

*Commentary*

## **COVID made me do it... The Physiotherapist's Role in Self-Management**

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**Abstract.** The COVID-19 pandemic has been the trigger and instigator of behaviour change in a very marked way in the field of Paediatric Physiotherapy locally. It has challenged and forced physiotherapists to adapt working practices and transition from face-to-face operation to remote online methods. Young patients and their caring families have had to move away from face-to-face interventions and learn to accept what physiotherapists have always been trying to advocate and teach, and that is self-management. Physiotherapists aim to encourage active participation in the rehabilitation journey, thereby teaching the patient and their carers how to cope and self-manage the chronic neurological condition. Due to the pandemic, families with children with complex and multiple needs, suddenly and unexpectedly lost access to almost all services in the national lockdown. Albeit, the enforced situation allowed one to appreciate the need and importance of psychological and physical self-care. Indeed, a new definition for health has been proposed by a group of researchers as “the ability to adapt and to self-manage”.

The preferred view on health must be adapted to encompass a new conceptual framework of health. This can support clinicians and health practitioners when communicating with patients as it focuses on empowerment of the patient. Change only happens when action is taken; when patients and their families

are empowered and given the right tools to apply to their lives, they will learn how to become more independent and physiotherapists become merely the consultants and no longer a constant provider.

**Keywords.** behaviour mechanisms, paediatrics, participation, physiotherapy, self-management, rehabilitation

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### **Commentary**

As with most work environments and teams, the COVID pandemic has caused major changes in their structures and work practices respectively and the Physiotherapy world is no different. Add in the paediatric population and things get even more complicated. Physiotherapists pride themselves on their manual skills and rely mostly on touch for assessment and proximity to treat, yet delivery of service had to somewhat continue without the possibility of all of this. A 6-month-old infant with a motor developmental delay cannot afford to wait weeks or months for their physiotherapy appointment as it only extends the delay causing possible secondary complications.

For that reason, the situation challenged and forced physiotherapists to adapt working practices and transition from face-to-face operation to using remote online methods known as telemedicine, including the Physiotherapy Team at the Child Development Assessment Unit. The families and children cared for face many stressors, struggles and hardships yet it is fascinating how they too have had to adapt, but the

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most striking part is that caring families have had to truly understand and embrace what self-management really is. They have had to move away from face-to-face interventions and instead face the reality and learn to accept what physiotherapists have always been trying to advocate and teach, and that is self-management of their child's chronic or long-term condition as a family unit.

Whether it is chronic back pain or a progressive chronic neurological condition, physiotherapists in all spheres advocate self-management as a lifelong lifestyle behavioural change. We aim to restore, facilitate and maintain mobility and function through physiotherapeutic intervention, but also encourage active participation in the rehabilitation journey thereby teaching the patient how to cope and self-manage the chronic condition. On paper, it is the ideal, but factually and practically it is a daily struggle with patients and in this case, their families.

Social distancing, shutdowns, teleworking, home schooling, financial burdens, loss of routine, fear of contracting the virus and general uncertainty about the future affected all family units on the island. This fundamental loss of our previous way of life and indeed *modus operandi* is causing anxiety, stress, loneliness, conflict, trauma but also loss and grief. Prior to the pandemic and emergency status, families caring for children with neurodevelopmental conditions and multiple complex needs had to juggle and cope with several appointments on a weekly basis to tap into various therapies and medical services, both within the public and private sector, over and above the day-to-day tasks related to family life. They may also have relied heavily on external support such that of carers, educators or via institutions offering respite. Having had to then, suddenly and unexpectedly lose access to almost all services in the national lockdown was a drastic blow. Moreover, the opportunities for children to learn, communicate and socialize were only decreased impacting mental and emotional health as well as physical health.

Thankfully, by using video call software and technology available, telemedicine was swiftly brought to life offering support to these families. In fact, telemedicine is now, being reimbursed in countries that rely on private healthcare as it has been acknowledged and recognized as a valid alternate solution to face-to-face sessions. This unprecedented jolt to our system did bring an upside though. It shed light on the importance of self-care, both psychological and physical care.

Caring families could finally appreciate and understand better how much their child really did participate in physical activity and movement on a daily basis and how much help, stimulation and motivation they need in order to achieve this. This is dealt with and discussed many times during a typical Physiotherapy session but knowingly or unknowingly would be pushed aside as families would be relying on external means or persons to achieve daily movement goals. Moreover, due to local cultural factors, such as transportation and recreational habits, only a minority of families really understand and focus on self-management. Statistics demonstrate low participation in physical activity in the paediatric population and adding a physical or intellectual disability only increases the barriers on the children and families (Bult et al. 2011). Interestingly, however, the interaction between siblings at home was a positive and stimulating one, and children who lacked and needed stimulation, found it by interacting with their siblings who would otherwise be at school. Being in a class setting for most of the day does allow for other important values such as discipline, structure and socialization but the full time input from parents and siblings was also a fruitful one as more time was spent together indoors. The Disabled Children's Partnership, UK (2020), in fact reported that most parent carers (72%) said they are providing a lot more care compared with the amount before lockdown and just over two thirds (68%) said non-disabled siblings were also providing a lot more care.

One young boy frequently mentioned in the British media is a perfect example of this. Tom Hudgell, at only 5 years old and a double amputee, who received a new set of prosthetic legs just before the first national lockdown in the UK has an inspiring story. His injuries were a result of horrific abuse sustained from his biological parents when he was only around one month old and was then later adopted at only 4 months old. His adoptive parents say he would not have survived if it was not for the impeccable care he received by the Evelina London Children's Hospital in Lambeth. So inspired by the newsworthy 100-year-old, Captain Sir Tom Moore walking laps of his garden to raise an impressive £32 million for the NHS, Tom set out a target to walk a modest 10 kilometres over the span of one month to raise £500 for the hospital that cared for him. He exceeded all of his own expectations and raised over £1 million and reached the 10 kilometres target five days early. Through his determination, he learnt how to use his new prosthetic legs by walking daily and also managed to progress

from a paediatric walking frame to using two crutches as he got stronger from his daily walk. He now plans to continue walking on a daily basis – the ultimate goal for us physiotherapists, and even more rewarding because he achieved it independently with only the support of his adoptive parents!

Sadly, this is not the reality faced by all and the British newspapers also reported a regional increase in child suicides over the lockdown. The children all had special educational needs including Autism Spectrum Disorder and Attention Deficit Hyperactivity Disorder and although the exact reasons are unclear it seems the restrictions to education, disruption to care and support services, tensions at home and social isolation appeared to be important factors that led to these tragedies. Locally, we are yet to discover the true psychological impact these last months had on our children and caring families.

In fact some years ago, a group of researchers and medical experts discussed how the WHO definition of health is no longer fit for purpose and since its introduction back in 1948, no longer encompasses and reflects the current global situation. Instead, they propose the formulation of health as “the ability to adapt and to self-manage” (Huber, Knottnerus & Green et al. 2011) as opposed to health as a constant state or function. The preferred view on health must be adapted to encompass a new conceptual framework. This can support clinicians and health practitioners when communicating with patients as it focuses on empowerment of the patient for example by changing lifestyle or behaviour. The current definition “minimises the role of the human capacity to cope autonomously with life’s ever changing physical, emotional, and social challenges and to function with fulfilment and a feeling of wellbeing with a chronic disease or disability” which cannot be more evident now while facing all these changes (Huber, Knottnerus & Green et al. 2011).

During online sessions with patients and their families, it has proven to be essential that each family is equipped with the right equipment to carry out tasks at home such as standing frames or walkers. If it were not for the work previously done through home and physical assessments, families would have found themselves without the right tools, which for some unfortunately did happen. The sessions were also an opportunity to identify issues that may not have arisen during an assessment such as seating options for the child, even though one would have asked about these areas. By seeing the home environment and contents of the living

spaces via video call, one can identify problems and work on solutions to the matter. Home modifications and parent instruction in biomechanics are so important and we are now seeing it live. As a paediatric Physiotherapy team we found ourselves embracing new roles beyond the routine physiotherapeutic interventions carried out on a weekly basis. We were offering advice and guidance, being creative and problem-solving for our patients and their families. Telemedicine has quickly managed to become a new embedded tool in our toolkit together with our consultancy role.

The children with the most complex health needs may continue to face numerous challenges, such as not leaving their home to carry on shielding, for a considerably long period of time and must receive additional support from all health practitioners and educators involved who must adapt to their clients’ new needs and barriers. Parents or caring families experienced and still continue experiencing exhaustion, stress, anxiety and isolation or abandonment and hopefully while trying to learn how to manage their daily challenges they turn to us for support. Indeed, some feedback has already been received via a preliminary patient satisfaction survey that was carried out by the department focusing on the use of online video calls with almost 100 responses collected so far. While they were highly satisfied with the service offered (75%), they thought the use of telemedicine was worth their time (almost 50%) and the majority looked forward to their online appointments. Yet, it is still controversial when it comes to adapting to the new changes and 38% of parents still prefer face-to-face visits to video calls.

In conclusion, how uncomfortable has the pandemic made us and our patients/families to make up our minds to change something? Moving away from the familiar, seeing global disorder, systems falling apart and the medical model coming apart, instead of trying to fix the matter, let us create something better and see through the illusion of what is taking place around us. The world is changing and we are learning from others and finding the best in ourselves, challenging our beliefs, overcoming our fears and transforming and creating change. Change only happens when action is taken; let us give our patients and their families the tools to apply to their lives, empower them to make a choice to create order once again and teach them how to become more self-dependent. In the end COVID made me do it – the pandemic brought new norms and a cultural change, a viral change you may say, but let us embrace it and continue on a path of inspired change and action

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## Conflicts of Interest

The author reports no conflicts of interest.

## References

- Bult, M.K., Verschuren, O., Jongmans, M.J. et al. (2011). What influences participation in leisure activities of children and youth with physical disabilities? A systematic review. *Research in Developmental Disabilities*, (32) pp 1521–29.
- Huber, M., Knottnerus, J.A., Green, L. et al. (2011). How should we define health? *The British Medical Journal* 343:d4163. [Online] Available at: <https://doi.org/10.1136/bmj.d4163>. [Accessed 1 July 2020].
- Disabled Children's Partnership. (2020). *#LeftInLockdown – Parent carers' experience of lockdown*. [Online] Available at: <https://disabledchildrenspartnership.org.uk/wp-content/uploads/2020/06/LeftInLockdown-Parent-carers%E2%80%99-experiences-of-lockdown-June-2020.pdf>. [Accessed 1 July 2020].
- Winch, G. May 14 (2020). The pandemic created a watershed moment of emotional health. *The Squeaky Wheel via Psychology Today*. [Online] Available at: <https://www.psychologytoday.com/us/blog/the-squeaky-wheel/202005/the-pandemic-created-watershed-moment-emotional-health> [Accessed 1 July 2020].