

Arrogance of the Rehabilitation Science in the Netherlands

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Abstract

Background/ Aim: In the Netherlands, a neurorehabilitation programme was established after 2006 that should be as evidence-based as possible. There is nothing wrong with that in itself, but much has not yet been researched and much is best-practice. Instead of seeking cooperation, best-practice was stripped of its roots, or on his best rather put on hold, and a new “approach” was created in record time.

Design: Back in history, until 2006, the knowledge network for stroke patients had been fully rolled out in the Netherlands, and all patients were treated by therapists/nurses according to the same concept. That concept was basically the Bobath-N.D.T. concept, and perhaps that was where the problem lay.

Result: A study of questionable quality indicated that this concept had no added value compared to other treatment concepts. But the others also had no added value compared to each other, and the evidence-based approach appeared to remain at the same level. Furthermore, it turned out that the evidence-based research was not so evidence-based, because the study design was not proper and replication was not possible.

Discussion and Conclusion: It shows a considerable amount of arrogance on the part of Dutch rehabilitation science to completely undermine an existing treatment chain with essentially no evidence. On the other hand, their research was structured differently and focused mainly on the 10% who were treated in their rehabilitation centres. Their priorities apparently did not receive that attention. Now, after almost 20 years, much knowledge and expertise have been lost among the practitioners of the treatment, and the network is much smaller. So, it is high time to get everyone on the same page again and to optimally treat everyone after a stroke, while continuing to test and research that treatment.

Kew Words: arrogance; rehabilitation research; bobath/ndt; therapy

Introduction

Around 2005 there is the publication of a thesis (Neurodevelopmental treatment after stroke [1]: a comparative study) which completely changes the treatment performance in the Netherlands. Of course there were other articles of investigation published, but this article was so devastating in the condemnation of the approach that was then dominant in the Netherlands. From the year 1950 in the Netherlands, the “classic” approach was changing to a more “hopeful” approach, as the Brunnstrom [2] and Bobath [3] methods and, at the end, the N.D.T. [4,5,6] (Neuro Developmental Treatment, a “next level” Bobath concept) were done in all situations that involved working with stroke survivors [7,8,9,10,11,12]. That gives the multidisciplinary team a framework in which every member has his task and was trained in the skills to manage the problem that, though the stroke, was developed. In this team the rehabilitation doctor has a binding role, but the role was less active in the

treatment performance. One of the discussion points at the end of the last century was the way people recover from a stroke. Burnnstrom gives us 6 stadia in which the tone increases to a high level with stereotyped movements that were poor and predictable. But in his view, this was replaced by more selectivity in the last stages and gave a full recovery.

The reality was totally different and was often dependent on where the stroke took place, how massive it was, etc. The recovery was poor, especially in the areas that had only “one” cortical pathway, such as the arm/hand, and less clear in the foot. Still, many articles/books on the rehabilitation sciences were based on the “positive” effects of this tone increase and plasticity. [13] Around 2005, in the Netherlands, the discussion was at its highest level about how to treat people after a stroke according to proven interventions and

science, investigating how fast recovery takes place and which of the stroke survivors has the best opportunities for a full recovery. That was also an investment for the arm and often accompanied by a new (old) treatment approach, CIMT. (Constrained Induced Movement therapy [15]) Old [14] was a treatment approach called “force used” that was changed in the new jacket. With this new approach (CIMT) and the most optimal prognosis of recovery, this approach made great progress in the treatment option, but the question was still justified:

“Was this an approach for all or for a limited group?”

There was a clear “battle” between the neurorehabilitation science and the workers on the floor, and then especially in the rehabilitation centres, the discussion of how to perform was intense. Again, no problem; this will only give all people that are involved more power to participate in the treatment of this group of patients and will make the treatment and the education in all areas only better.

But then there must be respect for all participants.

But then came the thesis [1].

The outcome of this investigation in which 6 hospitals participated. Three of this hospital were “trained” in the NDT (Bobath) way, and the control group does not have this training at that level. Here is the first problem because the comparison between the hospitals makes a rehearsal of this investigation almost impossible, and that gives the outcome less strength. This outcome was, that there was no clear surplus value of the N.D.T. (Bobath) concept in comparison with the control group treatment. The treatment of the control group was not clear but contained a hodgepodge of treatments, in which even elements of Bobath were present, often in the form of the Johnstone approach [9, 10].

Thus, the conclusion was no surplus value!!

The way an investigation was formed and executed was poor because no rehearsal was possible, but it wasn't the only investigation that was done in that way. In fact, almost all investigations that follow, but also the investigation in an early stage, have all a control group that was classified as “usable treatment” and make it thus impossible to rehearse that investigation.

Certainly, there was an outcry from the science group reaction that the quality of the investigation for the best treatment for stroke survivors was not done in this way, but here we see the first signs of the huge arrogance of the rehabilitation science, because they go on with investing in that way with a control group that wasn't clear. With so little correct evidence about the concept, there was in the world a reaction of 'waits and see' and, at the same time, an attempt to get better cooperation with all members of the people that were busy with the best possible treatment for stroke survivors in every situation. But in the Netherlands a coup d'état took place in which the coup plotters directly came out of the rehabilitation centres of the Netherlands that have the care of about 10% of all stroke survivors. The next form of extreme arrogance is to know what the best approach was for everyone and at the same time to “kill” an education (NDT-Bobath education for therapists and nurses) and set up a new education, and that with the practice skills from almost all NDT-Bobath teachers in the Netherlands. That this group participated is still a miracle because the whole course was too theoretical to get proper practical treatment for the patients.

The dramatic effect was that almost immediately:

1. The education based on skill exercise and learning on stroke survivors was only still present for a select group of therapists, mostly working in rehabilitation centres (only 10% of the stroke survivors will get there) [17]. Education of other participants in this multidisciplinary team was stopped and never reached that level as before. That means that in rehabilitation centres, there was often an intern education and less also in hospitals, but especially in the chronic phase in all his situations, this was no longer present.
2. The knowledge, but especially the skills, was fast gone, especially because so many people that did not directly participate in the care had read the papers and were therefore “convinced” and stopped putting money in that education. One of the dramatic problems was the chronic care and the care for the hemiplegic shoulder that fell back.
3. The last effect was the isolation that occurred for the leading therapist and special nurses from the international community, and that was a community that has practice and practice skills to be held in high regard, and that source was gone [12].

Table 1 Baseline characteristics of patients

Variable	NDT treatment (n = 223)	Non-NDT treatment (n = 101)
Stroke onset to admission (d)	0.32 (1.1)	0.59 (2.4)
<i>Demographic characteristics</i>		
Female (%)	101 (45%)	50 (50%)
Age (years)	68 (13)	72 (11)
Living alone	75 (34%)	53 (53%)
<i>Education</i>		
≤6 years	84 (38%)	33 (33%)
6–12 years	102 (46%)	55 (55%)
>12 years	36 (16%)	12 (16%)
<i>History</i>		
Stroke	47 (21%)	16 (16%)
Angina pectoris	38 (17%)	22 (22%)
Myocardial infarction	21 (9%)	14 (14%)
Hypertension	85 (38%)	38 (38%)
<i>Qualifying stroke</i>		
Cerebral infarction	202 (91%)	91 (90%)
Intracerebral haemorrhage	21 (9%)	9 (9%)
<i>Motor function disorder</i>		
Can walk unassisted	6 (3%)	7 (8%)
Left arm paresis	132 (59%)	53 (54%)
Left leg paresis	130 (58%)	57 (57%)
Right arm paresis	91 (41%)	44 (44%)
Right leg paresis	89 (40%)	41 (41%)
<i>Sensory function disorder</i>		
Left arm	66 (30%)	27 (27%)
Left leg	58 (26%)	25 (25%)
Right arm	34 (15%)	24 (24%)
Right leg	32 (14%)	19 (19%)
<i>Language function</i>		
Motor aphasia	30 (14%)	11 (11%)
Sensory aphasia	6 (3%)	2 (2%)
Combined aphasia	10 (5%)	5 (5%)
Hemianopia	64 (29%)	12 (12%)
Apraxia	30 (14%)	12 (12%)
Neglect	73 (33%)	10 (10%)
<i>Trunk ataxia</i>		
Severe	59 (27%)	10 (10%)
Moderate	74 (33%)	33 (33%)
None	90 (40%)	58 (57%)
<i>Health status</i>		
GCS	14 (14 to 14)	14 (14 to 14)
MRS	4 (4 to 5)	4 (4 to 5)
MBI	6 (3 to 10)	7 (4 to 10)
AbMMSE	10 (8 to 11)	9 (8 to 11)
CES-D	17 (14 to 20)	16 (13 to 20)

Values are n (%), mean (SD), or median (interquartile range). AbMMSE, abbreviated mini-mental state examination 0–12 (low score = low level of cognitive function)²¹; CES-D, Center of Epidemiological Studies depression scale (score >16 = depression)²²; GCS, Glasgow coma scale²³; MBI, modified Barthel index scale 0–20 (low score = low level of physical function)²⁴; MRS, modified Rankin scale 0–6 (0 = no handicap)²⁵; NDT, neurodevelopmental treatment.

Table 1: Directly from the article [1] and thesis by Thora Hafsteindottir, the conclusion is that the NDT (Bobath) approach has no surplus value. Meaning that the comparison between the two groups with two different treatments has no clear differences in the outcome. But the characteristics of the two groups weren't equal. There were huge differences, and that means that the comparison is difficult but also that the effect by the most severe group is equal on the less severe group, and that gives a conclusion that the treatment by the severe group has more positive effects than the other treatment. Look for yourself and compare it. Again, an arrogance to conclude that therapy doesn't work.

The belief in an outcome (no surplus value) of one investigation, with no rehearsal, and then so dramatically changing the way of education and treatment and the international isolation at the practice level of the therapist is of an arrogance level that isn't often seen.

A new approach was started.

An education was started with the cooperation of the practice skills of the "old"-IBITA teachers, in which the rehabilitation only implemented what, in their eyes, was "proven" as therapy. That also has as a consequence that all therapies that haven't invested were excluded from the course, and that means that only studies done in hospitals and especially [rehabilitation centres] were allowed in this course, and that makes this course very restricted. Again, most people that were in hospital go directly back to their home, 10% will enter a rehabilitation centre, and the most severe or difficult cases will end in nursing homes or long-stay facilities. The treatment was composed around the new scientific insights, and one of them was "more is better" [18]. Further, the treatment for the arm focused on the investigations around CIMT [15, 19, 20], the walking possibilities extended through huge

apparatus, and the focus on the treatment of the hand was robotic. In the CIMT articles there was some criticism to read about the choice that was made of which stroke survivor was implemented and the comparison with other patients that received a conventional treatment [20], an example being that the prescription of the control group isn't correct after so many years, even in 2022. The stroke survivors that have benefited from the CIMT approach are the people with the best recovery of arm and hand. And then it is very important to compare on an equal level qua time but also on intensity. That was immediately the greatest discussion because what is intensity? In the beginning was this, regrettably, more time!

More time was "equal" to intensity!!!!???

This "mantra" was the start of the scientific search for all kinds of treatments in which the skill of the therapist could be replaced by apparatus to create a treatment with a great amount of time. The hands-on approach with abilities to facilitate the movements with a direct relation to the ADL was replaced by apparatus and/or robotics. Walking, balance training and also hand/arm

training was done through commitment to technique and to obtain the more advanced time level.

Of course, there was the discussion about the “transfer” to the ADL, because that was the purpose of the rehabilitation.

The amount of literature that was published about the way of learning was immense, but in the area of motoric learning, it was often forgotten that a treatment isn't only learning but also training and that it asks for a certain amount of heaviness to get a reaction in all systems that manage the

coordination of our movement. Furthermore, there is a scale of problems through a stroke that all ask for different approaches and learning, but motoric learning is dependent on the remaining possibilities and the heaviness of the effort. [21, 22, 23, 24, 25]

Here it was clear that the mantra “more is better” wasn't equal with intensity, but regrettable was the arrogance of rehabilitation science that this stayed for years.



Photo 1



Photo 2

Photo 1 en 2: Examples of developments to increase the ability to give stroke survivors more opportunity to train without the presence of a skilled therapist, and mostly this was done additionally.

But the cost for this kind of apparatus was and is so high that only rehabilitation centres have the opportunity to give this treatment part. That there is evidence that this therapy can be effective is clear [26, 27], but the base (more is better) isn't correct, and the relation with daily life is difficult for both.

Still, it is clear that an a-functional hand has, certainly, in the chronic stage at this moment, only a change with the development of this robotic hand, but till today this will often work as a brace in the simple ADL actions.

In this period the focus lay on what science had found and found proven and thus suitable for the training. The skills of treatment of all kinds of problems, such as neck, shoulder, hand, wrist, oedema, and hip hypermobility, were quickly lost in the Netherlands because this wasn't invested in. So, was there often, in the eyes of the “directors”, too little evidence to support old training such as aquatic therapy, and was this a good reason to dismantle the pool? And even good investigations, such as by Tripp [28], were pushed aside, because rehabilitation science hasn't reacted positively. This period started in the Netherlands around 2007, and in the rest of the world there was discussion, but the cooperation and the respect for each other stayed, and the development of skills and treatment increased, and that was missed in the development of the people on the stroke survivors in all situations.

Around 2016, a reaction of the rehabilitation science top occurred when they set together and created the SRRR (Stroke Recovery Rehabilitation Roundtable) [30, 31] and started with a scientific base initiative to get the investigation on a level that it “means” something and could contribute to a further increase of optimal treatment.

This scientific shift starting in 2006 wasn't correct.

“More is better” wasn't the right way to give an indication about the intensity that is needed to stimulate the damaged brain to create plasticity. [32] It was clear that cortical pathways were much more vulnerable and that plasticity wasn't possible. Still the damaged brain asked for a certain heaviness (intensity) with a certain amount of time and rehearsal with a certain frequency. Only what counts for the great muscle pattern that has often much more innervation been different in demands than the fine motoric, etc. This asked for an individual approach and a combination of training and often implicit (differential) learning. [23, 24] Further, it was important to recognise the borders of recovery and see what is necessary to get further

improvements, and then there is the research for robotics as a way to improve, especially the arm and hand function.

The second important decision was the call for better and good clinimetric and a fast investigation agreement about the experimental group but especially the control group. Only then was it possible through replication to make the evidence robust; here they develop the Template for Intervention Description and Replication (TIDieR) Checklist and Guide. [33, 34, 35, 36, 37] That means that all guidelines are, at this moment, not TIDIER-proof and that calls for an effort of the rehabilitation sciences to get that done. [38] The start was in 2006 with the total elimination of an approach in the Netherlands that was hands-on direct with the patient and in relation with the ADL to restore as much as possible the possibilities of a stroke survivor with such good control over the abnormal tone and synergies. This elimination has led to more tone dis-control and dis-comfort, as we see in the increase of treatment with medicines and injection with BOTOX and/or operation. But give a good reason to keep alert on the tone because there is growing evidence that a tone out of control makes movement only difficult and thus independence far away. Good investigation about this topic is still poor and often not TIDIER-proof. [38, 39, 40, 41]

In the first 10 years after the “coup”, there was a treatment proposal on scientific “grounds” that pushed in the Netherlands the rehabilitation in a direction where only evidence was the base of a good treatment and led a lot of stroke survivors to “stand in the cold”. All that hasn't, had scientific support was considered “wrong” and could harm the patient. After 2016 there were some changes because the evidence wasn't there, and in the world, there was such a great amount of research that it was necessary to make that “evidence” robust. The template TIDIER should certainly take care for more robust evidence, but not everywhere is this used, and till today so many investigators still use the nomenclature for the control group with

“usual care”, conventional care, etc., and often it is a combination of all kinds of therapy approaches that have developed during the last two centuries. Don't forget that the therapist and others in all kinds of care institutes were working with stroke survivors long before rehabilitation science noticed that this group needed rehabilitation. World War Two was a start for the soldiers, but in the Netherlands in the 80s of the last centuries, there was room for stroke survivors (10%) in rehabilitation centres.

Thus, more robust evidence is now the mission for rehabilitation science, and this must be for all stroke survivors from hospitals, rehabilitation centres, and nursing homes, as in the home situation, and from the onset to the end.

With an open mind for all facets, then we will find what treatment can be effective and can be the best for each individual after a stroke.



Photo 3: This photo has been taken during one of the meetings of the International Stroke Recovery and Rehabilitation Alliance as they have developed the SRRR (Stroke Recovery Rehabilitation Roundtable).



Photo 4: These are the people that participated in the annual meeting of the IBITA (International Bobath Instructors Training Association) members across the world to meet each other and practice and learned. The discussion how to train people after a stroke is the main issue and here always scientist out the group on photo 3 are invited to discuss further improvement of the treatments.

Both groups can help to develop the treatment, not all elements, and not the focus on some elements and neglecting others, only because there are no scientific investigations that give a justification. Mostly no investigation is done and regrettably others don't meet the TIDIER standard.

Thus look Fysio wards today and what we miss on that floor.



Photo 5



Photo 6

Photo 5 and 6: The accommodation to train (not relearn) walking capacity and then is it obvious where the focus lie on. A great scala of systems that make walking save and easier in an environment that is make for training of that element.

The “transfer” to real world will an whole other story and the focus on only one element give this training less variation. And often the training- rules where not obtained with the consequences that the coordination and the power don’t increase.

People that believe that patient “re-learning” the walking possibilities, don’t think of the fact that though the brain damage, a lot of coordination and power is lost, and this asks for a training that gives muscle fatigue to restore that. The other element of plasticity and restoring of the selectivity will only be obtained when this is possible through training. Thus, not learning stand by restoring of body function primary, but training. Walking is a part, but other elements are maybe more important, because this can have a positive influence on the independency at home and the quality of life. Thus, it is important that treatment on all aspects is done, and that will give a great

variation of movements and need great skills of therapists. Therefore, all kinds of activities in the Physio ward, but also on the ward in clinic, but certainly at home, focus on all elements that can contribute to a higher level.

The collection of photos on the next page will give a picture of what people after a stroke need to recover optimally, and the key factor is the skilled therapist that knows how to hold the mobility at the highest level and continues to search for movements that have a purpose to make daily life easier.



Photos 7, 8, 9 and 10: Treatment and tone inhibition of the shoulder/shoulder blade to maintain optimal movement with as little risk of pain and limitations as possible. This is essential for all joints, including the foot, and requires skills that take a lot of practice.



Photo 10: Integration of standing up and standing at the kitchen counter while cooking and making coffee.



Photo 11



Photo 12

Photos 11 and 12: Balance training with lots of variation, in which it remains important to explore the limits together in order to practise perception of the body schema, but also to practise the muscle patterns that must “guard” these limits [43]. This training requires that the training be performed with sufficient repetition of 75% of 1 R.M. [42] so that muscle fatigue [19] occurs, which is the stimulus to improve coordination and power.



Photo 12



Photo 13

Photos 12 and 13: Balance training in a seated and standing position, again searching for the optimal limits and trying to maintain them. Standing on one leg, but again requiring sufficient power on the affected side so that the pelvis reaches and maintains an optimal position and can be trained according to the training rules.



Photo 14



Photo 15

Photos 14 and 15: Descending stairs in two different ways. Photo 15 shows the added value of a trained therapist in providing optimal training in descending stairs, and again it is possible to continue training according to the training rules.

The arrogance that only treatments that have been researched have added value ignores the fact that recovery depends primarily on how badly the brain is damaged and what is still possible. It is clear that these damaged brains must use systems [2,44] to enable some movement, but at what cost? It is clear that pathological tone in particular will eventually cause problems that

can significantly affect quality of life. And this often happens when most patients are no longer in the “view” of rehabilitation science and are in a chronic phase, struggling to maintain their level of functioning. The decline is often too great. [46].



Photo 16: Is this incorrect, or is it a brilliant variation to influence walking in such a way that more weight is placed on the affected side? Walking, already one of the most practised and machine-trained ways of moving, requires adaptation to one’s own situation. Walking with a four-legged stick requires a considerable amount of space and balance; technically, there is a lot of emphasis on the unaffected side, so this variation immediately increases the load, causing muscle fatigue that stimulates the system to improve coordination and power. This is an excellent example of how a trained therapist is able to create a safe situation in which balance and walking can be taken to a higher level. The damaged brain can benefit from this, which is not the case with a failure of the corticospinal tract to the hand, which makes selectivity much more difficult and often very limited.



Photo 17



Photo 18

Photos 17 and 18: Training movements in a lying position: direct training for the movements in and out of bed that are fundamental to independence. [46,47]

Research by rehabilitation specialists in the field of training aimed at restoring independence in and out of bed is marginal, as is proper research by Dutch rehabilitation scientists into the effect of training in water on independence.



Photo 19: Practising in water has been shown in literature to have an effect not only on pathological tone, reducing it and increasing the ability to move, but also, due to this increased movement and reduced tone, on selectivity.

It also appears to have a very positive effect on perception. [48,49,50,51] The counterpart, hanging in a device that reduces weight, on the other hand, appears to be a favourite research topic in rehabilitation [52], but no one talks about its limitations. Because walking, balance and standing up are all well and good, but that's where it ends, whereas in water, all the movements needed to function independently at home are possible and, thanks to the resistance, there is always an optimal situation for training according to the training rules.

To top it all off, it also makes it possible to provide extra ADL training, which is such an essential part of independence.

Conclusion

The conclusion can only be that the arrogance of rehabilitation science has led to the loss of a fantastic network for stroke patients and, not only that, but also a great deal of knowledge and expertise among those implementing the optimal approach identified by science. And it is precisely this new scientifically based approach that appears to be unsustainable due to poor and often one-sided research, as a result of which there is still no clarity about what works and what does not.

It would be to the credit of science, if they took a closer look at the workplace and provided their support there, so that stroke patients everywhere receive optimal support and the practitioners who do the work receive optimal support, instead of placing their ideas at the top of the guidelines in a dominant and one-sided manner.

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