

When Self is Mistaken for Other: Psycho-social Issues in the Guillain-Barre Syndrome

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The paper addresses concerns that arise during the recovery of functional loss due to an autoimmune disorder, the Guillain-Barre Syndrome (GBS). The first section elaborates upon the changes in energies of a person, when the 'self' is mistaken for the 'other,' and its relation to innate and learned defence systems of the body. Second section is a narrative on the experiences of loss after a person is taken over by an autoimmune disorder. The third section is on deliberate practice where the sufferer infuses the mind with willpower, effort and skill to master survival functions. The fourth section explores the mind and body dialogue in the context of two major issues that a GBS patient faces: the fatigue in body and mind, and the feelings vital in healing. The concluding section reviews some premises of enlarging the spheres of healing so that the journey of the wounded self becomes easier in real life within family, community, and larger social circles.

Keywords: Immune Systems. Interoception. Physiotherapy. Air-hunger. Quadriplegia. Fall. Willpower. Healing. Niche.

When death knocks the door, one needs courage, besides help from self and others. The paper focuses on the wounds that the autoimmune disorder leaves on the body and mind of person. No other memoir comes to mind so spontaneously as Jamison's (1995/2015) that narrates wounds of mind, and healing. On one side genes may have been responsible for the gloom, and on the other her brother overstretching wings to save her from suicide. And also, no less is the role of family, friends, and socio-religious circles to face such miseries (Kirmayer, 2024; Kelley et al., 2024; White, 2021).

In the teachings of Buddha, we find the *dukkha satya*, inevitability of suffering (Epstein, 2014). So, one has to face the inevitable, whatever it has, and whenever it dawns upon. It implies understanding suffering. Psychologists, on the other propose intolerance of uncertainty and want people positive, which now and then turns

into positive fantasies. Only a few psychologists recommend mastery of skills (e.g. Duckworth, 2016/2019) to mitigate challenges.

The experiences of authorities in medical profession, are in line with Buddha's *dukkha satya*. Jamison (2023; p. 22) repeats words of William Osler "*Death taught its own inevitability; it made clear the limits of healing.*" A doctor or a priest has to understand these limits, and not create illusion, and yet console the sufferer. In the Hindu world-view *moksha* has lofty meanings of self-transcendence. But a noted psychoanalyst Sudhir Kakar looks it an attempt of Hinduism to confront and resolve the fear of death (Kakar, 1978/2022). The goal for a Hindu prescribed is not evasion from miseries of life, but meander through it following the righteous path of dharma. These socio-religious perspectives have worth for healing. One may notice later in this essay

that it is more so for those meeting an autoimmune disorder, where self becomes an enemy.

Physiology of autoimmune disorder is not our focus here, rather our concerns arise from the functional *loss* in Guillain-Barre Syndrome (GBS), and the processes of its recovery. Despite of the evolved mechanisms in the natural immune system (NIS) of man (Gonzalez et al., 2011), errors are not uncommon, where the cells of 'self' are identified as 'other,' and gets killed in the process. There are various contexts where the immune defence cells fail to distinguish its own body cells from the cells of enemy (Dettmer, 2021). In the process a huge damage to some tissue of the body occurs. One becomes aware of it through symptoms such as the feeling of loss of energies in limbs. Sometimes the loss is irreparable and fatal for the survival of organism. The global incidence of GBS crudely is 1 to 2 cases per 100,000 persons-year (Sejvar et al., 2011), and it is increasing (Bragazzi et al., 2021). Only through culturally evolved strategies such errors of the NIS get detected.

In general, the rehabilitation of post-GBS patients is costly, it becomes clear from high- and low-intensity programmes (Khan et al., 2011). Moreover, the graduated physiotherapy is imperative (Schleip, 2014). It is worth considering in view of GBS patients as long-term disability is a shared loss. Rehabilitation improves lives of post-GBS patients (Orsini et al., 2010), so essential after the immunotherapy (Inokuchi et al., 2014). However, paucity of standard guidelines on rehabilitation processes for post-GBS patients limits its scope for change (Houlahan et al., 2023). Though every investigator raises psychological needs of post-GBS patients, the provision of cognitive, affective, and educational support for them has been missing. In this paper, we shall ponder upon the systems that keep people

alive in these situations, and also suggest ways to strengthen them.

Another important aspect of the body's homeostatic system, *not attended* by researchers in autoimmune disorders is the role of interoception in feeling and functional aspects of the GBS patients. Interoception is a dialogue between the mind and the body (Chen et al., 2021). A standard measure of GBS is quadriparesis, the weakness in arms and legs (Van den Berg et al., 2014). This weakness obviously is an experience, but has objective measures also. Consider another interoceptive feedback from the weak muscles of lungs, the feeling of suffocation or dyspnea in GBS patient. These feelings lead to conscious states of action in the affected person.

We hypothesise that the dialogue between mind and body through interoceptive processes is even more vital for post-GBS well-being of patient: first, physiotherapy activating weak muscles and nerves; second, via social, cultural, and religious elements of healing. Least understood problem in this disorder is the experience of fatigue from minor activities (de Varies et al., 2010), and the ensuing falls from overstraining of muscles (Davidson & Parker, 2022). Even the updates on interoception (Schoeller et al., 2024) lack reference to these issues of post-GBS patients, which this paper intends to highlight.

In view of the above, the paper first elaborates upon the changes in the energies of person, when the 'self' is mistaken for the 'other,' and its relation to innate and learned defence systems of body. The second section is a narrative of the experiences of a person taken over by an autoimmune disorder known as GBS. Third section is on the deliberate practice where willpower, effort and skill are suggested to permeate the mind of sufferer in learning survival functions to rise up from the fall. The fourth section explores the mind

and body dialogue in context of two major issues that a GBS patient faces: the fatigue in body and mind, and the feelings vital for healing. The last section briefly reviews some premises of enlarging the spheres of self so that the journey of a wounded self, like that of post-GBS patient, becomes easier in real life.

1. Systems that Keep us Alive

The well-being of person involves four aspects: physiological, mental, social, and even spiritual. These aspects provide essential elements for the rehabilitation of GBS patients, a major focus of this paper. The physiological processes implied in wellbeing begin at cellular level, and are the earliest in evolution. Our body is a multicellular organism, where groups of cells jointly keep homeostatic balance for good operation. A prerequisite is protection from enemies, the viruses, bacteria, and worms, ready to molest this integrity. Humans are rich food for these pathogens. But human body, and mind, have evolved devices to recognize potential enemies, and ways to fight or avoid them. These devices jointly form body's natural immune system or NIS (Dettmer, 2021). It is entirely physiological and cellular, and even molecular. Over a period, investigators are exploring some evolved behavioral and mental dispositions, together known as behavioral immune system (BIS) that saves people from enemies (Schaller, 2011; Ackerman et al., 2018).

These defence systems, the physiological and the behavioural, need a perspective of ownership, as referred above. A defence system, in either case, protects own body cells from others, the potential enemies. Therefore, the crucial test for a fighter cell of our defence system is to distinguish between 'self,' the cells of own body, from the 'other.' The NIS is highly complex organization, involving various kinds of cells— some are fearsome soldiers who

sacrifice for the sake of 'self,' when informed by cells that keep an eye on the 'other' (Fig. 1); there is a repository of weapons, the antibodies; specific training centres to teach self from other; high-ways to move to any part of body to defend each single cell; and lastly, systems to keep memories of enemies (see Dettmer, 2021).



Fig. 1 Macrophage, fights with enemy; Dendritic cell, keeps eye on enemy.

The BIS is not so well developed. Moreover, we have only hypothetical information about it. Humanity has, however, moved beyond these two innate defence systems. The flourishing of culturally evolved systems, including the medical sciences, have further strengthened these two systems. These alternative defence systems to protect human body and mind are enormous in its scope, manpower, and physical base. They have culturally evolved techniques to fill out lacunae of the NIS to distinguish own 'self' from 'other' and to provide soldiers from outside.

There are quite a few contexts where the immune defence cell fails to distinguish its own body cell from the cell of an enemy, and attacks it. These errors in the immune system are now detectible through the culturally evolved strategies in medical sciences. They are known as autoimmune disorders, one of them being the Guillain-Barre syndrome or GBS (Sejvar et al., 2011; Bragazzi et al., 2021), the focus of this essay. Now culturally evolved mechanisms are in practice, where

a large force of soldiers, the antibodies collected from donated blood, are injected into the body of a patient (IVIG therapy) to check further damage to tissue by the errant immune cells of own body (Dettmer, 2021). Whereas the healing of loss to neuromuscular system occurs slowly during the course of rehabilitation.

Our aim here is to understand the social and psychological base that make way for the flourishing of the cultural strategies that help us to mitigate the challenges of autoimmune disorders, among numerous others. Damasio (2023) underlines that this social and psychological base has biological foundation in homeostatic regulation, and in the mechanisms of social cooperation. In human body, unfathomably though, groups of cells specializing in different functions form a cooperative unit under unitary ownership. Moreover, the individual is conscious of this ownership. Earlier, Wilson (2012) has featured the centrality of such altruism and cooperation for survival. These affairs, besides the prosocial relationships (Kelley et al., 2024), have ramifications even in religious realms. And, the survival of GBS patient is embedded in such cohesive social systems.

Some basic cooperative relationships are easier to grasp from the societies of our monkey cousins (Pirta, 1986; Fig. 2). These patterns of cooperative relations include: interspecies and intraspecies cooperation, communal attack, communal defence, cooperative movement, and cooperative foraging. They are the genesis of group life. These relations develop through coalition relations, consort relationships, social grooming, and social play. And the conflicts in day-to-day life of the group are avoided through active interference patterns, such as cooperative attack, cooperative defence, and assuaging behaviour. In view of this paper, these pro-social relations have particular significance. First, in context of the BIS referred above, where a group protects its

members from external threats. Second, even more substantially, these social relations form a huge resource to meet physical, social, psychological, and spiritual needs arising in rehabilitation of GBS patient. The group becomes a secure base for individual suffering loss.

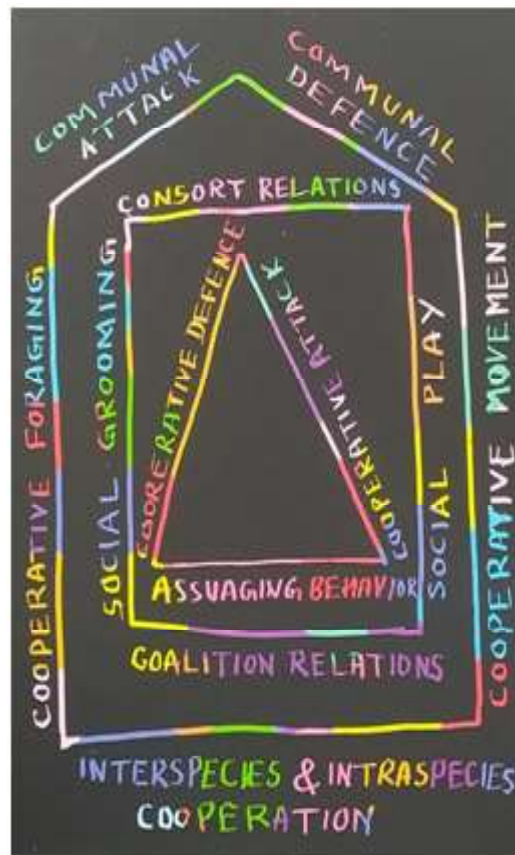


Fig. 2 Cooperative life of a primate group.

The discovery of imprinting by ethologist Konrad Lorenz was vital for cognising the formation of social bonds (see Lorenz, 1981). Similarly, the classic experiments of Harlow (1958) on warmth an infant monkey needs for survival, and side by side, the observations of Bowlby (1958) on socially supportive environment a child needs, in fact set apart social and physical factors necessary for development. But it was Niko Tinbergen (1973) who saw the relevance of these insights in stressful situations.

If the base of social support is good enough (Kolk, 2015), a patient can fall back on it. It is a dire necessity in post-GBS patients. The need for warmth and care for a post-GBS patient is similar to a helpless and dependent infant. A post-GBS patient may imbibe the spirit of an infant, only if there is supportive environment in the sense of John Bowlby. There is utter lack of cognizance on these social support systems, behavioural and social, in rehabilitation of the post-GBS patients. Even the national surveys on the rehabilitation of GBS patients (Davidson et al., 2009; Davidson & Parker, 2022) conclude that the provisions of rehabilitation require change in view of the needs of patients, especially the provisions of care in community.

In the next section, I am presenting my experiences of sufferings after fall to an autoimmune disorder.

2. Coming of the Inevitable

On the early morning of September 25, 2023 as I woke up in my bed, I sensed a little curliness in the middle fingers of both the hands. I thought I may have overexerted them. Though I felt little trouble in bathing, changing clothes, and eating due to curly fingers, I was busy in activities all over the day, and up to September 27 forenoon. At this time, I have returned from market with some luggage in van. On getting down from the vehicle, as I began to walk, I felt difficult to lift even a light hand bag. This was traumatising. A little further climbing on familiar steps, I fell backward over a Nepali worker following me. It was a miraculous escape from tumbling down over the hill slope. No loss of consciousness, only transitory shut down of muscular activity. I soon climbed up with the help of Nepali worker, and reached home. Now it was clear that I was heading for some serious problem, quite unintelligible to me at that time. Earlier to that, I had diarrhoea on 15, 16 and 17

September, which was controlled with light medicine. It did not affect my daily activity. But following the September 27 forenoon event, I felt weakness in all four limbs, increasing at a slow pace on 28, 29 and 30 September. It was decided within the family that I should move, as soon as possible, to a good medical facility in Delhi for a medical check-up.

And, on first of October I reached Gurugram, near Delhi, where my son lived. On October 2, after preliminary medical check-up at the emergency in the Artemis Hospital, I was admitted to the intensive care unit as a case of Guillain-Barre Syndrome (G 61.0 ICD 10; patient ID GN0000888159). The problem was of autoimmune nature, and GBS for short.

It was noted about the patient that the CNS was conscious and oriented; Extraocular muscle function full; Speech-normal; Tone-normal in all four limbs; No co-morbidities; No h/o paraesthesia/ dysarthria/ dysphagia/ visual and hearing disturbances/ bowel and bladder complaints, at the time of admission on October 2, 2023.

Examination showed LMN (lower motor neuron) Type quadriplegia without sensory and bladder involvement. MRI and CSF analyses were more or less normal, except age related changes. Possibility of GBS was kept. Nerve conduction study (NCS) of all 4 limbs, Sensorimotor Demyelinating > axonal polyradiculoneuropathy of all 4 limbs (AMSAN).

Medical report says, on the night of October 2, the patient was started on IVIG (Intravenous Immunoglobulin) 140 gm (2 gm/kg) over 5 days, which he tolerated well, and showed improvement. By October 7, 2023, the patient was able to walk without support, and discharged after counselling on further management. Some instructions were: socio-psychological support at home; avoid stress

and strenuous activities; activities as tolerated; ensure adequate fluid intake; and, report to the hospital in case of emergency.

In a follow-up visit on October 21, 2023 the doctors found improvement in the health of patient, but there was residual proximal weakness. Active physiotherapy of limbs involving a range of movements (ROM) at home was to continue for two months. After the two months, when the patient visited the Artemis Hospital on December 21, 2023, after behavioral examination the doctor, a neuroimmunologist, wrote that the patient has *recovered*, no further treatment was required.

The news was enlivening to everyone, including me. But the wounds, the autoimmune disorder has left on my body and mind, were yet to heal though. I was barely able to sit and stand, and walk alone for some distance inside room. The energies of the limbs were far lower than they were at

the inception of problem, about three months ago. *Whether I will regain my energies, or not, was an open question.*

After the IVIG therapy over the five days, though the progress of the autoimmune processes harming nerves and muscles may have stopped, but the loss that has occurred to the body was huge. The GBS has taken away most of my energies of body, and severely limited its movement. The only remedy was the physical therapy of the four limbs following a strict regime of active body movements. I was getting taste of dependence somewhat earlier though, just at the end of seventy-three. My experiences on 20 activities of day-to-day life at the beginning are shown in Table 1. For the next six months daily record was kept in notebook. After the end of every two months the improvement was summed up in the respective column: phase 1, phase 2, and phase 3.

Table 1. Improvement in activities over 6 months.

Activities	Improvement*				Transitions
	Beginning	Phase 1	Phase 2	Phase 3	
1. Eating	MD	MD	SD	SD	1
2. Drinking	SD	ND	ND	ND	1
3. Toilet use	GD	MD	SD	SD	2
4. Bathing self	GD	MD	SD	SD	2
5. Changing clothes	GD	MD	SD	SD	2
6. Exercising	GD	GD	MD	ND	2
7. Walking	GD	MD	SD	SD	2
8. Climbing stairs	GD	MD	MD	SD	2
9. Sit-to-stand	GD	GD	MD	MD	1
10. Catching ball	MD	MD	SD	SD	2
11. Lifting objects	GD	GD	MD	MD	1
12. Running	GD	GD	GD	GD	Deficit
13. Jumping	GD	GD	GD	GD	Deficit

14. Talking	ND	ND	ND	ND	Normal
15. Thinking	ND	ND	ND	ND	Normal
16. Reading	ND	ND	ND	ND	Normal
17. Writing	MD	SD	SD	SD	1
18. Drawing	MD	SD	SD	SD	1
19. Mobile use	GD	MD	MD	SD	2
20. Laptop use	GD	MD	SD	SD	2

*Over six months: Beginning Oct. 2, 2023 to Mar. 31, 2024; Phase 1: Oct. Nov.; Phase 2: Dec. Jan.; Phase 3: Feb. Mar.; Great difficulty GD; Moderate difficulty MD; Some difficulty SD; No difficulty ND. Scoring: Each activity = 3 Transitions; e.g., GD to MD = 1; MD to SD = 1; SD to ND = 1; No transitions = Deficit or Normal; Out of 45 transitions in 15 activities = 24 transitions observed.

The following section describes the healing process through which I have undergone for over 6 months since the fall from autoimmune disorder. These are reflections from my journey to regain my energies after loss.

3. Willpower, Effort, and the Rise

The first section presented a psychosocial position for the rehabilitation of post-GBS patient in view of his helplessness, and so dependence on others. The studies indicate that rehabilitation of these patients overlook these basic psychological processes. Therefore, a vital issue was the enrichment in transactions in the niche of post-GBS patient on the ideas of Lorenz, Tinbergen, Harlow, and Bowlby. These ideas derive from experiments and observations in ethology, psychology, and, psychiatry, and have crucial elements for enriching the niche of post-GBS patient.

These basic issues involve reference to some psychological concepts, which form the core of the survival strategy for a post-GBS patient. After diagnosis of my ailment as GBS, I was given IVIG treatment for five days in the hospital. The fifth day, on discharge from the hospital, the immediate question in my

mind was: Has this autoimmune disorder, where self is mistaken for other, limited my energies? And, even worrisome, whether this limit on my energies was temporary or permanent? The word energies have various meanings, broadly falling in two domains, the mental and the physical. The famous psychologist William James, in a heuristic essay, underlines that there is immense energy inside everyone, and one can use it as a resource. James (1907/1987; p. 1230) wrote, "*The normal opener of deeper and deeper levels of energy is the will.*" In other words, the key to unlock energy is within our willpower. Not long ago, the pioneer of sociobiology viewed will from the survival perspective. Where inborn and learned schemata or plans compete to influence formation of set in the mind (Wilson, 1978). Now, these processes come under interoception.

One has to imbibe a spirit of courage under the situations like those faced by a GBS patient. A courageous GBS patient is likely to summon willpower rather more efficiently to master the skills needed to empower the muscles. Willpower is an area of scientific exploration (Baumeister & Tierney, 2012), and a meeting point for

eastern contemplative tradition and western psychological research (Pirta & Misra, 2021). But the concept of willpower is not as simple as one may think (Ainslie, 2021). It is in fact self-control. For us it should suffice that willpower is a resource of strength and energy, like glucose for the muscles. The two main issues before me as post-GBS patient were: to empower myself with courage to face the immense loss of power felt in muscles, and, to regain it by investing good enough effort in physical exercises.

Some researchers use a rather more empirical term, the grit, a unique combination of passion and perseverance for greater achievement, physical as well as mental (Duckworth, 2016/2019), following lead from Seligman (2011/2013) on learned helplessness, and later its opposite learned optimism, which is not too far from willpower. And Duckworth applied it in her work on children who were not so talented. The task was to encourage lesser talented children to perform equal to, or even excel, the talented. She thought the problem needed concepts similar to James' concept of energies, to start with, and found evidence in case studies of achievers in various fields. Her curious finding was that even the lesser talented can achieve as much as the more talented, if they put more effort on skills needed for a given task. She simplified it in an equation: Talent X Effort = Skill; and, the greater effort by the lesser talented is shown by another equation: Effort X Skill = Achievement.

I saw that these equations have meaning for improving the quadriparesis in GBS patients, the weakness of the four limbs. The physiotherapist and the patient have to grasp it before getting on physiotherapy. In this adoption of the equations, my assumption was that the post-GBS patient was much poorer than the normal person in terms of the day-to-day functioning of the limbs. So, he may require much greater effort than a

normal person in learning the necessary skills to rise from the quadriparesis.

Thus, the equations for learning functional skills for a post-GBS patient are:

$$\text{Physiotherapy X Effort} = \text{Skill} \dots 1$$

$$\text{Skill X Effort} = \text{Achievement} \dots 2$$

Due to the much poor condition of the post-GBS patients we may need the factor of willpower (see Baumeister et al., 2018), keeping up the spirit of the 'energies' (see James, 1907/1987), and the new equations thus are:

$$\text{Physiotherapy X Willpower X Effort} = \text{Skill} \dots 3$$

$$\text{Effort X Willpower X Skill} = \text{Achievement} \dots 4$$

These equations have illustrative purpose only, to make willpower clearer from the viewpoint of counselling (Dubner, 2016). In this way, every improvement in a post-GBS patient's function, for example 'sit-to-stand' transition, would be like an acclaimed athlete's perfection by a small increment. The effort in the above equations is invested through *deliberate* practice in learning the necessary skills to achieve a goal. Where practice is a mere repetition of an exercise for stretching a muscle group, the deliberate practice is to invest all your effort in every trial, with full attention and a sense of achievement howsoever little it is.

The goal may be small, stretching the fingers of left hand. One by one, similar practice is done with every finger of left and right hands. Fingers of hands play important part in various functions, the higher-level goals: writing, grasping, eating, and so on. As a post-GBS patient masters these smaller-level goals, he is ready to engage in coordinated actions of further higher-level, where upper and lower limbs are involved. Take for example, 'sit-to-stand' transition by a post-GBS patient (Calefato, 2012); it may require from weeks to months, that too after regular effort. Once it is achieved, the patient

is ready to move in space with confidence, a still higher-level goal. The highest goal for a patient is to return to normal life.

The concerned people may get an idea of such hierarchical organization of behavior from the diagrams of ethologists. Studies of Niko Tinbergen on stickle-backs is good example (see Eibl-Eibesfeldt, 1975). Tinbergen is among the first scientists to underline relationships between stress disorders and muscular movements. His Nobel lecture narrates this relationship in view of Alexander's physiotherapy (Tinbergen, 1973), that has basis in naturalistic observation, and second, the focus on distortion of body musculature. Therefore, the goal of Alexander's therapy has been to restore proper use of musculature by patients, which may be as acute as loss of voice by misuse of vocal muscles.

The key-concept being *re-afference* (see Lorenz, 1981). It involves continuous monitoring of the movements of single muscle unit to complex behaviour by the brain. The brain does this by comparing a feedback report, that says order carried out. Lastly, Tinbergen (1973) cautions that in therapeutic practice the mind and body distinction is superfluous. These words make way for psychotherapy that goes side by side of physiotherapy. For, the healers of mind, Jamison (2023) notes, help in building walls to protect the mind. And, in this endeavour she goes back to include the oldest healers of mind, the priests with the physicians and psychotherapists. Consolation and confession are their tools.

What kind of feed-back goes to brain in case of post-GBS patient from inactive muscles of upper and lower limbs is not clear. The feeling of 'tiredness' is the first symptom of this autoimmune disorder. That my muscles have gone 'weak' is yet another expression. The bigger shock is though awaiting. The

person out of blue notices helplessness in performing every single movement of limbs. All of a sudden, immense need for dependence on others for survival sets in. All this needs, to begin with, consolation as balm. The post-GBS patients remains in serious conditions even after receiving immunotherapy, which is not easily affordable. Therefore, to recover from quadriparesis the rehabilitation of post-GBS patient is obligatory. Moreover, the functional loss, limitation on movement, and dependence on others are distressing for everyone. These psycho-social factors further aggravate mental life of post-GBS patient (Khan et al., 2011). First ointment is consolation. It makes ground in the dark recesses of mind, where seeds of courage sprout. For experienced physicians and psychologists, such as William Osler and Viktor Frankl, work was a true balm of hurt minds (Jamison, 2023). Work is any activity, which one likes, and is able to do.

We have no ideas about working of these internal resources, which are embedded in body and mind. It is perhaps interoception which charges mind through the feelings. These feedback mechanisms between different systems sustain life by keeping homeostatic balance. Just as many other systems of body and mind need nourishment from outside environment (e.g. food, water, oxygen etc.), so also the mental attributes such as courage, effort, purpose, and self-esteem flourish in social niche. In this niche transactions involve others of our kind in physical space. Early experiences of these attributes occur in the warm and secure lap of mother where the infant finds itself (Bowlby, 1948; Harlow, 1958; Lorenz, 1981). In this space, infant gains good enough courage to reach out; the mother actively encourages the infant; over a period, the mother only keeps watch on movements of infant in social and non-social environment.

A post-GBS patient finds himself a state of extreme dependence as his limbs are inactive. He is lying on the bed like an infant who has yet not learned to crawl. Though his mind is well, his limbs unable to lend a hand. The help from others is substantive, and catalyst to imbibe the spirit of courage. Day by day, deliberate practice of muscles, through feedback to brain, not only leads to recovery of function, it also infuses courage. In turn, the patient puts more effort and willpower in learning higher level exercises. The patient also devises his own ways to sit, stand and climb.

Let me now present my own evaluation imbibing the spirit of the above counsel myself for over six months. In brief, after IVIG treatment the threat of further loss of GBS has subsided though, but the loss to my energies was considerable enough. Some idea on improvement on 20 activities is presented above in Table 1. Each transition (e.g. Great difficulty GD to Moderate difficulty MD) was an improvement in an activity. From the beginning over phase 1, phase 2, and phase 3, the cognitive activities were normal: thinking, talking, reading. The 15 activities show 24 transitions out of possible total 45 transitions. The 2 activities showed no improvement despite tremendous effort: running and jumping. Thus, overall, there was moderate level of improvement in survival functions over the six months.

At this stage, the post-GBS patient, like me, who is suffering loss, needs more deeper level of counselling, a search for meaning in life. One has to prepare the mind and the body for surviving with loss. I would rather underline that one needs to be satisfied with whatever functional control one has achieved. Whenever, my imagination flowed I engaged in scratch painting where muscles of fingers were involved, and the visuals gave pleasant feedback to mind (Fig. 3). All the figures in this write-up shows my effort on

scratch-book during the six-month rehabilitation period.



Fig. 3 The scratches with imagination.

Such explorations could be in the areas of learning crafts, painting, writing, singing, dancing, cooking and so on. In context of the assertions made in this section we have to understand the processes that keeps the dialogue between mind and body alive.

4. Mind-Body Dialogue

Every organism needs information about potential threats to its survival, and essential elements about its growth and development. Much of this information is gathered through the three kinds of evolved intelligences (Damasio, 2023): exteroception, the information from eyes, ears, nose, tongue, and skin; interoception, the dialogue between mind and body including heart, lungs, and other visceral organs; and, proprioception, the muscles and bones that provide frame to body for movement. Among the three, the dialogue between mind and body is receiving immense attention of investigators from diverse areas of mental health (Nayok et al., 2023; Schoeller et al., 2024). This dialogue

has significance for, besides the assertions made in the preceding section, exploring two major issues that a post-GBS patient faces: the fatigue in body and mind, and the feelings necessary for healing.

4.1 Fatigue and the falls

The GBS patients in general report fatigue from the onset of the disease and it continues in them even after rehabilitation (Davidson et al., 2009). Physiologically, fatigue has two origins, the central in brain, and the peripheral in other parts of nervous system innervating the body (de Vries et al., 2010). In a way, the physiological fatigue is superimposed by mental fatigue, which is the experience of feedback to central nervous system (CNS) from neuromuscular junctions. Therefore, the feeling of fatigue is a mixture of central/mental and peripheral/experiential components. Those patients who have comorbidities (diabetes, hypertension etc.), the picture is complicated. Doctors use tests for the measurement of four components of fatigue: central, peripheral, mental, and experiential. Largely, the fatigue is believed

to subside in the course of rehabilitation the post-GBS patient.

Putting more strain on muscles of body is not limited to chronic fatigue, it may even be fatal. Let me narrate the event of my fourth fall, the three falls of similar nature have occurred before, when the GBS was at its peak, that is before rehabilitation (Table 2). The fourth fall occurred right in front of physiotherapists, and in their clinic on the October 4 afternoon. In the end of an hour-long exercises, I was gliding on a big ball stretching my body; my belly touching the ball, and the four limbs providing partial support. Though my body was exhausted, I was encouraged to go for one more exercise, the Hanuman posture. Lastly, supporting my body on the knees, on the coarse matting, the physiotherapists urged me to stand-up. It was challenging, I sought physiotherapist's help, but he could not hold my weight, and the whole body fell like a numb mass of flesh. They thought that I had some serious attack. But I got up soon putting my arm on the side of a couch, and walked to home.

Table 2. Fatal falls before and after rehabilitation.

Before rehabilitation	After rehabilitation
I. 27 September 2023 (on the way, Shimla) Grurgram)	IV. 04 November 2023 (physio clinic,
II. 30 September 2023 (at home, Shimla)	V. 19 December 2023 (at home, Grurgram)
III. 03 October 2024 (in hospital, Grurgram)	VI. 06 January 2024 (at home, Grurgram)

In between, I had a dialogue with a doctor friend, struggling with depression over decades, yet living comfortable life. He was alarmed knowing my schedule of physical exercises: twice climbing stairs up and down from the sixth floor to the ground floor; three, half hour sessions of breathing; half an hour walking on the ground floor; one our active physiotherapy (ROM) session with the expert; and in addition, two-hour session of physical exercises, one in the morning and one in the

afternoon. My doctor friend's questions were sharp. Are you not straining your muscles too much? Have you checked it with the physiotherapist? What is the body's response? I fumbled for answers to these questions. The climbing up and down of stairs from the sixth floor to the ground floor, twice was really exhausting for me, and full of danger of falling. It was sheer enthusiasm, a very costly one to my body. I immediately cancelled the evening session of climbing the

stairs, and cut down the remaining physical exercises by half.

In my reflection over this issue the following came out. The muscles of the post-GBS patient are weak. In normal case of athletes, the muscles can endure such strain, and become stronger. The GBS severely damages the axonal fibres innervating muscles of limbs. Therefore, too much strain through exercise on a few intact muscles alarms the CNS—it shuts down all channels of communication to the periphery. Consequently, the body becomes numb and falls. There is no loss of consciousness, and the body recovers. It is like shut down in electricity supply when there is heavy load on the system.

This is logically explained by the Central Governor Model (CGM) of fatigue in GBS and other disorders where fatigue is common symptom (de Vries et al., 2010). The model was proposed by Noakes and his colleagues in 2004 to explain fatigue due to overstraining of muscles during exercise (see Noakes, 2000; 2011). In CGM there is a forward information collection system about a specific muscular system. Its proper working conveys the strength in performing an action. If there is weakness in the system it is evaluated and converted into experience. This information collection system includes backward nerve fibres originating from the active muscles involved in an action, and is matched somewhere with the total fibres required for the action. The lesser the number of fibres from the total required for an action, the greater the probability of not able to perform that action. Obviously, there will be more strain on the remaining muscle fibres, resulting in the perception of more fatigue. Logically appealing, the CGM considers fatigue as a survival mechanism, saving the body from overexertion and its consequences.

A recent review on fatigue during physical exercise concludes that fatigue is due to the impairment of one or several physiological processes that allow muscles fibres to generate force. This process underlines task-dependent factors. Fatigue, in this view, is a decrease in task performance related to a rise within the real perceived difficulty of task or exercise (Tornero-Aguilera et al., 2022). Another study suggests that mental fatigue and physical fatigue, both affect postural control negatively in general in normal adults (Gebel et al., 2022), thus the consequences of fatigue for post-GBS patients are fatal. A national survey on falls in post-GBS patients in the United Kingdom concludes that out of 214 patients, 113 reported fallen in the past years, among them, high fatigue was a factor (Davidson & Parker, 2022). GBS may have not only led to balance deficiency, but also loss of saving reactions, causing faulty learning and alterations in the biomechanics of muscles. These investigators hypothesize fatigue as a key factor in falls among the post-GBS patients implicating CGM theorization.

Lastly, in view of willpower, as suggested in the previous section, the research on ego depletion model also has bearing on understanding fatigue in GBS patients. The relation between willpower and glucose is more than metaphorical. As glucose depletes in blood stream after exercise, so does influence of willpower diminish (the ego depletion) after mental or physical work. Therefore, it is theorised that ego depletion is essentially a kind of fatigue (Baumeister et al., 2018). Furthermore, the CGM suggests that normally functioning neuromuscular system wanes in postural control during strenuous and prolonged exercise. If that is the case my analysis of the total six falls that I had during six months, all are result of overstraining of muscles in overenthusiasm.

4.2 Enriching feedback to mind

Humans live in closely bound societies, where information flows culturally also to take care of the survival needs. For example, the vital information of wounded healers (e.g. Jamison, 2023), courage, help, and consolation from friends (Jamison, 1995/2015; Kolk, 2015), and the blessings of deities one seeks (McNamara, 2023), all contribute in healing mind and body. There are three universes information exteroception, interoception, and proprioception. They have immense scope of enrichment of feedback to mind, the healing processes. Healing is not limited to recovery of functions. Even if the recovery after six months is nominal, as we find in the present case, the enrichment helps achieve higher levels in the mental sphere after loss. The focus during the rehabilitation process is on enrichment through proprioceptive feedback from exercise of muscles. Further enrichment is possible by a variety of exteroceptive stimulation: reading, writing, painting, chanting, or music. But, the enrichment of interoception is entirely lacking. A suggestion is to improvise physical exercises in such a way that they stimulate interoceptive pathways, in addition to proprioceptive (Schleip, 2014). In recent reviews, the investigators see possibility of modulating interoceptive processes to affect the central nervous system (Chen et al., 2021; Schoeller et al., 2024).

These internal processes need rather deeper understanding in view of preceding suggestions. Working on this premise physiologists, for over a hundred year from now, were studying the internal feedback systems from the viscera that give rise to feelings of hunger, thirst, or satiation. Another important system in physiology and psychology is dyspnea (Benke et al., 2017), a better expression perhaps is air-hunger. It has immense significance in GBS, the focus of this study. Every few hours, after my

admission to the intensive care unit, the doctors and nurses would ask me to count as much as I can in one breath. My count was nearby 20 or slightly above. They interpreted it, my lung muscles were intact, and I was inhaling good amount of air, including oxygen. There was oximeter too capping my index finger. The GBS has already affected the nerves feeding the upper and lower limb muscles, thus making them non-functional. The sensation all over body surface, and the limbs was intact though. The brain was giving order to close the fist, or raise the right leg, but the performance of limbs was minimal.

The next target of the pathogens, or the errant immune cells, would have been the involuntary muscles of lungs, and then heart and other vital organs in the viscera innervated by the mighty vagal nerve, descending from the brain directly. The air-hunger is modulated by sensors on the walls of lungs where exchange of air molecules takes place (Damasio, 2023). If the air-hunger is acute, that is supply of oxygen in blood is low, the first reaction of the conscious mind is the feeling of suffocation. If the problem continues, as the lungs fail to function properly due to affected muscles, the breathing is short and requires much effort.

The work to explore the mechanisms of shortness of breathing or feeling of suffocation has begun much earlier than the use of the term interoception. There is a study of Paintal (1969) on shortness of breathing produced artificially in animals, and the analysis of signals to the brain in the vagal nerve from sensors in the pulmonary capillaries in walls of lungs. In pulmonary congestion, due to strenuous exercise, the sensors named as J-receptors, pick-up these signals which run through vagal afferent fibres to the brain. Brain interprets these signals as feeling of congestion, which is life-threatening, and the immediate action is to

stop exercise. My hunch is, when one engages in strenuous exercises, there may be a 'shut down' as described in the preceding section.

Investigators are working on similar line of thinking in the recent years. Where these sensory feedbacks are known as independent sources of information of the inner environment, the interoception (Damasio & Carvalho, 2013). And, the vagus nerve is a principal conduit of fine visceral information. They see these interoceptive pathways not only as arousal systems of feelings in animals and humans, as did William James long ago, but also major evolutionary mechanism for states of consciousness and complexity of mind in general (Carvalho & Damasio, 2021). In this new thesis of advent of feelings, Damasio (2023) visualises some interoceptive processes primary for the evolution of mind and states of consciousness. For example, the interoceptive feedback giving rise to feeling of 'air-hunger' and states of consciousness to perform behaviours to meet it out. In understanding feeling and its experience, the somatosensory afferents in case of cardiovascular state are also important (Khalsa et al., 2009). Since the mental experiences of GBS patients, such as fatigue, air-hunger, and heart states, have immense significance for the well-being of patient, we may require sensitive measures of interoception (Garfinkel et al., 2015) to record self-awareness of feelings.

The interoception in my view, also has significance in knowing the complications arising in GBS patients, such as bladder control, and the effects of several other comorbidities. In this regard, a study (Luettich et al., 2023) investigating brain-imaging and non-imaging variables in a sample of 19000 individuals provide convincing evidence of the significance of using data-sets from different approaches. The investigators studied variables about circuits and specific

regions of brain that were involved in interoception, that is sensation, perception, and integration of signals from within the body. These variables were found significantly related to different domains of comorbid conditions in these individuals. These indicators provide valuable information about interoceptive feedback resulting in experience of feelings indicative a homeostatic imbalance in the body (Benke et al., 2017). In case of GBS, approximately 25% patients are reported to suffer from respiratory-insufficiency or dyspnea (Van den Berg et al., 2014). However, we notice that even most recent exhaustive reviews on interoception (Schoeller et al., 2024) fail to notice the importance of interoception in GBS patients, and their rehabilitation.

Another important question arises here since the myelinated nerve fibres at the periphery are compromised in GBS patients. What happens to the functioning of unmyelinated nerve fibres (Fig. 4; after Damasio, 2023) that play significant role in the interoception?



Fig. 4 Interoceptors on two types of nerve fibres.

Precisely, "*Interceptors are molecular sensors or receptors in neurons that directly detect various interoceptive signals and transduce them into electrical, hormonal, or other non-neural signals to be integrated and interpreted by the brain.*" (Chen et al., 2021) An important example where interoception is

implied is the shut down or falls after strenuous exercise in the GBS patients discussed above. This seems also be the case with the levels of safety that the self observes in case of trauma and its after effects (Kolk, 2015; p. 104). Whatever may be the case, the role of interoception becomes all the more imminent. It is a dialogue between the body and the mind for individual's survival.

5. Spheres of Healing in Society

The self engages in dialogues with objects in the ever-growing circles around it for its survival. This becomes obvious from suggestions to broaden the perspective of mental health services from the limited premises of hospital to larger social, cultural, and ecological circles, which have elements for nourishment of human psyche. They have special meaning for post-GBS patients recovering the loss from a disorder, and face to face with real life within the family, community, or work places, for which they are yet not ready.

Culture-specific strategies to combat pathogens, and experiential factors to understand onset of problems such as the GBS, need careful consideration. On the other hand, the mental health problems may have different origins, other than the neurobiological (Gomez-Carrillo & Kirmayer, 2023), especially where cultural practices maintain social structures (Kirmayer, 2024). Such factor may have salience for positive or negative affect in one niche, but not in the other. For, the niche is more than where one lives, it is how one lives. Consider people facing adversity (Manning et al., 2023). The spirit of shamans, medicine men, mediums, and prophets (Singh, 2018) still survives in healing body and mind (McNamara, 2023; Kelley et al., 2024). These are ways of self-transcendence via enabling positive affect, courage, and need for affiliation to endure suffering (Ge & Yang, 2023; Potz, 2023).

Loss is likely to set in the psyche of post-GBS patients, since the recovery of functions is only partial. It is therefore necessary to inculcate ways of positive transformation where a person after enduring loss, learns new skills for self-transformation. The skills for transformation are as many as functions that one comes across in life. One has to master skills which he or she has access to and can afford. It implies the significance of work in healing. A vital dimension to this learning process is patient's reflection on the purpose, to transform the self for the sake of others. Some of these transformative cognitive processes are: antithetical, metaphorical, artifactual, dissipative, and simulative (Pirta, 2023). One way, for the sufferer is to bear the loss with courage (Jamison, 2014; 2023), and to imbibe the spirit of the *fire of biraha* (Pirta, 2024). Where the pain of loss due to the fatal autoimmune disorder becomes fuel for a lamp burning inside (Fig. 5), only to throw light on the external world, making it little brighter for the others.

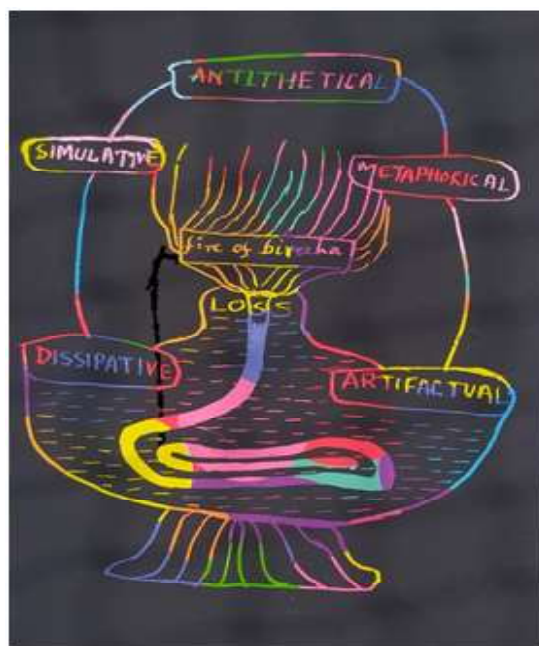


Fig. 5 Transformative cognitive changes.

The emotions orchestrating these behavioral responses are balancing acts of selective pressures (Wilson, 1978). These behaviors may be directed towards transcendent goals (Crook, 2009; White, 2021; Wilson, 2012). These processes may be facilitated by symbols, as words are key to mind (Chomsky & Moro, 2022). Moreover, the strands of such mental changes can be traced to Sumerian and Egyptian cultures where psychological pain first emerged in symbolic forms (Valentine, 2024). A person recovering from loss due to GBS may imbibe the spirit of any one or more of these positive transformations, along with engaging in some learning skills. This will, on the one hand, help to compensate the loss of function due to inactivity of some muscles. On the other, the new skills learned by the person, with a spirit to help others, will act as catalyst to transform the psyche (Baumeister & Tierney, 2012), as imagined in the *fire of biraha*. Only to experience life more meaningful.

A Recap

The autoimmune disorder that has been the focus of this paper invites various approaches, from the onset of the problem felt by a person, the treatment in the hospital, and during the long rehabilitation process. Whether first-person, second-person, or third-person, each data set provide significant information. For example, at the onset of GBS, a patient feels weakness in his limbs, which is spontaneous, and has no association with some preceding physical event. However the fatigue felt by a post-GBS patient during the process of rehabilitation is readily associated with some strenuous physical activity. And, fatigue also results in falls.

GBS has long-term debilitating effects on the life of the person, along with the lives of family members. Even the community is deprived of the services of its prospective members. The essay suggests that the least

understood problem in this disorder is the interoceptive experience from the body. Qualitative evidence presented here indicates that this dialogue between mind and body has significance in the post-GBS well-being of patients: first, in the calibration of physiotherapy for the activation of muscles and nerves; second, defining salient social, cultural, and religious elements for infusing willpower and meaning.

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