutions decided by consensus for each of the three predominant barrier areas are shown in Table 3. The top solutions for the barrier of Access to Care included demonstrating a reduction in health care costs with appropriate spasticity treatment, improving the articulation of care standards (eg, white paper), improving reimbursement for spasticity management, increasing the number of providers that treat spasticity, and improving coding and referral practices. For the barrier area of Patient and Caregiver Support, assessing available informational resources, establishing a "home base" or spasticity coalition website, and patient and caregiver education were top solutions to barriers in this area. The barrier area of Clinical Capacity and Capabilities group provided solutions that included developing and publishing a consensus guidance statement, creating an evidence-generation data plan for consensus, mobilizing local rehabilitation advocates to

TABLE 3 Top priorities and solutions identified by summit attendees in key barrier areas.

Top priorities by key barrier area	
Access to care	Document the extent and impact of the access challenge.
Patient and caregiver support	Improve caregiver and community awareness of spasticity and spasticity treatments for patient/caregiver empowerment.
Clinical capacity and capabilities	Increase clinician education on how to assess and treat patients with spasticity, especially outpatient versus institutional settings
Top solutions by key barrier area	
Access to care	Demonstrate with evidence that the overall cost of healthcare can be lowered with appropriate spasticity treatment
Patient and caregiver support	Assessment of currently available resources (informational resources, educational, eg, stroke.org/spasticity)
Clinical capacity and capabilities	Develop, publish, and disseminate a white paper/consensus guidance statement

address and advance spasticity issues in the community, improving workflow for the continuity of patient care, and creating a “Center of Excellence” program to recognize spasticity providers.

Full group discussion: Solutions to spasticity care barriers

Results from the full group consensus for solutions to the barriers are shown in Table 4. Total attendee votes indicate a similar level of priority for the solutions identified for all three barrier areas: 81 votes for Access to Care (32.3% votes, 81/251), 84 votes for Patient and Caregiver Support (33.5% votes, 84/251), and 86 votes for Clinical Capacity and Capabilities (34.3% votes, 86/251).

Within the clinicians and health care providers category, votes from the subcategory of PM&R physicians were recorded. Of 123 total votes from clinicians and health care providers, PM&R physicians accounted for 69.1% (85/123). Furthermore, out of 85 total PM&R physicians votes, the barrier area of Clinical Capacity and Capability (37.6%, 32/85) received the highest number of votes, followed by Access to Care (34.1%, 29/85), and Patient and Caregiver Support solutions (28.2%, 24/85).

A detailed analysis of voting for each specific barrier area is also described in Table 4. For the barrier area of Access to Care, increasing the number of providers who treat spasticity received the highest number of votes (27.2%, 22/81) from attendees. For the barrier area of Patient and Caregiver Support, education of patients and caregivers received the greatest number of votes (36.9%, 31/84). Developing and publishing a consensus guidance statement received the highest votes (33.7%, 29/86) within the barrier area of Clinical Capacity and Capabilities.

Postsummit consensus survey results

Of 29 participants, 26 completed and 3 partially completed the postsummit surveys. The responses to rankings are shown in Figure 1. Write-in responses for additional consideration or to modify ranking are shown in Supplemental Material (Table S1). For Access to Care, there was a majority consensus of 76.9% (20/26) of attendees who agreed with the solutions rankings from the summit. A strong consensus was reached for solutions in the Patient and Caregiver Support area, with 88.5% (23/26) of attendees agreeing with the summit rankings. In addition, for Clinical Capacity and Capabilities, 84.6% (22/26) of attendees agreed with the solutions ranking.

DISCUSSION

The multidisciplinary team caring for individuals with spasticity must ensure that patients receive proper care. The goal of the AAPM&R Spasticity Summit was to bring together a group of attendees with diverse experience, talent, and knowledge to define the barriers of high priority related to spasticity care and to identify potential solutions. Discussions were structured to build consensus on the top barriers that, if solved, would have the most significant impact in addressing gaps in spasticity care. In addition, a vital component of the summit was for attendees to identify and prioritize actionable solutions to address prioritized barriers. The conversation format of shared individual perspectives, acknowledgment of all views, and participation in the consensus-building process were essential for productive outcomes to enact an improvement in spasticity care. The results demonstrated a consensus for the three critical areas addressed by the summit, with >50% of attendees agreeing on ranking the top three barriers, and a consensus of >75% was achieved for ranking top solutions to improve spasticity care.

There is an urgent need to remove barriers to receiving interventions for spasticity in the United States. The outcome of the summit will be a 3–5-year plan to implement solutions identified and a commitment to continue

TABLE 4 Priorities and consensus from the full group discussion for the top solutions to barriers for the three key areas.

Priorities	Number of attendee votes Clinicians and HCP (Including PM&R) *n* = 123	Patient advocates *n* = 20	Industry and payor *n* = 108	PM&R specialists only *n* = 85	All attendees *n* = 251
Access to care					
No. 1: Increase providers who can offer spasticity management/increase workforce	9	2	11	8	22
No. 2: Demonstrate with evidence that the overall cost of healthcare can be lowered with appropriate spasticity treatment	12	0	6	8	18
No. 3: Improve reimbursement for spasticity management	8	2	7	5	17
No. 4: Improve articulation of care standards (academy white paper)	6	0	10	5	16
No. 5: Improve coding and referral practices for spasticity-related diagnoses	5	2	1	3	8
Patient and caregiver support					
No. 1: Education	12	2	17	6	31
No. 2: Identify and organize a "home base" for spasticity	10	4	7	8	21
No. 3: Create a spasticity coalition ("home base") website linked to multiple channels/other organizational websites	8	0	8	5	16
No. 4: Assessment of currently available resources (informational resources, educational, eg, stroke.org/spasticity)	9	2	5	5	16
Clinical capacity and capabilities					
No. 1: Develop, publish, and disseminate a white paper/consensus guidance statement	14	2	13	10	29
No. 2: Improve continuation of care by working with primary care physicians and other stakeholders to create ideal workflows for patients with spasticity	14	2	6	9	22
No. 3: Create an evidence-generation plan aggregating data across all spasticity organizations for consensus with a systematic review of the data gathered	8	2	10	5	20
No. 4: Create a "Center of Excellence" program to recognize providers of spasticity	6	0	5	6	11
No. 5: Mobilize local PM&R champions (physiatrists, local organizations) to address and advance issues in spasticity in local institutions and communities	2	0	2	2	4

Note: Each participant had up to nine votes, and a priority could receive more than one vote per participant.
Abbreviations: HCP, health care provider; PM&R, physical medicine and rehabilitation.

conversations and accountability to improve spasticity care. There is a need to document the inequality of access to care driven by geography and clinician shortage. Education of patients and caregivers and their partnership is essential to improve care for spasticity patients. In addition, there is a need to increase the number of providers with the expertise to provide the care needed by individuals with spasticity. It is vital that the standard of care is articulated; when the best practice is defined, the multidisciplinary team can identify and mitigate gaps in care to better serve patients. There is a significant need to complete research and gather data to provide proof of the depth of the problems to justify the improvement of care. The better understanding and documentation of the challenges to spasticity care achieved by the AAPM&R Spasticity Summit will be instrumental in optimizing patient outcomes.

LIMITATIONS

There were fewer participants representing patient advocates compared to other groups. More diversity in clinical representation related to geographic and practice setting would have been beneficial. Not all attendees completed both the presummit survey and

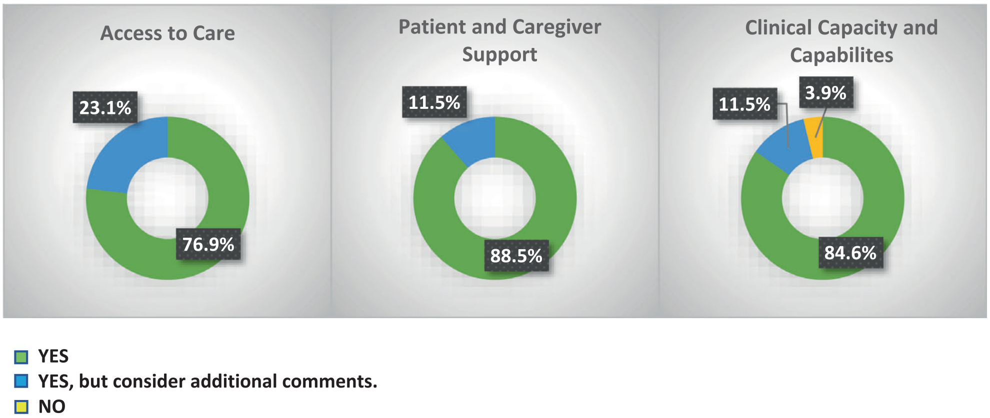

FIGURE 1 Postsummit consensus survey: summit attendee agreement with top solutions identified.

the postsummit survey. However, the response rate to both surveys (27/29 and 26/29, respectively) was considered adequate to represent the group opinion.

CONCLUSIONS

The Delphi process used to identify the barriers to spasticity care and potential solutions yielded valuable insights. Consensus was reached for the top three barriers and potential solutions via the participants of AAPM&R's Spasticity Summit. The barriers consisted of the need for comprehensive documentation listing all the challenges related to access of care for spasticity, increased caregiver and community awareness of spasticity, and education of clinicians regarding patient needs. The solutions to the identified barriers included increasing the number of providers who treat spasticity, enhancing patient and caregiver education, and developing and publishing a consensus guidance statement.

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SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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