Device Assisted Therapies: MDS-HP-SIG Basecamp Meeting, April 20-25, 2018

From: Samantha Surillo
Date: Fri, 20 Apr 2018 at 6:52am

Welcome Everyone!

Dear All,

Please feel welcome to provide feedback and suggestions NOW through April 25, 2018:

AIM OF THE MEETING: A focused discussion surrounding Device Assisted Therapies in Movement Disorders.

Introduction

Device Assisted Therapies

Technology and device assisted therapies are increasingly being used to manage Movement Disorders and improve patient outcomes. Health Care Professionals (HPs) often have a significant, but poorly differentiated, role in supporting these treatments. The HP role may include assessing suitability, teaching prospective patients about the treatments, titrating infused therapies, and assisting in the programming of Deep Brain Stimulation (DBS).

Following commencement of treatments, HPs continue to provide care, which often includes managing side effects of treatment, supporting specific rehabilitation needs, and teaching and counselling care-givers of the patient. The role of the HP may be poorly defined, supported, and under-recognized by colleagues and patient-managers.

Purpose and Aim of focused Meeting on Basecamp

The focus of this Basecamp discussion is to identify the support that Multidisciplinary professionals play in supporting device assisted therapies (i.e. DBS, Apomorphine, Duo-dopa, etc.) and to also share our clinical practice experiences as HPs.

AGENDA

Please provide your comments to the following:

1. What team members are involved in patient selection for a device assisted therapy?
2. Do you know of any Evidence supporting a Multi- or Inter- disciplinary approach to instituting and supporting device assisted therapies?
3. What role do you play in supporting patients considering a device assisted therapy and do you use any scales or measures to identify suitable candidates?
4. The role of patient- and caregiver- teaching is essential, both in ensuring patient expectation and understanding of the technology addressed? a. In your practice, is this led by HPs?b. Is Patient- and caregiver- teaching identified, along with resources, part of the HP role?
5. DBS is an ever increasingly complex therapy and programming the stimulator is a role which may be performed by a HP. a. Who programs and alters Stimulation settings in your practice? b. If the setting is adjusted by a HP, are there any "competencies" you need in order to do this? c. What role do HPs play in identifying the need for review and evaluation of success?
6. Have device assisted therapies added additional care and rehabilitation needs to your role? If so, has there been a commensurate increase in the resources available?

During this online conversation, we welcome you to also feel free to share any additional comments, thoughts, or observations you may have on this topic.

Please contribute your thoughts to the agenda items ***starting Now*** **through end-of-day April 25, 2018.**

As done previously, please utilize the meeting as an ongoing discussion or just a platform to share your feedback and ideas.

Thank you in advance for your time and participation!

Kind regards, *Samantha*
MDS International Secretariat

AGENDA_HP-SIG Basecamp Mtg_Devise Assisted Therapies_APR 20-25, 2018.pdf
29.5 KB

Gila Bronner Sat, 21 Apr at 2:46am via email

Hello everyone

Due to my specific role in the area of intimate and sexual relationship- I'm involved in assessing extreme sexual behaviors (compulsive and hypersexual) and discussing with the neurologist optional advanced therapies to reduce dopaminergic doses (e.g. DBS, LCIG). After the procedure I'll be part of the team that assesses changes in the sexual behavior of the patient. Usually we'll try to meet patients and care givers together and alone- in order to achieve best assessment.
Best regards
Gila

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Bhanu Ramaswamy Sat, 21 Apr at 2:43pm

My first comment to note is that this is a broad term and you seem to have included only the medicines and surgical therapies. I am unsure if this is an oversight as to me, a physiotherapist, your inclusion example terms are too narrow. I visit people who use device assisted therapies/ technology such as telephone or iPad Apps to monitor things like sleep patterns, safe behaviour e.g. smart pressure devices to check if people are getting up and wandering; technology to monitor and record exercise or access programmes of exercise e.g. exergaming through Apps, console games, and communication e.g. Skype, FaceTime to communicate with me between clinic appointments.
If you are only looking for the medicinal and surgical use of such technology, then my role would be to monitor behaviour and to then liaise with the nurse specialist of medical consultant about the possibility of altering dosage. I would be interested to know if people only think 'medical' when the word 'therapy' is used. Bhanu

Michelle Tosin Sat, 21 Apr at 8:30pm

Hello everyone!
Here are my considerations on the subject.

1. What team members are involved in patient selection for a device assisted therapy?
In my practical experience in Brazil, which has only surgical therapy (DBS) as a device assisted therapy, the team members involved are: neurosurgeon, neurologist, speech therapist, psychologist and physiotherapist. The nurse is in charge of hospital and intraoperative care. In this way, we still have much to advance in this field.

2. Do you know of any Evidence supporting a Multi- or Inter- disciplinary approach to instituting and supporting device assisted therapies?
Yes, I attach some references that address the topic.

3. What role do you play in supporting patients considering a device assisted therapy and do you use any scales or measures to identify suitable candidates?
As I said earlier, Brazilian nurses still have a long way to go, in order to effectively integrate into interprofessional health.
Taking the example of the American, European and Australian nurses, we are working on the improvement of nursing care, which in the near future, will allow the effective inclusion of this professional in the interprofessional team of device assisted therapy.

4. The role of patient- and caregiver- teaching is essential, both in ensuring patient expectation and understanding of the technology addressed? a. In your practice, is this led by HPs?b. Is Patient- and caregiver- teaching identified, along with resources, part of the HP role?
No, but surely it should be.

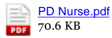
5. DBS is an ever increasingly complex therapy and programming the stimulator is a role which may be performed by a HP. a. Who programs and alters Stimulation settings in your practice? b. If the setting is adjusted by a HP, are there any "competencies" you need in order to do this? c. What role do HPs play in identifying the need for review and evaluation of success?
In Brazil, these are the duties of physicians.

6. Have device assisted therapies added additional care and rehabilitation needs to your role? If so, has there been a commensurate increase in the resources available?
It certainly increases. Look what the third study I have attached has concluded:
"The time commitment is considerable for both the nurse clinician and patient, ranging from 18 to 41.4 hours in the first year of treatment. These time requirements need to be recognized during the development of such programs, so that appropriate personnel requirements, funding, and patient education are budgeted."

In conclusion, I believe that health professionals play an important role in the education of patients and their families/ care partners, promoting therapeutic adherence, reducing health complications, optimizing treatment, and promoting patient autonomy through of their empowerment.

I agree with the words of Bhanu Ramaswamy, because in the Portuguese translation, the term "device assisted therapy" is very broad and could cover all other therapies involving technological devices.

Michelle Tosin, PhD student, MSN, RN
São Paulo - Brazil.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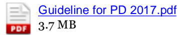
Guideline for PD 2017.pdf
3.7 MB

_Nursing Time to Program and Assess Deep Brain Stimulators in Movement Disorder Patients.pdf
215 KB

Mariella Graziano Sun, 22 Apr at 12:17am

When I read the title of this discussion on device assisted therapies, my first thought was: what an interesting topic for a multidisciplinary team, as we will be able to have some insight in how fast advancing modern technology impacts daily practice. Then I realised the topic refers to medical devices. I agree with Bhanu Ramaswamy on the need to further define the term "medical "and "therapy" in this context.
This said, the role of physiotherapy on Deep Brain Stimulation (DBS) in the region of Luxembourg, is not as established, as it is the role of neuropsychology and nursing. Both professions are involved in the pre selection criteria and monitoring of the device in a hospital setting.
As an individual therapist I do treat people with Parkinson's (PwPs) with DBS in the community and, work together with the person and the carer on the changes the device has on daily functioning, from the impairment level, like changes of tone and decrease bradykinesia, to changes of activities of daily life and participation in society. Sometimes when the device is successful and the person is more independent, the dynamics of the family may change and the carer may find himself or herself with no role. This poses a problem, at the psychological and economical level and calls for a more specific intervention of the multidisciplinary team not only at the hospital level but also in the community.

Marcela Leon Barrera Mon, 23 Apr at 7:07pm

Hello everyone.

A bit of context in Chile:

1.- DBS: There are 2 private clinics where the intervention is performed and recently the first DBS surgery was performed in the public health system, we are very happy about it. Also, there are several patients who have made the decision to travel to Spain for their DBS surgery.
The health team consists of a neurologist, surgeon, electrophysiologist, within the medical team. A neuropsychologist participates in the evaluation of inclusion and exclusion criteria for surgery.
Usually the rehabilitation team participates in order to:
Assess the baseline situation and visualize critical areas of intervention before undergoing surgery.
Health education to the person and their family regarding the expectations of the intervention, adherence to treatment and monitoring results in a more objective way.
Post surgical accompaniment to resume activities of daily life in this new functional situation.
Evaluation by speech therapist: we have observed that the quality of speech has been frequently affected post surgery.

2.- Recently there has been a high interest in Chile in spinal cord stimulation surgery, based on research and an article of February 2018 MDS has put us a challenge.
This surgery would be focused on axial disorders, so the selection and management criteria are focused on evaluations related to balance and gait, particularly freezing of gait.
In that sense, we are applying an evaluation protocol with instrumented balance and gait evaluations with wearables sensors during the day.

Also for us in Chile, "device assisted therapy" cover a lot more than DBS.

Thank you!

Marcela León
Physiotherapist
Chile

Meg Morris Mon, 23 Apr at 7:36pm via email

Greeting from sunny Australia. DBS is being done on a routine basis here now, but what we are really lacking is "prehabilitation" and proper "movement rehabilitation". To foster neuroplasticity it would seem to give people exercises (progressive resistance strength training, cueing, physical activities such as walking, tai chi, dancing and hydrotherapy) well before their DBS surgery to get them in the best possible condition, and then again immediately after surgery, so the brain adaptations with the new neural substrates are optimised. The real challenge is funding – there is no direct funding line for physiotherapy or other allied health pre and post-DBS; this seems to be the limiting factor.

Also please see attached a few of our recent Parkinson's RCTs on hydrotherapy, dancing and cueing

Cheers
Meg

Carroll & Morris 2017 Hydro.pdf
523 KB

Priscila rct ijtr.2018.25.2.64.pdf
121 KB

JoP PD falls 2017 Morris.pdf
521 KB

John Dean Mon, 23 Apr at 9:25pm via email

These areas are a little beyond my wheelhouse so I hesitate to answer directly to the topic at hand. I have worked with a number people who have undergone DBS but only one who's undergone a procedure for the duodenal pump. I've not seen anyone using either of the pump formulations (Apomorphine or levodopa).

I took a class on DBS programming several years ago taught by Sierra Faris and while it was fascinating material, I was not confident that I would ever want to undertake anything like that unless it was as part of an interdisciplinary team at a clinic doing DBS.

Speaking directly to Dr. Morris's comments, the interdisciplinary rehab team I found ~8 years was able to convince some doctors performing DBS to send us patients before undergoing the procedure but more than one pointed out that there wasn't a lot of evidence to support it. Is there a body of published data indicated that people undergoing "pre-hab" have better outcomes post surgically?

As an SLP, I always found it harder to do some of my speech work after someone has undergone DBS. In a perfect world, I'd like to do all the calibration and training of an approach like LSVT before they undergo the surgery but again, I'm not sure I could point to any data to support that.

That having been said, I consider people who have undergone DBS, to be a separate phenotype of Parkinson's, particularly if they had a tremor dominant phenotype to begin with. These individuals have

significant resolution of the tremor and rigidity but have more significant issues with speech as well as other axial symptoms like balance.

I'm very interested in the potential of current steering technologies to mitigate the possible affects of stimulation on speech function. In the past, I think it's always been a matter of improving gait and addressing other motor symptoms at the expense of speech (and I agree that reducing falls is always of primary importance). Hopefully, with the emergence of current steering technology, it maybe possible to realize those improvements without having such a negative influence on speech. There was a pilot study from Italy that demonstrated just that exact impact but I can't seem to find it right now. Nonetheless, here's a link for a small study done in England that indicates that current steering resulted in lesser deterioration of intelligibility scores http://jnnp.bmj.com/content/87/12/1388

Several years ago, I was part of a start up and part of the project included some opportunities to record people during the off/on testing when they were under consideration for DBS. We were using accelerometry primarily but we recorded audio signal to assess potential changes (such as acoustic markers of changes caused by pulling due to stimulation of the internal capsule). Unfortunately, that start up is gone but I do think there's a role for a technology like that.

-John

PS -Bhanu and others bring up an interesting point about our use of technologies in the clinic and by our patients in their own homes. I did a presentation for the Israeli Speech Language Hearing Association several months ago on the topic of App-based and computer tools that I use for Telepractice as well as a discussion of some other commonly used technology options. I think many of us are using different apps and other devices in our practice. I think that would be an interesting topic for future conversations with more direct application to our respective practices. I put those slides up on slideshare just in case anyone's interested (https://www.slideshare.net/JohnDean29/technologies-for-the-clinic-and-beyond)

PPS - I'm currently involved in another start up, this time working out of an accelerator in Lisbon. We are focused once again on making use of emerging technologies in order to extend our clinical capabilities. That having been said, technology will not replace us anytime soon (but it can certainly van extend our clinical capabilities)

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Uzoamaka Anosike Mon, 23 Apr at 9:55pm

(Responses are based on DBS as device assisted therapy)
1. Team members involved in patient selection are the Neurologist (Movement disorder Specialist physician), Neuropsychologist, Neurosurgeon, Nurse practitioner (plays the role of nurse navigator for DBS patients).
General Neurologist and primary care providers in the community refer their patients who they think will be candidates for DBS to the team.

2. Multidisciplinary approach has been beneficial in proper patient selection for our team. I hope as healthcare continues to advance that we can have an interdisciplinary team focused on DBS patients that includes physical therapist, speech therapist and occupational therapist, social worker in addition to our current team members.
Multidisciplinary care of patients with Parkinson's disease: https://onlinelibrary.wiley.com/doi/pdf/10.1002/pnp.230

3. My role is nurse practitioner/nurse navigator. My role includes patient education, assessing expectations from DBS and assisting patients with setting realistic expectations, educating patient and caregivers on the process involved with DBS-preop, intraop, post op, and programming process.
I also use the Unified Parkinson's Disease Rating Scale (UPDRS) part 3 to do "ON/OFF" testing (dopaminergic evaluation), record OFF medications UPDRS and ON medication UPDRS and compare to see changes in scores.
4. a-Yes, education is done by nurse practitioner.
b- In my practice, teaching is identified but there's limited resources available or dedicated to teaching. Teaching is currently done by phone communication and during office visits; time constraints during office visits may not allow for adequate teaching sessions).
5. a- Neurologist or nurse practitioner can program and alter settings
b- We had training with the DBS manufacturers; supervision by more experienced programmers and frequent practice also help.
c- HP play a role by assessing patient's current symptoms, decides if programming is needed, and monitors the patient after programming to ensure final settings are effective.

6. Yes, DBS has expanded the treatment options available to our patients, added additional needs but unfortunately available resources do not commensurate with the increase.

Thank you,
Uzoamaka Anosike, NP-C
Nurse Practitioner
South Carolina, USA.

Vicki Segro Tue, 24 Apr at 10:14am via email

1. We consider assistive device therapies as "invasive therapies" for the treatment of PD in our center. We have a well established DBS program incorporating neurologist, neurosurgeon, neuropsychologist, physiatrist (with therapies if needed) and DBS nurse programmer. They meet approximately monthly to review upcoming cases and discuss the care plan for individuals. For pump therapies, several of the patients have neyropsychological evaluations which have excluded them from DBS. We (of course) have GI or interventional radiology assist with the tube placement. Pump programming is provided over a few days by neurology in conjunction with an RN or LPN to provide ongoing teaching'
2. I haven't read any information about studies supporting multidiciplanary programs in the care of these patients.
3. As an NP, I identify patients appropriate for these therapies. We do "on and off" exams prior to DBS and sometimes prior to Duopa to determine if the patients will have an adequate response. We also review nonmotor symptoms during this appointment and assess whether the nonmotor symptoms will improve with the therapy.
4. Patient and caregiver trenching is both my responsibility and the DBS nurse educators. Caregiver teaching is more intense for patients receiving Duopa therapy.
5. DBS programming is performed by a DBS nurse in conjunction with the neurologist. I am not providing the programming because it is to time intensive for me and not cost effective.
6. As the patients progress with their PD and many have developed dementia over the years (we have DBS patients that were implanted in the late 1990s) the care of these patients becomes more complicated. Rehab needs increase for the patients and our physiatrist is more involved with their care. We have a good neuropalliative care clinic available for very advanced patients. There is surely an increase in utilized resourses for these advanced patients

Best Regards,

Victoria Segro MSN C-ANP

Nurse Practitioner

Rocky Mountain Movement Disorders Center

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Susan Heath Tue, 24 Apr at 12:44pm via email

My practice is very similar to Vicki's of Rocky Mountain Denver's program except I do the DBS and duopa programming and pt case management for the initial few months post device implant.

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PADRECC websites http://www.parkinsons.va.gov/
PADRECC education VA Parkinson's Playlist on YouTube<https://www.youtube.com/playlist?list=PL3AQ_JVoBEyxd5tkfQG-S3p_SDYBFtJ6c>

Siok-Bee Tan Tue, 24 Apr at 7:54pm

Response from Singapore Team

1. What team members are involved in patient selection for a device assisted therapy? All members in the movement disorders multidisciplinary team – Neurologist, neurosurgeon, Advanced Practice Nurse, Physiotherapist, Occupational Therapist, Speech Therapist, Dietitian, Medical Social worker, Psychologist.
2. Do you know of any Evidence supporting a Multi- or Inter- disciplinary approach to instituting and supporting device assisted therapies? Patient selection and evaluation – evidence available.Tertiary hospitals in hospitals have practiced multidisciplinary approach in supporting DBS and Apo-morphine.
3. What role do you play in supporting patients considering a device assisted therapy and do you use any scales or measures to identify suitable candidates? Nurses and allied health play an important role in assessment , education to identify suitable candidate . Multiple assessment tools are necessary ,such as : on and off evaluation , MOCA , Motor fluctuation , PDQ39 , BDI etc
4. The role of patient- and caregiver- teaching is essential, both in ensuring patient expectation and understanding of the technology addressed? a. In your practice, is this led by HPs? b. Is Patient- and caregiver- teaching identified, along with resources, part of the HP role? Yes, patient and caregiver teaching is led by HPs.
5. DBS is an ever increasingly complex therapy and programming the stimulator is a role which may be performed by a HP. a. Who programs and alters Stimulation settings in your practice? b. If the setting is adjusted by a HP, are there any "competencies" you need in order to do this? c. What role do HPs play in identifying the need for review and evaluation of success? Either an advanced practice nurse or the neurologist do DBS programming . the HP needs to be trained by the device manufacturer and clinically competent to do the procedure. Based on patient's condition, follow-up will be scheduled accordingly and review on time.
6. Have device assisted therapies added additional care and rehabilitation needs to your role? If so, has there been a commensurate increase in the resources available? Device assisted therapies require tremendous effort to care for the patients such as follow up call for monitoring , troubleshooting device problem. Manpower is still a big issue to manage the increased workload. However, technical support from the manufacturer has improved.

Maria Elisa Pimentel Piemonte Wed, 25 Apr at 9:49am

Dear colleagues,
I am very glad to verify the experience's sharing from distinct parts of the World promoted by this basecamp!

In Brazil, we have several public and private hospital that offer DBS as treatment of PD. Unfortunately, we have no regulations for other kind of devices so far.
The routine for patient's selection for DBS involves an interprofissional team, including physiotherapist, speech therapists and neuropsychologist, besides neurologists and neurosurgeons, of course. This team considers, besides clinical aspects, social aspects too as support for transportation to reach the hospital, since this is crucial barrier for long term treatment in Brazil.
However, despite the interprofessional pre-surgery evaluation is a routine in Brazil, the follow-ups of these patients are very precarious: several patients have no access even to physiotherapy, the more developed no-medical area in Brazil.
In several regions, the wait time to reach a physiotherapy treatment in a public service can reach 24 months.
Then, usually in our public service we receive patients who were submitted to DBS many years ago, but have had no interprofessional support besides the neurologist and neurosurgeon.
In contrast, in private services, accessible only for richest people, the pre and pos surgery interprofessional care are considered excellent according to international level.
Unfortunately, the distance between the quality of public and private interprofessional care in Brazil is very long and we have worked very hard to short this distance…..

Han Wang Wed, 25 Apr at 10:32am via email

From Chinese HPs' reply~

What team members are involved in patient selection for a device assisted therapy?—-Generally neurologist, sometimes, in selected hospital, neurosurgeon alone for, let's say, DBS eligibility (apomorphine and durdopa are not available in China.) Psychologist and PT are becoming involved in some high-ranked hospitals.
Do you know of any Evidence supporting a Multi- or Inter- disciplinary approach to instituting and supporting device assisted therapies?—-Not know.
What role do you play in supporting patients considering a device assisted therapy and do you use any scales or measures to identify suitable candidates?—-As a neurologist, my work in DBS patient selection include: 1, identifying eligible patients, make sure they have already received BMT before DBS therapy, and recommend the time window to receive DBS therapy; 2, excluding ineligible patients that will not benefit from DBS.
The role of patient- and caregiver- teaching is essential, both in ensuring patient expectation and understanding of the technology addressed? a. In your practice, is this led by HPs?—-Yes. We provide patient education program offline and online irregularly. b. Is Patient- and caregiver- teaching identified, along with resources, part of the HP role?—-Currently, not enough, due to the heavy medical work…
DBS is an ever increasingly complex therapy and programming the stimulator is a role which may be performed by a HP. a. Who programs and alters Stimulation settings in your practice?—-It depends, by neurologist or by neurosurgeon, in different medical facilities. b. If the setting is adjusted by a HP, are there any "competencies" you need in order to do this?—-It should be reasonably paid, for it is so time-consuming and energy-taking. c. What role do HPs play in identifying the need for review and evaluation of success?—-Sorry, not sure I've understood the question. Do you mean how to make sure it has been programmed good enough? Usually the patients will be asked to come back to be reviewed and evaluated in fixed timetable. Sometime, HPs will actively make phone call or through online tools.
Have device assisted therapies added additional care and rehabilitation needs to your role? If so, has there been a commensurate increase in the resources available?—-Yes. More resources appear with the increasing needs and attention that has been paid by physicians.
Regards,
Han
—
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At 2018-04-20 19:54:31, "Samantha Surillo" <notifications@themovementdisordersociety.basecamphq.com> wrote:

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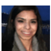

Samantha Surillo Fri, 27 Apr at 11:16am

Thank you for everyone's time and sharing of experiences.

If anyone has any further thoughts or comments you would like to make, please do so in the next 24-to-48 hours as the Secretariat will then begin the summary process on Monday, April 30, 2018.

Please feel welcome to email me at ssurillo@movementdisorders.org if you have any questions in the meantime.

Warm regards, Samantha

Samantha Surillo
MDS International Secretariat

Belen Sancho Iglesias Sat, 28 Apr at 1:17am

Hello from Basque Country (Spain),

In my clinical experience the decision about DBS is made by the neurosurgeon, neurologist, psychologist.
In my experience as physiotherapist, I believe that technology can help us enormously in this field. New devices can detect the tremor and registered it which can help us in patients treatments.
Here we have the associations that help patients providing rehabilitation because in the public system is very limited. in the public system not know device assisted therapy.
Here patients did not support education programs in the public system. Only by association.
Who programs and alters Stimulation settings in your practice? neurologist or by neurosurgeon
b. If the setting is adjusted by a HP, are there any "competencies" you need in order to do this? yes, patients capabilities in the activities of the daily life.
Have device assisted therapies added additional care and rehabilitation needs to your role? If so, has there been a commensurate increase in the resources available?—-Yes. We identified more rehabilitation needs improving balance and walking capabilities.

Thank you very much for the basecamp opportunity.

Kind regards,
Belén Sancho