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Deep brain stimulation for Parkinson's disease - Does measuring quality matter?

Deep brain stimulation (DBS) is the surgical standard of care to treat Parkinson's disease (PD) that is insufficiently controlled with medications. It has become the most significant treatment option for PD after levodopa, with clear evidence of its superiority over continued best medical management of cardinal PD motor symptoms, treatment-induced motor complications, and overall quality of life in carefully selected patients [1–3]. Recent technological advances have brought innovations to multiple aspects of the therapy, from surgical planning to electrode design, and novel programming techniques, all with the intent of improving therapeutic outcomes. The advent of closed-loop recording and adaptive DBS on the horizon further signifies the potential for a major paradigm shift in the way therapy is delivered.

Beyond the attention paid to the technical aspect of DBS, the question of *how* DBS treatment is applied to improve PD clinical outcomes remains under-investigated. Despite data supporting its benefits, several gaps in the evidence base exist surrounding DBS therapy implementation, including best practices for patient selection, surgical techniques and post-operative management. Results from randomized trials or from single-center studies are not fully applicable to the broad range of sites performing the procedure or a heterogeneous patient population. Although consensus statements [4–10] and screening tools [11–13] exist, they are rarely driven by evidence linking the use of such recommendations to improved outcomes. Furthermore, the procedures surrounding various aspects of DBS therapy are known to differ greatly amongst centers [14,15], including surgical methods and post-operative management - likely as a result of the lack of a sufficient evidence base. At the same time, clinicians must consider cost-effectiveness and the appropriate allocation of health care resources. Consequently, the clinical outcome from DBS can vary significantly between centers, which is complicated by the lack of standardized outcome measures [16] but is substantiated by the heterogeneous etiologies of so-called DBS “failures” seen at referral clinics [17]. Related factors include, but are not limited to, the use of appropriate patient screening procedures, the experience and preferences of the health care professionals performing DBS surgery and programming, the patient's access to DBS programming and an interdisciplinary team, and the ability to identify and effectively troubleshoot DBS complications [17].

In the current issue of Parkinsonism & Related Disorders, Haas et al. present the “Development of evidence-based Quality Indicators for Deep Brain Stimulation in Patients with Parkinson's Disease and first year experience of implementation of a nation-wide registry”. Given the heterogeneity of DBS practice across sites, the likelihood that this heterogeneity contributes to variability in outcomes, and the fact that no consolidated efforts have established a “gold standard” of performance, Haas et al. carefully identified evidence-based quality indicators (QIs) to be used to improve DBS care amongst PD patients. Three dimensions of health care quality were considered (structure, process, and outcome) across three phases of DBS therapy: pre-operative, intra-operative and post-operative. A pilot study to assess the feasibility of documenting the QI set was conducted, followed by implementation of a formal multi-site German registry (Quali-Pa). Benchmarks on the QIs were created with performance reports delivered back to participating sites.

The foreseeable significance of Quali-Pa is to standardize DBS care in PD, thereby potentially leading to improved outcomes for patients. Sites with less experience in DBS may also benefit from implementation of the QI set in order to establish a high-quality program. In this early report on the Quali-Pa registry, the authors confirm that heterogeneity in DBS practice exists across sites (for some measures more than others), and attest to the feasibility of measuring QIs systematically at multiple centers performing DBS for PD. Continuous data collection will be required to appreciate how or whether this effort will lead to changes in practice at participating sites, or whether these changes will translate into improved outcomes. Regardless, this work represents an important step towards standardizing and improving DBS care for PD patients.

It is important to note that QIs are not meant to represent the best practices. Rather, QIs, which are developed on the basis of existing evidence, may help bridge the gap between guidelines/best evidence and clinical practice. They represent a practical guide to physicians on steps to further improve the quality of care offered to patients. In this way, the QIs identified for Quali-Pa establish a way to monitor whether the most appropriate DBS care is delivered.

An alternative to standardizing *care* is to standardize *measurements* of DBS delivery and outcomes to effect change or improvement. Currently, a large multi-center patient registry, RAD-PD (Registry for the Advancement of DBS in Parkinson's Disease) is underway in the United States and Canada using this slightly different methodology. The objectives of RAD-PD are to identify the best practices surrounding DBS therapy, to identify the adverse effects of DBS and their determinants, and to identify the health economics and disparities in outcomes related to DBS therapy by implementing a standard assessment battery and image analysis across sites [16]. A large and heterogeneous PD cohort undergoing DBS will thus be prospectively and comprehensively characterized in a homogeneous manner. Similar to Quali-Pa, actionable data in RAD-PD will be benchmarked and delivered back to sites, but with the added element of discussion and investigation into the determinants of disparities in outcomes. Best practices can then be defined using real-world data, which may be more broadly applicable to patients receiving therapy in the community.

But does measuring quality matter? Because many of the gaps in the DBS evidence base for PD are not readily or practically addressed by standard clinical trials, registry efforts are an appealing option to investigate key clinical factors that may have significant impact on care

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delivery and outcomes. Quality improvement registries have the further advantage of making systematic measurements and feeding benchmarked and actionable data back to participating sites to implement change(s) that can achieve those outcomes. In this respect, measuring the quality of care and the quality of outcomes as described in the Quali-Pa and RAD-PD registries truly *does* matter. After all, if you cannot measure it, you cannot improve it.

References

[1] G. Deuschl, C. Schade-Brittinger, P. Krack, J. Volkmann, H. Schafer, K. Botzel, C. Daniels, A. Deutschlander, U. Dillmann, W. Eisner, D. Gruber, W. Hamel, J. Herzog, R. Hilker, S. Klebe, M. Kloß, J. Koy, M. Krause, A. Kupsch, D. Lorenz, S. Lorenzl, H.M. Mehdorn, J.R. Moringlane, W. Oertel, M.O. Pinsker, H. Reichmann, A. Reuß, G.H. Schneider, A. Schnitzler, U. Steude, V. Sturm, L. Timmermann, V. Tronnier, T. Trottenberg, L. Wojtecki, E. Wolf, W. Poewe, J. Voges, N.S. German Parkinson Study Group, A randomized trial of deep-brain stimulation for Parkinson's disease, N. Engl. J. Med. 355 (9) (2006) 896–908.

[2] F.M. Weaver, K. Follett, M. Stern, K. Hur, C. Harris, W.J. Marks Jr., J. Rothlind, O. Sagher, D. Reda, C.S. Moy, R. Pahwa, K. Burchiel, P. Hogarth, E.C. Lai, J.E. Duda, K. Holloway, A. Samii, S. Horn, J. Bronstein, G. Stoner, J. Heemskerk, G.D. Huang, Group CSPS, Bilateral deep brain stimulation vs best medical therapy for patients with advanced Parkinson disease: a randomized controlled trial, J. Am. Med. Assoc. JAMA. J. Am. Med. Assoc. 301 (2009) 63–73.

[3] A. Williams, S. Gill, T. Varma, C. Jenkinson, N. Quinn, R. Mitchell, R. Scott, N. Ives, C. Rick, J. Daniels, S. Patel, K. Wheatley, P.S.C. Group, Deep brain stimulation plus best medical therapy versus best medical therapy alone for advanced Parkinson's disease (PD SURG trial): a randomised, open-label trial, Lancet. Neurol. 9 (6) (2010) 581–591.

[4] J.M. Bronstein, M. Tagliati, R.L. Alterman, A.M. Lozano, J. Volkmann, A. Stefani, F.B. Horak, M.S. Okun, K.D. Foote, P. Krack, R. Pahwa, J.M. Henderson, M.I. Hariz, R.A. Bakay, A. Rezai, W.J. Marks Jr., E. Moro, J.L. Vitek, F.M. Weaver, R.E. Gross, M.R. DeLong, Deep brain stimulation for Parkinson disease: an expert consensus and review of key issues, Arch. Neurol. 68 (2011) 165.

[5] G. Deuschl, J. Herzog, G. Kleiner-Fisman, C. Kubu, A.M. Lozano, K.E. Lyons, M.C. Rodriguez-Oroz, F. Tamma, A.I. Troster, J.L. Vitek, J. Volkmann, V. Voon, Deep brain stimulation: postoperative issues, Mov. Disord. 21 (S14) (2006) S219–S237.

[6] A.E. Lang, J.L. Houeto, P. Krack, C. Kubu, K.E. Lyons, E. Moro, W. Ondo, R. Pahwa, W. Poewe, A.I. Troster, R. Uitti, V. Voon, Deep brain stimulation: preoperative issues, Mov. Disord. 21 (S14) (2006) S171–S196.

[7] M. Picillo, A.M. Lozano, N. Kou, R. Puppi Munhoz, A. Fasano, Programming deep brain stimulation for Parkinson's disease: the toronto western hospital algorithms, Brain. stimul. 9 (3) (2016) 425–437.

[8] A. Machado, A.R. Rezai, B.H. Kopell, R.E. Gross, A.D. Sharan, A.L. Benabid, Deep brain stimulation for Parkinson's disease: surgical technique and perioperative management, Mov. Disord. 21 (S14) (2006) S247–S258.

[9] V. Voon, C. Kubu, P. Krack, J.L. Houeto, A.I. Troster, Deep brain stimulation: neuropsychological and neuropsychiatric issues, Mov. Disord. 21 (S14) (2006) S305–S327.

[10] A.R. Rezai, B.H. Kopell, R.E. Gross, J.L. Vitek, A.D. Sharan, P. Limousin, A.L. Benabid, Deep brain stimulation for Parkinson's disease: surgical issues, Mov. Disord. 21 (S14) (2006) S197–S218.

[11] M.S. Okun, H.H. Fernandez, O. Pedraza, M. Misra, K.E. Lyons, R. Pahwa, D. Tarsy, L. Scollins, K. Corapi, G.M. Friehs, J. Grace, J. Romrell, K.D. Foote, Development and initial validation of a screening tool for Parkinson disease surgical candidates, Neurology 63 (1) (2004) 161–163.

[12] T. Wachter, A. Minguez-Castellanos, F. Valldeoriola, J. Herzog, H. Stoevelaar, A tool to improve pre-selection for deep brain stimulation in patients with Parkinson's disease, J. Neurol. 258 (4) (2011) 641–646.

[13] E. Moro, N. Allert, R. Eleopra, J.L. Houeto, T.M. Phan, H. Stoevelaar, A decision tool to support appropriate referral for deep brain stimulation in Parkinson's disease, J. Neurol. 256 (1) (2009) 83–88.

[14] W.G. Ondo, H. Bronte-Stewart, D.B.S.S. Group, The North American survey of placement and adjustment strategies for deep brain stimulation, Stereotact. Funct. Neurosurg. 83 (4) (2005) 142–147.

[15] A. Abosch, L. Timmermann, S. Bartley, H.G. Rietkerk, D. Whiting, P.J. Connolly, D. Lanctin, M.I. Hariz, An international survey of deep brain stimulation procedural steps, Stereotact. Funct. Neurosurg. 91 (1) (2013) 1–11.

[16] J. Jimenez-Shahed, M. Burack, E. Farace, J. McInerney, J. Kirk, R. Saunders-Pullman, J. Schwalb, L. Shih, M. Spindler, E. Moro, M. York, RAD-PD: registry for the advancement of DBS in Parkinson's disease, Mov. Disord. 32 (2017) E14.

[17] M.S. Okun, M. Tagliati, M. Pourfar, H.H. Fernandez, R.L. Rodriguez, R.L. Alterman, K.D. Foote, Management of referred deep brain stimulation failures, Arch. Neurol. 62 (8) (2005) 1250–1255.

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