**Physical Disability**

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1. **INTRODUCTION**

While I am talking, I want you to keep in mind that I became disabled 21 years ago and that OT as it is today must have improved since then, along with teaching methods. Furthermore, you have to keep in mind that 21 years ago, Vona du Toit’s theory on creative ability was not widely used yet, and I am certain it was not applied in my rehabilitation sessions.

I will concentrate on isolated incidents in the beginning of my disability and emphasize levels of tone, self differentiation and self presentation. Because of lack of time, I will only touch on participation but will highlight some motivational factors that carried me over to this and higher levels of creative ability.

1. **LEVELS OF PHYSICAL DEVELOPMENT**
   1. **Tone:**

Thinking back, I now realise what a big effect those first months after my accident had on me. It was a motor car accident that got me thrown out of the car with my one foot still up on the door frame when I came by the first time. There was and ambulance and a man knelt next to me. I tried to lift my arm but it flopped over my face and my first words were: “*I am paralysed. I will not do the high jump tonight”.* To put those of you who don’t know into perspective, I was an athlete on my way to the S.A. Games. The year before that, I was the under 16 S.A. Champion for high jump.

I think I was on a level of tone from that moment on and for a long time to come. I lost consciousness again in the ambulance and remember when I came by in hospital again, a doctor told me he was going to cut my hair to put a steel rod in my skull (I later got to know the term ‘cone callipers’) and that he had to stitch up the side of my nose which would hurt a bit. I had long hair that was my beauty and my pride, but my response was: “*Do what you want to”.*

I must have been in a state of shock, but never showed any signs of it. I was calm and collected and never cried the whole time I was in hospital – I spent nearly eight months there. After about a month in my bed, my mother told me that the doctor asked her to talk to me. He told her that I frustrated him because I don’t ask him anything. Not what was wrong with me or whether I would walk again – nothing. My only response was: “*Ek weet mos wat is verkeerd met my.”*

I say I was on a level of tone, because although I spoke those first words: “*I am paralysed”,* all this time in bed, which lasted two months, I never actively thought what it really meant. My mind was a blank and I listened passively to stories read by my mother. I had a catheter and my bladder had to be rinsed each morning. I did not know what the nurses did when they lifted the sheets with this huge syringe in their hands – I only had this very uncomfortable feeling when they were busy, but I never asked what they were doing.

The first time I saw an OT was after about four weeks. She put mirrors up so I could see what was going on around me. This lifted my spirits a bit because I could see my visitors’ faces now. Before, I could only see the wall behind me because my back was lifted onto pillows and I had nothing under my head. During this time she also told me that the Technikon where I studied Film Production said I could come back if I could write scripts. At that time, my only thought was that I could not use my hands and would never be able to do that. Today, I cannot understand why that particular OT did not grab that opportunity to explore the possibilities (of course not during those first critical weeks of my hospitalization, but definitely towards my discharge from hospital!). I never mentioned it again and neither did she.

How did I get out of this quiet spell? I honestly don’t know. It lasted through other levels of development or growth. I built a wall around me not to be penetrated by anyone. It was part of me and it protected me from being hurt. It helped me to go through the daily motions of sometimes going to OT or physio and sometimes giving them the slip, but never consciously to think about my circumstances.

Advice I would give OTs is never to trust the good patient. I don’t fully agree with a statement that Vona du Toit made that the patient who had a high level of creative ability before his disability is the one who will accept his problem soon and will work towards recovery as soon as possible. I say it is possible, but it is also just that person who has enough creative capacity to fool everybody around him, including himself.

I never went through the stage of positive tone, where according to I. Shipham, the patient “*reveals a high morale which is not based on a realistic assessment of his physical capacities”.* I rather had a negative response in the belief that I would never be able to do anything, which was promoted by a psychologist that saw me the day before I was discharged (by the way, it was the first [and last] time I saw a psychologist during my hospitalisation). His advice to me was to accept that I would never be able to work.

* 1. **Self Differentiation and Self Presentation**

I. Shipham is correct in saying that a patient’s volition must become directed towards a quantitative self-awareness to obtain a realistic view of his abilities. In a case like mine, if the therapist was able to pick up the tell tales of my negativity and destructiveness, it might have been used in therapy sessions to discover what the reality for me was.

I remember I was given a wooden rack, first to sand down. I was frustrated every minute I was busy with it because my movements were uncoordinated and I was not strong enough to make an impression on the wood. The therapist finished sanding it and gave it back to me to varnish. The rack was just a little too high to reach comfortably and I could not insert the brush without a lot of effort into the tin in which she poured the varnish – I guess the idea was for me to try and lift my arms, which was not only difficult but rather impossible since I do not have triceps. So my response to this was destructive. I shifted the rack out of the way, turned the tin over and varnished the table. Had this therapist given me an activity which was easy to accomplish and where I could feel satisfaction by doing it, she might have given me the opportunity to start identifying with my new body.

Another incident I remember is that the other quads in hospital with me learned how to write. I had hypersensitive thumbs and could not stand anything touching them. So the therapist told me that I would not be able to write. She made me a splint to type with instead. The ‘writing group’ stayed together in one building and I was taken away to the Medical Fitness for Work Unit where I had to practice typing. I hated every minute of this. The other patients at this unit were mostly brain injured and I felt done in. I longed to be able to write and to be with my friends who had a lot of fun in their group. But again, I never spoke up. My response was to slip OT, which was again destructive. I had a friend who picked me up early in the morning when possible and I disappeared for the day. The OT knew I gave her the slip, but she never took time to find out why I did it and what to do about it.

Another very important factor that aggravated my negativity about myself was that my friends started staying away more and more. For the first few months after my accident, dozens of people came to see me each day. There was no more room in my ward for flowers and the nurses had to put them on trolleys in the passage. It became less and less until it was only the dry arrangements that lasted and one or two old faithful friends that are still there for me today. It hit me like a stone that they could not handle to see me in a wheelchair – how could I accept it myself? Again, I never talked about this to anyone.

But it was only when I was discharged, when I was alone at home, when I really confronted the new me.There were no patients and staff around all day long, no jokes, no long talks into the small hours of the night with other patients. I remember lying awake and wondering why this had happened to me. I remember trying to move my toes just to realise that I don’t even know where my feet are in the dark. I blamed God for doing that to me and now rejecting me. I hated this unfeeling, uncomfortable body so much that I could not look at myself in a mirror. I now realised that I had nothing in common with other young people anymore. I went to an athletic gathering one day, just to find that most of the athletes avoided me. I had come to terms with my swollen feet and not being able to wear mini dresses which were the fashion then.

This stage of self differentiation is one that I believe continues through all other levels of growth. I do not believe that a patient first has to experience full acceptance before he can go on to self presentation. In fact, I don’t see self differentiation and self presentation as two separate levels. I see self differentiation as an internal process in the patient and self presentation as an externalisation of this process to the outside world. It is discovering changed and new abilities and testing it against norms and reactions of other people. It is a dynamic process of continually changing and adapting or fine tuning until you are comfortable with you new way. An example of this is that at first, I would not eat in public. Then I realised people with me felt uncomfortable to eat alone. So I allowed them to feed me. This embarrassed me, but I was in a conflict because my specially adapted spoon also embarrassed me. I had to reach a point where I decided that I do things differently and that it is OK no matter what reactions I get from the outside world.

I believe that self differentiation and self presentation are the most critical of all levels and that it can hamper development of other levels if not worked through adequately initially – that is, soon after becoming disabled. I would go as far as to say that if a patient has not worked on self differentiation intensively, that further treatment is a waste of time. Effective OT at this level would provide a patient with a basis to generalise from when he experiences problems with self differentiation while operating on a higher level of development.

* 1. **Participation**

I also do not believe that a patient has to positively explore his residual abilities before he can progress to levels of participation and contribution. But residual abilities can certainly be drawn upon while putting newly acquired or changed abilities discovered during self differentiation and self presentation to use. My experience on the level of participation was that I learned a lot from other patients who had been in their chairs for a long time, first through passively watching them and then trying to imitate what they did. All the while, self differentiation and self presentation play an active role. Once I found ways that worked, I was ready to actively participate using my own initiative and becoming competitive again.

1. **MOTIVATIONAL FACTORS**

I would like to say something about motivational factors. For me, it was mostly people who cared. During the time I was on a level of tone, the person who made a difference was my mother. During the first two months of my hospitalisation while I was flat on my back in bed, she was there every single day even though she did not stay in Pretoria. She read to me, she fed me and moved my fingers or rubbed my feet with hand lotion. Sometimes she just sat there silently with me and her face was so sad that I had to go on for her sake.

The most important person to help me with self differentiation and self presentation was my youngest sister. She understood me so well. I remember one night while I visited two of my sisters in Johannesburg, it started raining. She knew how I loved walking in the rain before my accident and without a word, she pushed me out for a walk in the rain. She did not put a rain coat on me or anything. She knew I needed to feel the rain on my bare skin and not to hear the words: *“Jy gaan siek word”* which are the words people associate with disability. She also used to run with me in my chair and made fun of me. It made my wheelchair more acceptable as a vehicle and not something that tied me down while she was around. She also got me my first job in Cape Town as a typist in the claims department at an insurance company. She believed in me. When I found out I was paid less than the messenger, I told her to push me to the manager’s office because I would not be used as cheap labour and I was going to quit, she did the same. We were staying in a hotel and one night she took all my clothes and said she was going to streak with me through the passages. I was hysterical ... The message I got from her constantly was that my body, my whole being, was acceptable.

The person who made the major difference in my life was an OT. I was rehospitalised for kidney stones in 1976. She was not my therapist but I used to watch her with other patients. It was her attitude, the way she put all of her energy into everything she did with her patients; it was the way she cared. I needed *“daai ding”* and I approached her. We eventually became best of friends and almost everything I did after that, I did in order not to let her down. She also believed in me, so much that it scared me. Through her ever present support and faith in me, I grew from a timid, easily intimated quad to a self confident person in my own right. I want to emphasise that the relationship that especially the OT builds up with her patient is one of the most important events in the life of a newly disabled person. I am talking on behalf of lots of other disabled people who I know enjoyed going to OT and many times it was not because of the activities. It was the therapist who made the difference – but only if she was honest, realistic and caring.

I moved to Durban, and there I met another OT that made an impact on my life. She also was a friend, not my therapist but I guess you all know Dain van der Reyden. That was not long before I was so fired up that I started studying and it started to dawn on me that maybe I could do something with my life.

My electric wheelchair was one object that had another major effect on my motivational level. When I had my accident, a newspaper wanted to donate me a power chair but the Sister-in-Charge of the Spinal Unit told them rather to give me a manual chair because I was a 5/6 quad and had to push myself. I remember in hospital not being able to go with the para’s and stronger quads to some places and later at home when there were no more smoothly tiled floors, sitting in one place all day long. I remember when I moved to a Quad Home not being able to join the other quads in their power chairs to go on shopping trips. I accepted it as part of my limited existence and never complained. Seven years after my accident, another quad and her friends raised funds without my knowing and bought me a power chair. I suddenly knew what it must feel like for a bird to escape from its cage. I cannot begin to tell you what a difference it made to my self confidence.

People suddenly had to talk to me because there was nobody behind my chair through whom to address me. That poor chair only lasted me about three years!

1. **CONCLUSION**

In conclusion, I want to tell you that at first I did not want to come here today. I am in a work situation operating on the levels of contribution and competitive participation and generally I am not treated any differently from my colleagues. I felt that by speaking here today, I was being placed back into the role of a patient and that I do not need that in my life anymore.

But then I realised that this was a destructive response again. More importantly, I realised there was something deeper keeping me from talking. If I had resolved all conflicts about myself on the level of self differentiation, I wouldn’t have had a problem talking about my experiences to a bunch of professional people. There was, in your language, those old negative effects of anxiety creeping up on me. To use some more of your jargon, I had to apply maximal effort, but at the same time I had to go through self differentiation again, in order to present myself to you.

I guess what I’m trying to say is that for a physically disabled person, these levels are so interwoven that it is not really possible to say with certainty that a person is operating on this or that level – and it gets more complex the further a person develops. I’d like to share one more example with you. In the beginning after my disability, I did not really think of life or death. I just existed and did not care about anything: as I said, my mind was a blank. Later, especially when I first went home, I had a constant death wish. I sat and waited to die but of course, sooner or later, you find out that you don’t die that easily. Several things happened: I moved away from home, met some significant people and started doing things. And even though my whole life changed and I felt that for a change I made a difference to other people’s lives and had something to contribute, there were many many days that I still felt it would have been better had I died in that accident. I sometimes still wake up in the morning and wonder how long do I have to go on with the daily struggle of asking for help, waiting patiently for it, having things done for me in a different way than I would have done it and still say thank you. I do hope that what I said here today can somehow be of benefit to you in your relationships with your patients.