

A MULTIDISCIPLINARY APPROACH TO MEDICALLY FRAGILE CHILDREN

ABSTRACT

Progress is determined by motivation and motivation is determined by confidence. In managing children with multiple deficits, it is necessary to extract underlying obstacles in order to make therapy most effective. The client, a ten-year-old girl presents with significant fear of movement. She presents with multiple fractures secondary to distal renal tubular acidosis and osteopenia. After confining herself to bed, post orthopedic surgery, she was referred to the Director of Programmes of Circle of Care, a center catering to children with special needs and promoting inclusion. Individual and parental counseling along with movement and art instruction yielded mobility and improved management of activities of daily life with moderate support from equipment and family members. As a result of collaborative work and systemic awareness, client was able to exit her state of immobility and become independent in problem-solving. A multimodal approach accounts for the physical impairments as well as the social limitations presented in a child. Multidisciplinary approach with importance on counseling makes therapy effective and progress visible particularly in children who present with multiple or frail disorders/diseases.

KEY WORDS

Multidisciplinary Approach, Multiple Deficit, Inclusion, Systemic Awareness, Motivation, Cognitive Behavior Therapy, Fragile Children, Tonic Immobility.

Aysha S. Jamall

Director Programmes,
Circle of Care,
Therapy Works
aysha.s.jamall@gmail
.com

Faizan Masood

Expressive Art
Instructor, Circle of
Care, Therapy Works
fm.hipa@gmail.com

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CASE HISTORY

A 9.7 years old girl's parents came to us in March 2014 with deep concern regarding her fear of movement. This condition had developed after her surgery which had confined her to bed. The girl suffers from Distal Renal Tubular Acidosis and has had multiple fractures due to Osteopenia according to her doctors.

She is an extremely intelligent and resilient 9.7 years old girl, who is well aware of both her medical as well as her mental condition. Our work with her has been around working with her fears so that she is able to experience life to the fullest. Through one on one counseling, Movement and Art Instructions and counseling and workshops for parents, we tried to look at her issues with a more holistic perspective¹.

Our programme aimed for more inclusion for her in the long run with a multidisciplinary approach to treatment.

The Circle of Care Program believes in inclusion. Inclusion is a way of living that celebrates diversity in all its grandeur².

It is a way we can hope to achieve an integrated society where equal opportunities are provided for every child. In our treatment plan systemic awareness helped us in creating an environment which will allow her to experience herself meaningfully, rather than feel secluded or excluded by her environment³.

However, there are very few schools that are inclusive in nature in Karachi and therefore getting her into an inclusive school is our foreseeable challenge. Parents concern was for her, to achieve some mobility so that she could travel abroad for rehabilitation and if required, another surgery.

UNDERSTANDING CLIENT'S CONDITION

The post operation effect of the surgery was akin to what is called tonic immobility. If animals were physically restrained and frightened, they are seen to go into altered state of consciousness where they are unable to move. And it turns out that this is one of the key survival features that animals use to protect themselves from any foreseeable danger—in this case from extreme threat in the client's mind that her bones would break if she moved. Initially it was fear of the surgery and the fact that a new surgeon was handling her case as her own surgeon was traveling. Furthermore, the fact that she knew the details of her illness as well as treatment and the procedure involved and from whatever she has shared, it may be accurate to say she even knew the extent of the dangers involved during and after surgery⁴.

To further expand on the idea of why we thought or correlated the case to 'tonic immobility' it is important to understand there are three basic neural energy subsystems. These three systems support the overall state of the nervous system as well as the correlative behaviors and emotions, leading to three defensive strategies to threat. These systems are composed by the primitive structures in our brainstem that is, the upper part of the brainstem. They are instinctive and almost reflexive. The tonic immobility is the most primitive system, traces back to 500 million years. It is a combination of freezing and collapsing where the muscles go limp, the person is left without any energy. The next in evolutionary development is the sympathetic nervous system, the fight-or-flight response. And this system evolved from the reptilian period which can be traced back to 300 million years ago. And its function is enhanced action, and that is fight-or-flight and all your senses go on hyper alert mode in the

client's case as it was limited by the cast it manifested in the Jamall AS & Masood F. A Multidisciplinary Approach to Medically Fragile Children form of heightened sense of smell and nausea as any smell that reminded her of the hospital she was unable to cope with⁵. Finally, the third and most recent system is the social engagement system, and this occurs only in mammals. Its purpose is to drive social engagement like making friends, with the purpose to defuse the aggression or tension. In the client's case it was important to increase her circle and defuse her current hyper alert state.

INTERVENTION PLAN- A MULTIDISCIPLINARY APPROACH

Address fear using integrative therapy and with a deep understanding of somatic experience we used Person Centered, Transactional Analysis⁶, Cognitive Behavioral Therapy and Art, and making use of the animation Frozen. By acknowledging her fears and quantifying them we were able to give her empathy and acceptance. The more concrete we made it for her through a Cognitive Behaviour Therapy approach measuring and rating her fears, categorizing and comparing them the more she was able to address them with less stress⁷.

Once she started coming to terms with her fears we introduced Movement and Art instruction where through music, arts and movement of her hands she was able to explore her creative side.

Increasing her sphere of social interaction was also something we had to work with the parents so we used the animation movie Frozen with both the client and her parents. With the client we used it to talk about the fears of the character Elsa the Snow Queen. However with her parents we spoke about Elsa's parents decision to isolate her and explored other possibilities and how they could have protected her without isolating her from the world. We worked on developing problem solving skills with the client by asking her how if she were Elsa's witch doctor would she have dealt with her powers to which she came up with an instant solution that she would have given Elsa a water bottle and asked her to freeze and unfreeze till she developed better control over her powers. From then onwards we explored other mobility issues that if she were to guide someone how safe would she feel if she took charge of how she should be moved from the bed to a wheel chair and that got her thinking and discussing about the subject which before she refused even to hear about⁸.

Once we had established a good therapeutic alliance we used 'Enactments' where she was able to explore her behavioural patterns regarding inability to accept no and immediate gratification. In these enactments it was seen that she would regress into a three year old with onset of tantrums entering the therapeutic space and it is in these moments of rupture in the system that we made the most progress⁹.

With a systemic approach we worked towards building parental support system through counselling, psychoeducation and support programme. Thus by supporting the systems that held the client we were able to address issues of boundaries, space and taking care of themselves in order to help their daughter in her recovery¹⁰.

CONCLUSION

The Client has begun taking interest in her self-grooming, dressing up and wearing sandals just like her therapist. She started off by exploring ways she could get off her bed and when the family shifted their premises she was able to deal with her fears. Now she is able to visit the park outside her apartment on a wheel

chair and play with girls of her age. Her reaction a month back when she had a hairline fracture in her arms and the way she coped with the incident was a huge milestone for us in not only managing her own fears but also her parents', and taking charge in decision making if she Jamall AS & Masood F. A Multidisciplinary Approach to Medically Fragile Children Pakistan needed immediate attention of the doctor or it could wait. Also her academic achievement this year and the screening of a short film that she produced, wrote and directed were all indicative of the fact that we had moved forward.

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