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Family's sufferings from asymptomatic COVID: Clinicians' perspective

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Abstract

Anticipating dire consequences, in 2020 the world braced itself for the unparalleled pandemic by resorting to unprecedented measures including stringent lockdowns, unforeseen social isolations, spotlight focus, resource diversions besides reorganized healthcare systems to name the quintessential few. Such unifocal convergence enhanced the vulnerabilities of patients dependent on non-COVID healthcare assistance. For a nation with a meagre allocation of 0.7 hospital beds per 1000 people and a lopsided doctor-population ratio of 1:1800, COVID-centric measures created unintended complications. Ironically, many succumbed in myriad ways, not due to the pandemic but due to the attributes of the survival measures. While such consequences cannot be reversed, we need to be able to draw learnings from all such experiences. Particularly, as healthcare advances into the 21st century and we evolve towards an individualized care model, the contrasting “blanket treatment approach,” while an understandable contingency measure for pandemic emergencies, warrants serious attention.

With this narrative, we would like to highlight the anguish and frustration faced by the parents and the doctors as multifarious elements complexly entangled to delay a crucial surgery in a two-year-old child with prolonged RT-PCR positivity. Knowing that mankind is likely to face such pandemics again, future responses require us to visualize the whole picture from a zoomed-out perspective to be able to roll out a synchronized holistic strategy. One needs to introspect on the mutilations incurred, to help redesign our disaster management responses, in order to address “all cause” damage and not just the pandemic ones.

Keywords

Patient experience, continuum of care, patient centered care, COVID-19 sufferings, COVID-19 Environments, pandemic learnings, pandemic preparedness

Introduction

We encountered a unique but trying situation around September 2020 when COVID-19 cases were widespread across the country and the global tally was rising. In a first of its kind across the world, policy makers and healthcare providers were unified in their intensive efforts towards thwarting the ill effects of the pandemic and steering mankind towards safety. Stringent lockdowns, public health messaging, contact tracing exercises, reallocation of medical resources towards COVID were some of the common practices engaged by authorities across the globe.

Such re-structured environments augmented the vulnerabilities of patients dependent on healthcare support as they manoeuvred through the continuously changing attributes of the pandemic, altering administrative strategies and reprioritised healthcare services. On one hand factors such as regional disease burdens, demographic profile, population characteristics, geopolitical influences, social constructs, state of the economy, percentage pandemic health infrastructure

reservation, manpower provisions, community support structures complexly interacted and dented the system's ability to address any individualistic need. On the other as trust with COVID extended, medical and scientific communities continued to unearth novel facts around the entity thereby furthering the knowledge available. Such ongoing revelations created continual modifications in existing practices, some of which were promptly imbibed, while some witnessed delay from practical limitations posed by regional factors especially within over-populated and overloaded systems. While keeping pace with the rapidly evolving clinical recommendations, many struggled with the implications of stalled executions amidst taxing work conditions. This dynamic interplay impacted care delivery approach towards the “specific need” of a patient for clinicians serving such settings.

Our incident recounts the agony, distress and frustration experienced by a patient's family and the clinician's alike, when a combination of diverse factors stemming from such modified environments particularly in a resource strained set up complexly intertwined to delay a crucial

surgery in a two-year-old boy despite dedicated efforts of the team to conclude early.

When we grappled with this predicament, India had surged to the second position in the world COVID tally and this alarming rise posed an enormous strain on the nation's burdened and fragile healthcare infrastructure. With only 0.7 hospital beds per 1:1000 people, accommodating an average occupancy of nearly 75%, a skewed doctor population ratio of 1:1800 backed by a measly 1.5% of total GDP expenditure towards health, there existed a huge gap between supply and demand. Consequently, with the introduction of COVID diversions, its population of 1.34 billion citizens and the medical workforce witnessed drastic measures and extreme circumstances.

Meanwhile as the infection spread, facing exposure from infected adults, infections in children also steadily rose.¹ Epidemiological studies suggested that 45-90% of children with COVID were predominantly asymptomatic or experienced only mild to moderate disease manifestations. However due to prioritization of testing in symptomatic and sick individuals who were mostly adults, the true incidence of the disease in children could not be ascertained precisely. Consequently, there was limited understanding of their viral dynamics or infectivity patterns. Infectivity data from adults meanwhile highlighted a mean SARS-CoV-2 RNA shedding duration of 17 days (maximum 83 days) in the upper respiratory tract.² While symptomatic children shed virus longer than adults,^{3,4,5} there continued to be scarcity of literature at that time regarding asymptomatic ones. A newfound study had recently revealed that prolonged PCR positivity in mildly ill and asymptomatic individuals was likely non-infectious.⁶ It was reported that while shedding of SARS-CoV-2RNA virus in affected individuals was prolonged, duration of viable virus capable of spreading infection to others appeared comparatively short-lived.⁶

With this background and theoretical context, we would like to describe the impact of "prolonged asymptomatic RT-PCR positivity" towards conclusion of a critical surgery in a two-year-old amid pandemic reactions. This incident portrays the vulnerabilities of a middle-class Indian family within strained healthcare systems and the disconcerting choices faced by the healthcare providers in an evolving pandemic, as these entwined to shape an unintentional deferral.

Synopsis of the Story

A two-year-old male child, detected with significant left PUJ (Pelvi-ureteric Junction) obstruction in February 2020 was left with no choice but to postpone surgery from the imposed lockdown in March 2020. On learning that their medical insurance did not cover this congenital condition, parents sought care from government funded hospitals.

They met with long wait times, recently worsened by backlog from the lockdown as well as reservation of infrastructure for COVID-19 patients. After a forced waiting of around four months, they approached the pediatric surgeon at our centre, Sitaram Bhartia Institute of Science and Research (SBISR), a 70-bedded non-profit, pay-for-care private hospital in June 2020.

Besides detailed discussion on the two-stage surgery required for the disorder as well as the modified processes warranted in pandemic times, cost implications resulting from such adaptations were shared with the family. These included the mandatory pre-admission RT-PCR screen and likely incidentals from PPE (Personal Protective Equipment) required by medical staff, comprehensive sterilization practices, as well as upkeep of negative air isolation units specific to a COVID-positive status in a patient.

With an informed consent, parents proceeded for treatment. Following a normal pre-admission screen, the child underwent a successful pyeloplasty with stent insertion in July 2020. Subsequently stent removal was scheduled 4-6 weeks later in mid-August.

Ahead of the second surgery, the child's RT-PCR screen surfaced positive and a corresponding evaluation confirmed an asymptomatic status. As per national policy, all family members (who were also asymptomatic), were quarantined at their residence and subjected to rapid antigen testing by government health officials soon after. Family members reports were negative. Perturbed by the stigma and sense of guilt centred around failure to protect their child, anxious parents rushed to conduct the child's RT-PCR test after a week. The report remained positive.

Worried about the underlying stent in the backdrop of a COVID infection, parents approached the pediatric surgeon. Noting the child's urological status, he reiterated the need for stent removal and suggested proceeding with COVID-centric precautions. Feeling inconvenienced and financially burdened by pandemic protocols, parents decided to wait for a negative report and deferred consent. They approached the government-funded hospitals again but could not be allocated a surgery slot in the proximate time frame due to the ongoing backlog from infrastructure reservation. Repeat testing towards the end of the third week also remained positive and parents sought an additional pediatric medicine consult in pursuit of a cure from the positive status but were dejected on learning the limited pharmaco-therapeutic options in children. Doctors also reviewed the prevailing national and regional infection control policies for asymptomatic patients. However, despite evolving scientific data suggesting non-infective status for such patients, updated recommendations were not yet protocolised or established at the regional level.

Family was thus advised to proceed for the second stage surgical intervention with COVID-centric precautions. Three weeks behind schedule, parents organized logistics to proceed but the surgeon contracted mild COVID illness. The surgeon's mandatory 14-day quarantine in accordance with national policy, suspended further preparations. Protocol warranted a fresh RT-PCR assessment prior to the rescheduled surgery and this too emerged positive for the fourth time.

Fatigued, distressed and financially drained from the consequences of the prolonged viral detection, parents struggled with their options. Ironically, for the parents who were now five weeks behind schedule, their previous COVID-related expenses (all RT-PCR screens and multidisciplinary doctor consultations) plus imminent additional expenses from surgery in a "COVID patient", matched the total cost of stent removal, the second surgical procedure.

Cognizant of the harm to the child and limitations of the COVID environment, the medical team brainstormed to mitigate parental concerns and exposure risk to the healthcare staff. The surgeon, who had recently recovered from the COVID infection offered to operate without a comprehensive PPE suit, while the anaesthesia department enrolled only half the operation theatre team and allocated dual responsibilities to the recruited staff. This minimized the total workforce, thereby reducing the risk of exposure to healthcare staff as well as the procedural expenditure borne by the family. Parents consented and stent removal was successfully undertaken on 26th September (nearly five and a half weeks past the scheduled date). Clinical course thereafter remained uneventful.

Our Experience

This incident bared open the profound despondency and vulnerability felt by both sides - the care receivers and the providers in their endeavour to safeguard a two-year old's interest and well-being.

It exposed the defencelessness of a middle-income family, struck by the news of a birth defect in their child, fielding the panic, terror and stigma from COVID in the community as they submitted to the demands of a modified COVID-centric healthcare system. Their journey to pursue a straightforward treatment which otherwise would have concluded at a much lower cost and much earlier, oscillated to the other extreme all because of COVID-focussed environments and an anxious atmosphere.

The family suffered in myriad ways. Firstly, shocked by the positive screen and compelled by the terror surrounding COVID, parents naively rushed a repeat test, incurring upon themselves wasteful expenditure and stress. They

also dealt with immense parental guilt around their failure to protect their ward which was amplified by the widespread societal dishonour and ostracization prevalent towards COVID patients. Further, already hard pressed from private sector expenditures and closed public sector options, parents ended up exhausting their savings on "serial tests" and multidisciplinary consultations in the hope of a negative report - their solitary safeguard against infection control expenditure. Besides all this, they endured unceasing delays in treatment, firstly from the national lockdowns, later the prolonged COVID positive status and subsequently the surgeon's infection, all of which only worsened their torment and anguish.

Equally so, the clinicians who were well aware of the urgency of the intervention and the disease spectrum in children were pained by the family's sufferings and disheartened by their own limitations in addressing the roadblock.

Despite upcoming scientific data favouring a non-infectious state in the child by his 3rd week of testing, medical team was bound by prevailing regional protocols to approach the case strictly with "comprehensive" infection control measures as warranted by any fresh case. This prevailed despite 5th week of the disease when the 4th report still necessitated COVID incidentals for the surgery. Eventually when the family consented, COVID infection in the surgeon demanded a 14-day quarantine, detaining the procedure further. This unforeseen and unexpected delay also added to the exasperation of the surgeon, who also felt partly accountable for the hold up. Despite their will and intent to help, doctors seemingly handcuffed by rigid protocols experienced regret as well as sense of defeat seeing their patient suffer.

Reflections

This particular case highlights a family's predicament as they sought cure for a non-COVID disease in pandemic times but faced delays and increased expenditure from an otherwise benign asymptomatic infection. Today when the world tracks a global COVID tally of nearly 492 million in April 2022 and ventures successfully into the vaccination phase, what remains unaddressed are scores of patient experiences that suffered not from COVID but from limitations of our responses.

A disaster of this magnitude elicited unprecedented measures - extensive lockdowns, travel bans, shutdown of work units like never before. Scientific advisory bodies, administrative and governing forces, media houses, virtual communities, medical experts all from different domains, partnered lengthy hours to keep damage at bay. They liaised to devise guidelines, policies, support groups, helplines, education material at breakneck speed.

Unfortunately, spotlight on infection control and calamity mitigation diverged attention from non-COVID emergencies and the singular emphasis subconsciously fuelled inadvertent anxiety and stigma. Low- and middle-income nations like ours experienced a brutal impact from the economic slowdown. Another undesirable outcome as several elements integrated was the healthcare's reorientation from its evolved patient-centric, individualized care model to a general blanket treatment approach. This was intended to safeguard the majority from a common threat. While it addressed the imminent upheaval, ironically, the scaffolding upholding healthcare delivery crumbled, and stability plummeted for many in diverse and unforeseen ways. Not only did the healthcare workers brave risks, work gruelling hours in PPE and lose comrades, they also suffered to see their chronic patients succumb to inaccessible healthcare, scarce resources, and re-prioritized systems.

This patient experience with its surrounding circumstances highlights that as a nation and as a world, our preparedness for a pandemic disaster was suboptimal. While the need for healthcare rationing in any pandemic cannot be denied, the criticality of triaging non-pandemic healthcare needs cannot be overemphasized. Unfortunately, this is not the first or last time that humanity has faced a pandemic. We need to be able to draw in from the learnings of the current and past pandemics as well as natural disaster plans to create a pandemic preparedness plan.

This plan should include a stepwise escalation of graded responses towards managing and mitigating pandemic mortality, while also allowing resource stratification towards non-pandemic priorities. There must be a dedicated task force operating at regional levels to track and monitor the non-pandemic disease burden and bring timely attention towards vulnerable ailments awaiting life-saving interventions. Liaison channels between the units devoted towards pandemic and non-pandemic priorities must be created and supported. Hospital resource allocations must include enhancement protocols for pandemic surge management in their plans and de-escalation protocols to realign services towards the overlooked front. Regimented protocols must retain scope for a flexible approach to accommodate patient or disease-oriented requirements. The purpose should be to minimize all-cause mortality and not to substitute pandemic related mortality with other causes. Additionally, the "shadow" pandemic of panic and anxiety festering underneath such adverse environments must be dealt proactively with precognizant planning. Anticipatory preparations must focus on media management and public communication to create a "secure and confident" atmosphere. Thus, necessary processes warrant "proactive and purposive improvisations" to ensure minimum service disruption and

retain their humane element when thwarting a pandemic wave.

When disaster strikes, some damage is inevitable, but future responses must strive to minimize this by ensuring a better balance between attacking the adversity and retaining a crucial founding principle of healthcare - "*primum non nocere*" (*first do no harm*).

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