

Impact of daytime routine modifications on people with severe intellectual disability amid COVID-19 pandemic

To the Editor,

Increasing evidence has shown that a holistic approach considering the well-being and overall life satisfaction of people with mental health issues is the most effective and worthwhile approach.¹

Intellectual disability is a mental impairment resulting in significant cognitive deficits most often associated with psychiatric disorders and behavioral abnormalities. The importance of daytime routines in maintaining the stability of people with mental health problems is well-known. In a recent study, Lyall et al.² found that the disruption of a regular daytime routine and circadian rhythmicity is associated with various adverse mental health and well-being outcomes.

However, despite being emphasized as a critical outcome variable in people with intellectual disabilities and psychiatric disorders, quality of life is not always sufficiently considered in cases of acute comorbidities, after emergency needs have been addressed.

The Oasi Research Institute is an independent nonprofit healthcare and research organization based in Troina, Sicily, Italy, providing specialized services including diagnostic work-ups and physical and cognitive rehabilitation for inpatients and outpatients with intellectual disability and its comorbidities. The center has recently overcome a health crisis due to the COVID-19 pandemic, which caused the contamination of over 109 patients and 71 health workers, and its subsequent lockdown. The implications of COVID-19 infection in individuals with severe intellectual disability, and the frequent involvement of multiple organs and systems due to genetic or acquired etiologies, are difficult to predict.

We report three adult patients with severe intellectual disability and a recent COVID-19 infection. As they were transferred to a COVID-center hospital; abruptly interrupting their affective relationships, treatments, and the daytime routines of their long-term residential treatment program, they developed food rejection behaviors.

Case 1: A 43-year-old woman with severe intellectual disability and autism spectrum disorder. Her psychopharmacological treatment included bromazepam (18 mg/die), levomepromazine (300 mg/die), clonidine (40 mg/die). She contracted COVID-19 in March 2020 and was admitted to a COVID-19 hospital as her respiratory conditions deteriorated. Although the patient had a rapid clinical improvement, she promptly developed opposition behaviors, food rejection, and a failure to adapt to new environments.

Therefore, a swift return to Oasi Research Institute has been necessary to gradually restore proper eating habits.

Case 2: A 42-year-old woman with severe intellectual disability and Lennox-Gastaut syndrome. The patient received the following daily psychopharmacological medications: clobazam (10 mg/die), lacosamide (250 mg/die), valproic acid (1000 mg/die), felbamate (1200 mg/die), and lamotrigine (300 mg/die). She was infected in May 2020 and admitted to a COVID-19 hospital due to oxygen desaturation episodes. During her hospitalization, she developed food rejection and emotional withdrawal. Her clinical condition did not allow for the rapid restoration of her daytime routine. Thus, two familiar health workers to the patient were sent to ease her nutrition and to restore a semblance of normality.

Case 3: A 30-year-old woman with severe intellectual disability, epilepsy, tetraplegia, and behavioral disturbances due to Xq22.3 duplication. In the months of April and May, the patient was twice hospitalized in a COVID-19 hospital due to related respiratory complications. At the time of admission, the patient received the following psychopharmacological therapy: valproic acid (750 mg/die), clobazam (5 mg/die), lamotrigine (300 mg/die), lacosamide (250 mg/die), and levomepromazine (37.5 mg/die). During both hospitalizations, the patient showed food rejection and excessive fidgetiness and restlessness, which complicated the clinical course. These behavioral disturbances significantly decreased when she returned to a familiar routine and restored her emotional ties.

We find it compelling to underline how these patients developed behavioral and adaptive disorders after their COVID-19 infection-related hospitalization, similar to previous literature data showing that people with intellectual disability have acutely poor hospital experiences.³ Returning to their familiar daily routine and restoring affective relationships allowed them to resolve or limit these anomalies, underlining the critical importance of a safe emotional and affective balance for the health and well-being of people with severe intellectual disability.

Stress, anxiety, depression, and withdrawal are triggered by routine changes, especially in people with cognitive impairment and psychiatric disorders.⁴

These feelings have heterogeneous effects on food intake, which are often stimulatory but sometimes cause prolonged cessation of eating and anorexia.⁵

Interestingly, there is evidence that aversive environments often produce short-term anorexia, along with freezing behaviors. This food rejection is an adaptive mechanism that postpones feeding when there is an imminent danger. However, it becomes maladaptive when sustained stress impairs physiological feeding, causing energy-depleted states that are often more dangerous than the medical condition having caused the patient's hospitalization. The neuronal networks mediating anorexigenic effects are not completely known, but it is widely believed that the prefrontal-amygdala-hypothalamic circuitry is critical.⁶

In our opinion, reporting these cases is critical because, in patients with cognitive and psychiatric disorders, the prompt re-establishment of a reassuring and familiar daytime routine after a medical emergency is critical to mitigate complications and reduced quality of life.

Feelings of well-being, participation in enjoyable occupational activities, autonomy, and a sense of belonging are crucial elements in the management of intellectual disability. Health workers should never neglect these factors, especially in states of health emergency.

ACKNOWLEDGMENTS

We acknowledge the patients and their families for their participation in the study. Special acknowledgments are due to Dr. Rossella Maria Rindone for the English linguistic revision of the manuscript. This study was supported by the Italian Ministry of Health, Grant "RicercaCorrente 2020."

CONFLICT OF INTERESTS

The authors declare that there are no conflict of interests

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