

Changing Balance of Care in COVID-19 lockdown for Children with Autism

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Short Communication

The world and its people are in the midst of COVID-19 outbreak and it becomes increasingly certain that the imposition of stringent measures can curtail the chain of contagion. Solitude is praised and movement is censured. However, lockdown has unsettling consequences on family sustenance, health management, education, employment, economy, social activities and governance. All are dynamically interdependent on one another and are the subject for extensive global dialogue. A segment of society that is impacted by social restrictions involves the present generation of children who are halted in returning to their regular interactive pursuits and learning in kindergartens, junior schools, special support services and developmental programs. Happy parenting in the year 2020 no longer describes a traditional concept. The term has broadened to embrace a changing role for parents in their efforts to safeguard children from SARS-CoV-2 infection and transmission. It includes a calling to pursue remote activities and to perform in e-learning classrooms.

Yet this wholesome package is insufficient for a small cohort of children who need more deliberation from Health Care Providers (HCPs). Parenting for children with Autistic Spectrum Disorder (ASD) is a daunting career. ASD is not rare as shown by some numbers in the present decade. The prevalence of ASD (number of children with autism per 10,000 children) is recorded highest in Hong Kong (372) followed by South Korea (263), USA (222) and Japan (181). The aetiology of this neurodevelopmental disorder is complex. It is not a single disease entity but a spectrum of multiple health disorders without sameness afflicting each child. The striking nonverbal comportment has core characteristic features of repetitive and restrictive behaviours coupled with maladjustment in communication and social conduct. The presence of co-existent medical abnormalities such as, epilepsy, psychiatric illness and gastrointestinal disturbances, increase the burden of care [1].

Autistic children thrive in a structured environment that encourages engagement to a fixed timetable of educational assignments and sessional therapy (for example, speech, social or physical skills), as deemed appropriate for each child's level of dysfunction and progress. Holistic management in children with ASD is ideally entrusted to professionals who are hands-on in the treatments for the myriad display of complaints present in ASD. The partners-in-care in the Multidisciplinary Team (MDT) are specialist teachers, speech and occupational therapists, paediatric psychologists and other specialised service providers. They strategize therapies and follow through each child's improvement in behaviour and skills. The prescription of a care bundle is tailored to the level of severity in the spectrum of ASD [2,3]. The growing awareness of autism has stretched the boundaries of scientific investigations in the search to enhance healing, such as, the evidence that music therapy is a tool to promote positive behavioural adjustments in children subsisting on nonverbal communication [4]. However, International advocacy establishments for autistic children are dissimilar. There are limits to care offered by poor countries compared to countries with advanced economies that nurture technological innovations and research, and maintain a strong cohesive professional body. A paper has been published that addresses this global disparity and it emphasizes the expediency that developing nations take on bold outreach initiatives [5].

COVID-19 has further derailed the fragile care bundle in many nations.

Lockdown is hostile to the stability and future independence in ASD children. Their problems are many, relative to confinement, transition and adaptation. The loss of institutional education and enriching social interactions, and the suspension of professional services such as speech and occupational therapies, are onerous services to replicate at home. With their discordant capabilities, it is not surprising that they cannot reconcile with changes or to tune in docilely to remote learning and remedial treatments and to accept video communications. The hardships from disconnection to social activities and discontinuation of routine agendas can trigger a range of emotional meltdowns that are problematic (aggression, depression, mood instability, self-injury).

It is no wonder that lockdown at home must be the dreaded 8-letter word for parents who are now taking on a significant portion of the chain of duties required for daily attention in ASD households. In the multidisciplinary protective care for autistic children, what can HCPs offer during the period of contraction in institutional, educational and therapeutic facilities?

A review on all available lifelines by specialists is a prerequisite before take-off on the drawing board to design a blueprint on the standing order of care, inclusive of an introduction to parents on resources within reach. Parents can sign in to an abundant literature and advocacy platforms for the wellness in this group of special needs children. Blogs devoted to autism contain useful tips and advice to mitigate isolation agony. On-line information and explanation are accessible to guide parents on what to say to autistic children on the threat of COVID-19 and purpose of lockdown. Cyberspace is appreciated as a super highway that connects autism centres, support services and special schools to homes with virtual meetings for video therapy sessions or e-educational assignments. It has proven to be a fountain of information to provide “all you need to know” about ASD and motivate parents to find solutions for their disabled charges [2].

The closure of rehabilitation units has opened a promising alternative on the usage of telerehabilitation. It has a pertinent role in the restoration and continuity of supportive therapies under guidance from HCPs. On the other hand, telemedicine is touted to be the way forward to replace visits to clinics for check-ups and evaluations. It is a speedy solution for parents during urgent circumstances or to consult on medications for co-existing medical sickness. However, specialized one-to-one screen-based modality may not be offered over the internet for children with severe autism. In France, due to the loss of professional appointments and services, an interesting “Coronavirus Tool Kit” is accessible *via* a link [6]. The contents are scientifically evidence-based to concentrate on the practical aspects in living with autistic children and are crafted mindfully for problem-solving settings. In the kit are 30 instructional modules with strategies to support families, such as, managing screen use and practical steps to take during encounters with conflicting behaviours [6].

The outcome and satisfaction of both parties (parent and child) arising from this changing balance of care bundle depends on many factors, including availability of digital devices and the quantum of compliance in simplex or multiplex ASD. Other elements in the equation of wellness are cramped living conditions, household burdens and parental fatigue, frustration and mental health decline. The daily sunrise-to-sunset schedule of activities has shifted gears towards home services. Moving forward on the transition road is an uphill task and it is not impossible that internet glitches and human setbacks are risks that can occur over the medium to long term individualised care, when previously, care has revolved around a shared MDT authority and appraisal.

Reports on the media during lockdown speak of parental fear over the withdrawal from classroom education, deficiencies of remote teaching and the deprivation of crucial skills that are harmful for youngsters. This is especially dreadful in ASD children and pertinent questions include: will my child forget what has been learnt months ago? Will my child lose years of developmental mileage (mental, emotional and physical) from a lockdown? Only the HCPs in the MDT can provide a hopeful answer.

Parents of mildly autistic children may be receptive of change and adapt quite effortlessly into isolation mode while handling any headwinds in their stride, but there are others who are stressed and unable to come to terms equitably in COVID-19

restricted lifestyle and need more help. To tide over this critical transition period, a possible arrangement to assist parents in great turmoil and conflict is the virtual presence of a modulator, such as a specialist teacher.

There is empathy from HCPs who understand that parents cannot restore a new balance on their own. A harmonization period for parents allows them to re-define their role with courage and determination. An open mind-set can propel them to embrace change and adapt to a contemporary arrangement that is best fitted to their particular circumstances and care at home. With guidance from the MDT, each parent plays a vital role to reach out to resources and opportunities available in their region. As parents acquire fresh solutions and become a novice role model, autistic children are in a more comfortable position to also adapt accordingly and absorb progressive integration to function with minimum discord.

The future for autistic children relies greatly on the changing balance of care. A paradigm shift in the change of care may eventually evolve into a novel care bundle of connectivity and continuity for the children's growing years during lockdown. Thus, all is not grim. The big picture is still promising and there is hope that the bridge is not too long for ASD children to travel to a new norm.

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