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Translation and Validation of the Paediatric Family Needs Questionnaire in the Hong Kong Chinese Population and the Local Application

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Introduction

When a child sustains an acquired brain injury (ABI), the entire family system is affected. Significant sequelae in terms of medical issues, cognitive impairment, and emotional behavioural impact throughout different stages of development and rehabilitation impose great challenges. In the immediate and long-term rehabilitation pathway, high levels of family stress and caregiver burden are reported. Several studies found many of the family needs after ABI were often unmet or inadequately prioritised, including ABI information, medical and practical support, emotional and psychosocial support, stress management and school support.[1,2] Compared to adults with acquired cognitive impairment (ACI), cognitive impairment in children may not be immediately obvious after injury but becomes apparent as the child grows and faces increasing challenges.

Translation and validation of the Family Needs Questionnaire – Paediatric Version (FNQ-P)

The Family Needs Questionnaire (FNQ) was first designed for caregivers of adults with ABI to gather information on family needs and to evaluate how well these needs have been met.[3] It was adapted and modified for use in families with children or adolescents with ABI by the modified Delphi technique conducted by The Holland Bloorview Hospital team and was named the Family Needs Questionnaire – Paediatric Version (FNQ-P).[4] It included additional items related to family involvement and incorporated a set of five school-related items. With it, clinicians can assess the extent to which needs have been met, thereby facilitating services evaluation, informing programme planning and enabling ongoing monitoring of families' changing needs over time. The FNQ-P has a strength-based and family-centered focus, which is consistent with the delivery of family-centered care. Its test-retest reliability has been demonstrated to be good in the multi-site validation study.[5] It was also translated into various languages, such as, Swedish, Spanish and Norwegian.

There are 40 items across 6 categories in FNQ-P: Health information (n=10 items), Emotional support (n=6), Instrumental support (n=4), Professional support (n=6), Community support (n=6) and Involvement of care (n=8) (Table 1). Parents or the main caregivers rate needs on a 5-point response scale ranging from "1" to "5" (1 = not at all met, 2 = met very little, 3 = somewhat met, 4 = met a lot, 5 = completely met) (Table 2). For needs that are not applicable or a priority at the time of administration, the participant can check the "not needed" option, which scores "0". The total FNQ-P score and the category scores are calculated by adding up the scores of all the

items. The mean total FNQ-P and the mean FNQ-P category scores are calculated by adding up all the scores of items divided by number of valid items in the questionnaires and categories, respectively. Higher scores reflect more needs are met and vice versa.

Table 1. Categories and sample items from FNQ-P

Category	Number of items	Sample item
Health information	10	Q2. To have information on how the brain injury will impact my child' s abilities in the future and into adulthood, including information on prognosis.
Emotional support	6	Q11. To share my feelings about my child with someone who has gone through a similar experience.
Instrumental support	4	Q17. To have help to educate and involve family and friends to share my challenges and responsibilities for my child.
Community support	6	Q23. To be given information about how to access future support and services (e.g., transition to adulthood, employment, post-secondary).
Professional support	6	Q27. To have help to understand the impact of my child' s brain injury on my family in the present and future.
Involvement with care	8	Q33. To feel that medical or rehabilitation staff show respect for my child's and family's needs or wishes.

Table 2. Five-point response scale of FNQ-P

How much has each need been met? Please **circle the number** that shows **how much** each of the following needs has been met. Or, **check the box** if it is not a need that you have at this time.	Not needed	1. Not at all met	2. Met very little	3. Somewhat met	4. Met a lot	5. Completely met
#. Advice on how to stay healthy.	☐	1	2	3	4	5

Translation included forward translation into traditional Chinese, reconciliation, backward translation and pilot testing. The interpretability, comprehensibility of the items, acceptability of the questionnaire and cultural adaptation were reviewed. Children or adolescents with ABI who have been assessed and managed by the multidisciplinary ACI team in the Child Assessment Service (CAS) in the past 15 years were recruited over the phone or during the assessment. Parents or caregivers completed the FNQ-P (Chinese) questionnaires, and selected families completed the second set of questionnaires to evaluate the test-retest reliability.

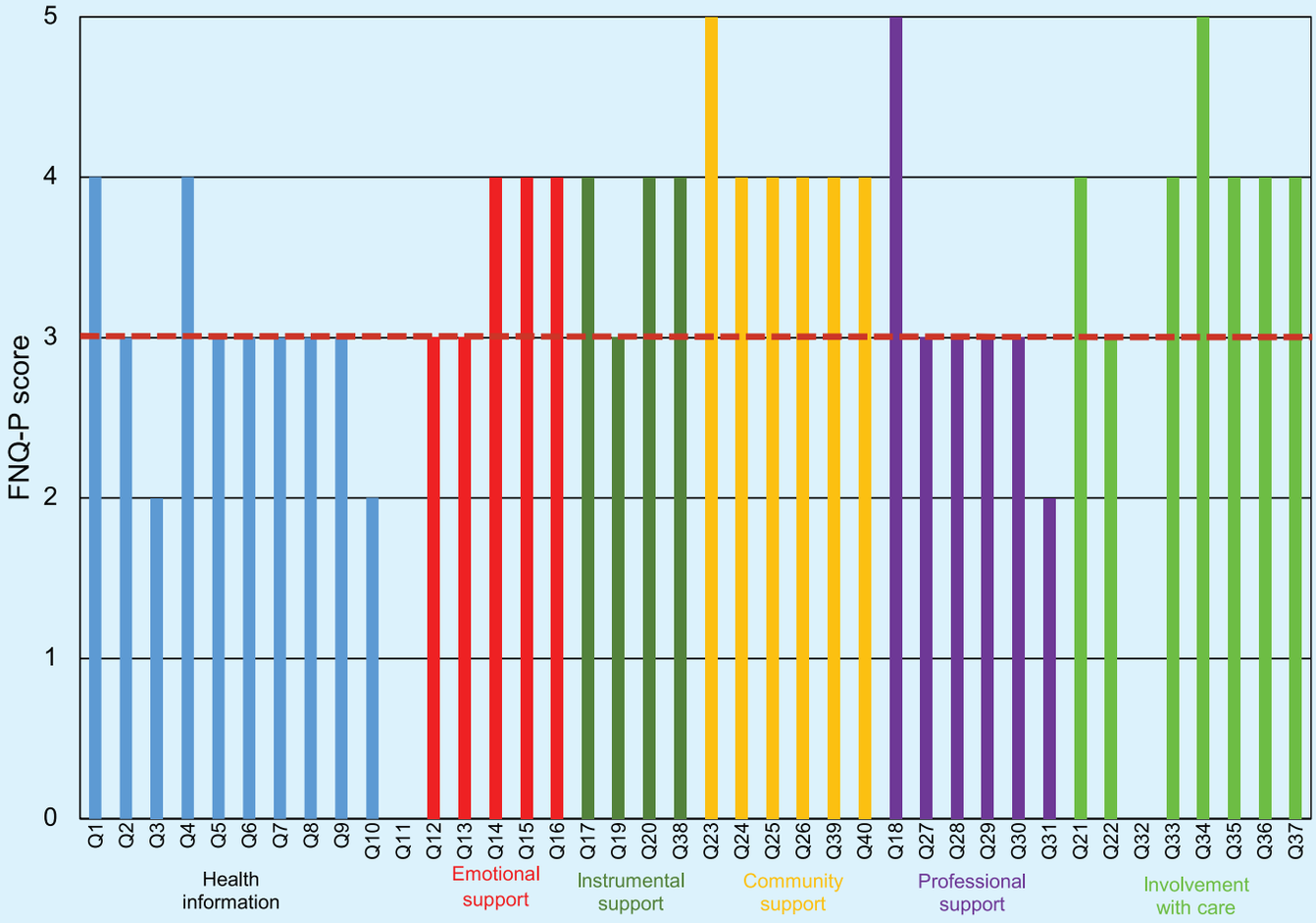
Seventy-nine questionnaires out of 108 were returned. The response rate was 73%. Twenty-three families completed the retest FNQ-P (Chinese) after a mean interval of 6.7 weeks. The mean age of the children or adolescents was 10.8 years old (SD 4.1 years, range 3.3–17.8 years). The mean age at the time of the acquired brain injury (ABI) was 4.4 years (SD 3.9 years, range 0–15.8 years), and the mean time post-injury was 6.4 years (SD 3.4 years, range 0.7–14.1 years). Around half of them were boys (49%, n=38). Regarding the type of ABI, around half (49%, n=38) suffered from primary or secondary brain tumors. Around 20% (n=15) had intractable epilepsy, 9% (n=7) suffered from strokes or intracranial haemorrhage, 9% (n=7) suffered from traumatic ABI and 8% (n=6) had meningitis or encephalitis.

The total FNQ-P (Chinese) achieved Cronbach's alpha (α) of 0.97, and the α estimates for all the subscales ranged from 0.75 to 0.92, suggesting good to excellent internal consistency. For the total FNQ-P (Chinese) score, the Intraclass Correlation Coefficient (ICC) achieved 0.92 (95% confidence interval 0.81–0.97), which showed good stability in the test-retest scores. The construct validity was assessed by examining the relationship between the total FNQ-P score and all the subscale scores of the Measure of Processes of Care (MPOC-20).[6] The total FNQ-P (Chinese) score showed a positive, moderate and significant correlation with all the MPOC-20 subscale scores (r=0.58–0.67, all p<0.001). In conclusion, the FNQ-P (Chinese) shows good psychometric properties, and its use in the Chinese population is supported.

Application of the FNQ-P (Chinese) in the local setting

CY, an 11-year-old primary school student, suffered from a left frontal lobe haemorrhage at the age of 10. His worst Glasgow Coma Scale (GCS) was 9/15. A computed tomography (CT) scan showed a big left frontal intracranial haematoma with mass effect, and a craniotomy for clot evacuation was performed. Postoperatively, he experienced suspected seizure activity characterised by limb twitching and was administered a prophylactic anticonvulsant. At an initial assessment by our team five months post-injury, he

Figure 1. FNQ-P (Chinese) scores distribution in different family need domains of CY



presented right hemiparesis, poor right upper limb control and impaired bilateral coordination, which affected his daily activities and handwriting. He was also reported to have poor memory and emotional lability following the brain injury. Assessment by a clinical psychologist revealed average intelligence but significant variability in different composite indices. CY exhibited neurocognitive impairments in verbal functioning and processing speed. Memory tests revealed better visual memory but weak auditory memory. Speech and language assessment revealed a significant language disorder associated with brain injury. The FNQ-P (Chinese) was administered to address the family's needs and to aid goal setting and rehabilitation planning.

The FNQ-P (Chinese) was completed by the father, who was the main caregiver; only two items (Q11 and Q32) were rated "not needed". More than half (21 items, 55%) of the family needs were rated "met a lot" or "completely met", indicating a satisfactory level of family need fulfilment. Fourteen items (37%) were rated "somewhat met", which indicated fair satisfaction. Among the different family need domains, "Health information" and "Professional support" were less fulfilled (Figure 1). Five months post-injury, the family received disease information and ABI education during their hospital stay and outpatient visits; however, the family expressed a need for more information. One item regarding information about the child's care needs was rated "met very little", reflecting inadequacy in the provision of information. Other information concerning the expected rehabilitation plan, medical care of ABI and physical and cognitive challenges of ABI were rated fair satisfaction. Our multidisciplinary team made good use of FNQ-P to tailor information sharing, formulate the management plan and set goals with CY and his parents. Among the "Professional support" family needs, the item concerning strategies and coping tools for managing emotional or behavioural problems was rated "met very little". Based on the FNQ-P result and information from parents, our

team identified the family's prioritised needs and provided additional guidance on coping strategies for ABI-related emotional or behavioural problems.

Given CY's motor problems, including right hemiparesis, weak handwriting and difficulties with self-care, he was recommended to study in a special school for children with physical disabilities, where his motor and learning needs could be adequately addressed through specialised education. Our multidisciplinary team held the case conference with CY and his parents to share the assessment results, suggest the school recommendations and set goals. After discussing the advantages and disadvantages of mainstream and special schools, the parents preferred that CY to remain in and repeat a grade at his original mainstream school. Our team suggested various recommendations and remedial support for CY's reintegration. Continual updates with CY's parents and close liaison with the school's educational psychologist revealed certain difficulties and obstacles. Shortly after returning to school, a school conference with the school principal, educational psychologist, teachers, speech therapist, parents and our team members was held. The team provided detailed explanations of CY's medical, neurocognitive and motor difficulties to the school team. School support and accommodation in various aspects such as health, curriculum and homework were worked out together. Our team would continue to monitor his progress to facilitate further planning for his transition to secondary school.

Conclusion

The case illustrates the application of the FNQ-P (Chinese) in assessing the family needs of children and adolescents with ABI. It is a useful adjunct in the systematic assessment of family needs during the rehabilitation process, facilitating service planning, goal setting and transition planning. During follow-up, families could reflect on and be provided with a roadmap of their changing needs throughout the care continuum. FNQ-P (Chinese) can be utilized more frequently in the assessment and rehabilitation planning of children and adolescents with ABI within the CAS and other relevant local settings.

References

1. Gan C, Gargaro J, Brandys C, Gerber G, Boschen K. Family caregivers' support needs after brain injury: a synthesis of perspectives from caregivers, programs, and researchers. NeuroRehabilitation. 2010;27(1):5–18. doi:10.3233/NRE-2010-0577.

2. Keetley R, Radford K, Manning JC. A scoping review of the needs of children and young people with acquired brain injuries and their families. Brain Inj. 2019;33(9):1117–1128. doi:10.1080/02699052.2019.1637542. Epub 2019 Jul 7.

3. Armstrong K, Kerns KA. The assessment of parent needs following paediatric traumatic brain injury. Pediatr Rehabil. 2002 Jul–Sep;5(3):149–60. doi:10.1080/1363849021000039353.

4. Gan C, Wright FV. Development of the family needs questionnaire – pediatric version [FNQ-P] – phase I. Brain Inj. 2019;33(5):623–632. doi:10.1080/02699052.2019.1566836. Epub 2019 Jan 24.

5. Gan C, Van't Hooft I, Brookes N, Prasauskiene A, Wales L, Wright FV. First stage international validation of the pediatric family needs questionnaire (FNQ-P). Brain Inj. 2020 Jul 2;34(8):1074–1083. doi:10.1080/02699052.2020.1782474. Epub 2020 Jun 28.

6. Wang M, Petrini MA, Guan Q. Evaluation of family-centered services from parents of Chinese children with cerebral palsy with the Measure of Processes of Care. Child Care Health Dev. 2015 May;41(3):408–15. doi:10.1111/cch.12183. Epub 2014 Jul 31.

The Paediatric Neurocognitive Interventions Model and Its Local Application

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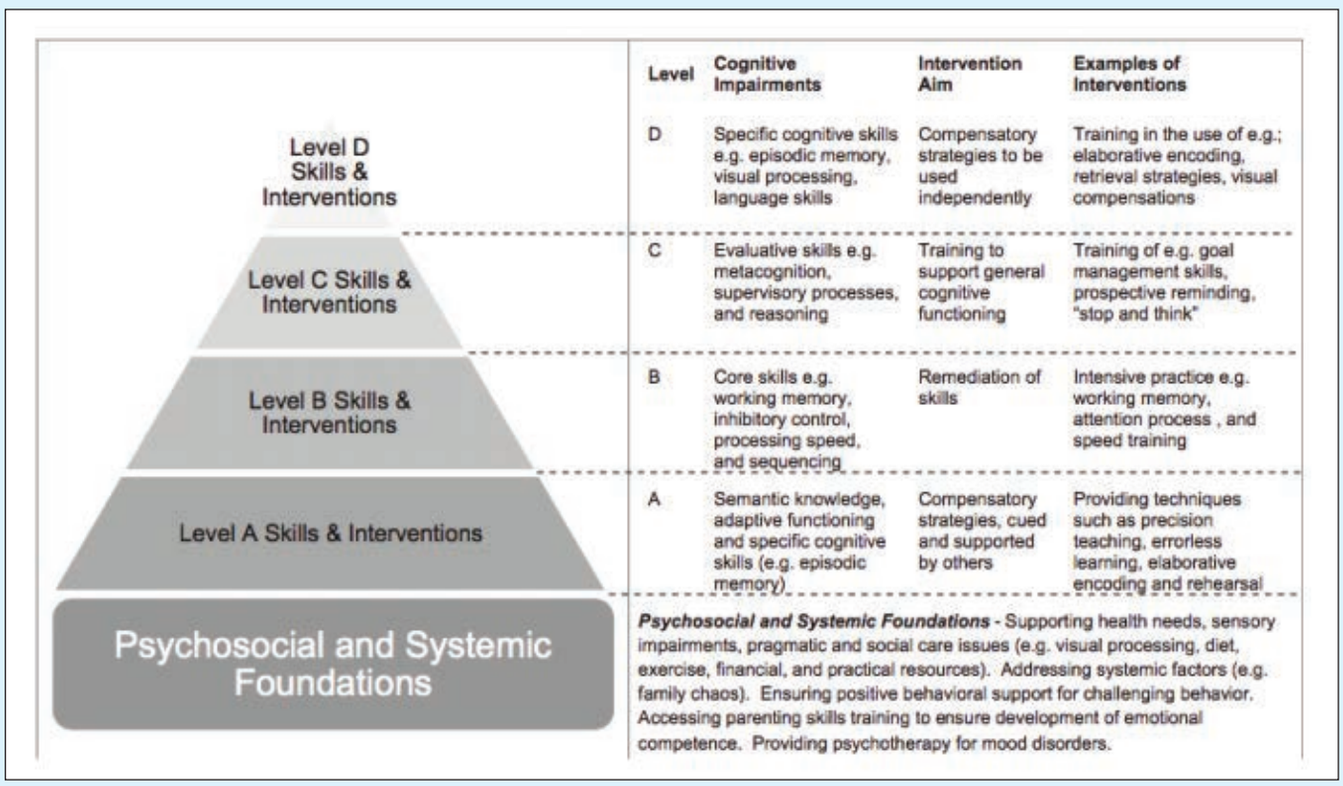
The Paediatric Neurocognitive Interventions (PNI) model[1] (Figure 1) is a valuable conceptual framework that guides the formulation of a young person's cognitive difficulties post injury; takes account of the heterogeneity of brain injury sequelae and crucial developmental factors that complicate assessment and intervention; and shows which cognitive rehabilitation techniques should be considered, when and in what order they should be applied, how they relate to psychosocial needs and how they can be evaluated.[2]

The model is hierarchical and accommodates the developmental level of the child, the maturation of their brain and the functioning of those supporting them. Level A describes intensive, supported interventions that help the development of semantic knowledge, adaptive functioning and specific cognitive skills such as memory. Level B describes the remediation of cognitive processes such as inhibitory control, working memory and attention. Level C describes interventions to increase skills such as awareness, problem-solving and prospective memory. Level D describes compensatory strategies that can be *independently* used by an individual with a brain injury. Limond and Adlam[1,2] recommend that cognitive processes are comprehensively assessed and considered in the context of cognitive development and the individual's wider psychosocial environment.

The importance of the psychosocial foundations for pediatric neurorehabilitation

Before considering any intervention with a young person, it is essential to consider the psychosocial context in which the injury occurred and the systemic foundations on which the intervention will be built, according to their level of dependence on their carers. A primary-school-aged child is unlikely to have the skills to

Figure 1. Paediatric neurocognitive interventions model



Level	Cognitive Impairments	Intervention Aim	Examples of Interventions
D	Specific cognitive skills e.g. episodic memory, visual processing, language skills	Compensatory strategies to be used independently	Training in the use of e.g.; elaborative encoding, retrieval strategies, visual compensations
C	Evaluative skills e.g. metacognition, supervisory processes, and reasoning	Training to support general cognitive functioning	Training of e.g. goal management skills, prospective reminding, "stop and think"
B	Core skills e.g. working memory, inhibitory control, processing speed, and sequencing	Remediation of skills	Intensive practice e.g. working memory, attention process , and speed training
A	Semantic knowledge, adaptive functioning and specific cognitive skills (e.g. episodic memory)	Compensatory strategies, cued and supported by others	Providing techniques such as precision teaching, errorless learning, elaborative encoding and rehearsal
	Psychosocial and Systemic Foundations - Supporting health needs, sensory impairments, pragmatic and social care issues (e.g. visual processing, diet, exercise, financial, and practical resources). Addressing systemic factors (e.g. family chaos). Ensuring positive behavioral support for challenging behavior. Accessing parenting skills training to ensure development of emotional competence. Providing psychotherapy for mood disorders.		

independently access Level D. In fact, it is rare (in paediatrics) for intervention at Level D alone to be sufficient following a significant brain injury.

There is evidence that outcomes for children can be better when intervention is delivered by parents trained in delivering rehabilitation in comparison to children receiving therapy once a week.[3] Not only are the parents able to deliver this rehabilitation in the children's participatory contexts, but they are able to do this with greater frequency. However, we have to consider the resources of those we would like to deliver our interventions. This requires an assessment of the resources of parents and school staff as well as the cognitive functioning of the young person. Our data in Cambridge shows that it is normal for parents of children who have suffered traumatic brain injuries to have experienced an acute stress response when their child is in hospital (Woolgar, in press). Indeed, the diagnostic criteria for posttraumatic stress disorder include the experience of a life-threatening event of someone you love. For example, up to 68% of mothers and 57% of fathers have posttraumatic stress symptoms (PTSS) in the moderate to severe range one month postdiagnosis of their child's cancer.[4]

In simple terms, it is difficult for a young child to engage in Level A, B, C or D if their parents are terrified to leave the house, struggling to witness their child's difficulties and are re-experiencing a traumatic event. What happens when the caregiver is suffering from PTSD? The PNI model helps us to think about what resources those supporting and delivering the interventions have. Is there a teaching assistant available at school? Have they delivered "precision teaching" before? Do they have availability to do this at the required frequency? What support would they need to do this with the young person?

The PNI model emphasises the need to ensure base-level needs are being met before considering interventions at other levels. The child's psychosocial environment needs requisite stability and resources to support rehabilitation goals, and much of the rehabilitation team's initial work may need to focus here. It may also be possible to work on multiple levels simultaneously.

Using the model to formulate and re-formulate

There are other models that help us make sense of a young person's difficulty after a brain injury,[5,6] but the PNI model is the only model that directly addresses the assessment and intervention for a young person's cognitive functioning. We may set out to improve a young person's working memory with a training programme, but without the compensatory adaptive skills—or the carer to pay for the Wi-Fi—success is unlikely. Formulations evolve over time. We continue to learn more information, and it is often in the implementation of an intervention that our formulation deepens and we are able to come back to the model to reconsider our best approach to support young people with their goals.

Application of the PNI model in the local setting

Below are two cases to illustrate the application of the PNI model in the Child Assessment Service (CAS) which could guide our team to formulate, monitor and review our management and rehabilitation goals.

Case one: CC

CC was a child who sustained a severe traumatic brain injury after being hit by a vehicle, witnessed by the family, at the age of nine. On first assessment by our team five months post-injury, he was found to have cerebellar ataxia and spasticity in both ankles. Cognitively, he was assessed with borderline intelligence as well as

impairment in memory, attention and executive functioning. The family was solely supported by the mother, who was a single parent and had a major chronic illness. Although the mother attempted to present a tough exterior, she appeared overwhelmed by the child's aggressive outbursts (e.g., throwing objects and hitting family members), the need to take care of sibling's emotions (e.g., survivor's guilt) as well as the legal proceedings relating to the accident.

Based on the PNI model, the primary rehabilitation goal was thus to ensure that the psychosocial foundation was strengthened. Specifically, we ensured that the mother had an easy point of access to support via our case manager to establish a trusting relationship with our team. With this foundation, we shared the interdisciplinary formulation of CC with her to make sense of CC's current challenges. The family was receiving psychotherapy from a clinical psychologist at the hospital, focusing on their psychological adjustment and family dynamics following the accident. Meanwhile, targeted management of CC's mood and behavioural problems had not yet been implemented, and he was thus referred to the child psychiatric service. He was diagnosed with organic personality disorder there, and medication was prescribed for mood management.

Several team conferences were held with CC's school to facilitate their understanding of his physical and neurocognitive profiles. Advice was given by our therapists to ensure the school environment was safe and conducive to his physical rehabilitation. External aids such as visual cues, social stories and emotion cards (Level A) were also discussed to facilitate CC's emotional control and learning. As academic stress was identified as a major trigger of CC's emotional meltdowns, liaison with school was made to allow CC to repeat a grade in order to alleviate pressure.

At a follow-up review three years later, in preparation for CC's transition to secondary school, the mother reported that her own mood was more settled as CC's behavior and family dynamics appeared more manageable. Meanwhile, standardised testing indicated that CC had impaired theory of mind, which appeared to contribute to increasing difficulties, including inappropriate social behaviour towards the opposite sex. Goal setting with CC as a teenager and mother was thus made to heighten his awareness in deciphering social cues (Level C). Recent update on CC's progress reported satisfactory coping to date, with a review planned to support his transition to adulthood.

Case two: KF

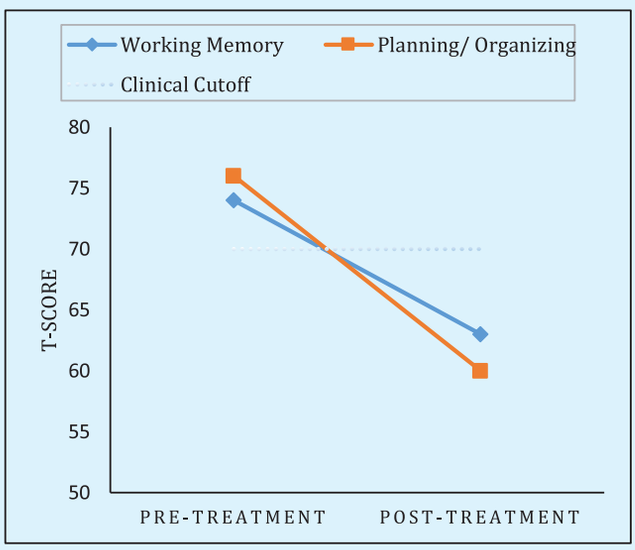
The second case was KF, an eight-year-old primary school student suffering from bilateral intraventricular haemorrhage due to arteriovenous malformation and nodal aneurysm. Parents noted she had exacerbated difficulties in her everyday memory following the brain injury. She would frequently forget to bring homework back to school, misplace her belongings and forget to follow through with daily routines. She seemed to have difficulty recalling what she had done at school. On assessment, KF's intellectual functioning scores were in the average range. Daily memory functioning was assessed to be mildly to moderately impaired, while retrieval cues could improve her performance. The profile on the Behavior Rating Inventory of Executive Function-2 (BRIEF-2), as rated by the mother, showed clinically elevated scores on the Working Memory and Planning/Organizing scales, with T-scores of 74 and 76, respectively).

KF's parents were supportive, stable and committed to parent-led intervention outside the clinic. With these psychosocial foundations in place, treatment sessions with the family were able to focus on training KF to make use of compensatory aids, including a memory notebook, checklists, environmental cues as well as mnemonics (e.g., chunking, storytelling, visualisation and association) and organisational strategies (e.g., mind

maps) (Level A) to improve her daily memory performance.

The use of promptings and systematic reinforcement were discussed with the parents. They were also taught how to model and support KF in metacognitive skills in evaluating the situation and selecting an appropriate strategy to tackle the problem (Level C). Progress was good at the beginning as the parents supported the child in organising her workspace, generating lists and using cues to aid her memory. However, as treatment progressed, the parents tried to withdraw promptings prematurely in the hope that the child could remember to use the strategies independently. The PNI model was thus reiterated to the parents in illustrating the importance of scaffolding by adjusting the levels of cueing to encourage independent use at a later stage (Level D). At the end of the intervention, KF could take the initiative to pack her school bag at a specific time of the day and remind herself of the necessary items based on memory strategies generated by herself. She was also able to recall and report school happenings independently utilising the organisational strategy of the 5W1H (what, when, where, who, why, how). The BRIEF-2 outcome measure, as completed by the mother, indicated improvement in KF's scores on the Working Memory and Planning/Organizing scales, with T-scores of 63 and 60, respectively (Figure 2).

Figure 2. Treatment outcome on BRIEF-2



Conclusion

These two cases illustrate the application of the PNI model in the rehabilitation of children following an acquired brain injury. With secure psychosocial foundations, the team was able to start working at Level A for KF, but it was intervention for those psychosocial foundations that was required for work to begin with CC. When KF's family wished to move to Level D with the independent use of compensatory strategies, help in understanding the steps to this could be given. The PNI model is a useful model for planning interventions when there can be so many complex needs following childhood acquired brain injury.

Remarks: Identifying details of the cases were changed to protect the clients' confidentiality.

References

1. Limond J, Adlam AL, Cormack M. A model for pediatric neurocognitive interventions: considering the role of development and maturation in rehabilitation planning. Clin Neuropsychol. 2014;28(2):181–98. doi:10.1080/13854046.2013.873083.

2. Limond J, Adlam ALR. Cognitive interventions for children with acquired brain injury. In: Reed J, Byard K, Fine H, editors. Neuropsychological Rehabilitation of Childhood Brain Injury: A Practical Guide. Palgrave Macmillan Publishers Limited: Hampshire; 2015. p. 82–105.

3. Braga LW, Da Paz AC, Ylvisaker M. Direct clinician-delivered versus indirect family-supported rehabilitation of children with traumatic brain injury: a randomized controlled trial. Brain Inj. 2005 Sep;19(10):819–31. doi:10.1080/02699050500110165.

4. Kazak AE, Boeving CA, Alderfer MA, Hwang WT, Reilly A. Posttraumatic stress symptoms during treatment in parents of children with cancer. J Clin Oncol. 2005 Oct 20;23(30):7405–10. doi:10.1200/JCO.2005.09.110.

5. Watson S, Gracey F. Assessment in paediatric acquired brain injury. In: Jim J, Cole E, editors. Psychological Therapy for Paediatric Acquired Brain Injury: Innovations for Children, Young People and Families. Routledge: London; 2020. p. 43–69.

6. Jim J, Liddiard H. Using biopsychosocial formulations in paediatric neurorehabilitation. In: Jim J, Cole E, editors. Psychological Therapy for Paediatric Acquired Brain Injury: Innovations for Children, Young People and Families. Routledge: London; 2020. p. 70–90.

Children with Post-COVID-19 Condition

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Definition

Since the World Health Organization (WHO) declared COVID-19 a pandemic in March 2020, there have been over 777 million cases and 7 million deaths globally.[1] COVID-19 can severely damage multiple organs in children, causing serious complications such as multisystem inflammation syndrome (MIS), acute encephalitis and even death. After initial infection, some children, including those who experienced mild or asymptomatic disease, develop persistent symptoms or new symptoms. There are different terminologies such as Long COVID, postacute COVID-19 and postacute sequelae of SARS-CoV-2 infection (PASC). In February 2023, the WHO defined post-COVID-19 condition (Long COVID) as the continuation or development of new symptoms three months after the initial SARS-CoV-2 infection, with symptoms lasting for at least two months and not attributable to another diagnosis.[2] The National Institute for Health and Care Excellence (NICE)[3] also defined post-COVID-19 syndrome as "signs and symptoms that develop during or after an infection consistent with COVID-19, continue for more than 12 weeks and are not explained by an alternative diagnosis". This is different from ongoing symptomatic COVID-19, which is characterised by signs and symptoms of COVID-19 from 4 to 12 weeks.

Prevalence

The prevalence of post-COVID-19 in children varies considerably between studies. From a systematic review and meta-analyses published in June 2022, the pooled prevalence of post-COVID-19 in children and adolescents was 25.25%.[4] The five most prevalent clinical manifestations were mood symptoms (16.5%), fatigue (9.66%), sleep disorders (8.42%), headache (7.84%) and respiratory symptoms (7.62%). Another meta-analysis and systematic review, published in May 2023 and based on 40 studies, found the pooled prevalence of any post-COVID-19 condition was 23.36%.[5] The most widely reported symptoms included generalised symptoms, respiratory, neurological and psychiatric symptoms. In an overview published in May 2024, the overall prevalence of post-COVID-19 in children varies from 4% to 66%.[6] Another recent narrative review reported estimates of around 10% to 20% within the first 6 months after acute infection.[7] The wide variability could be attributed to the heterogeneous characteristics such as the different study designs, sample sizes and case definitions, varying follow-up durations and different assessment modalities.

Pathophysiology

There are many theories on the causative mechanisms of post-COVID-19 presenting with neurological and neuropsychiatric symptoms, though it is not yet fully understood. The pathophysiology is attributed to several factors—such as acute organ damage, viral persistence in tissue, underlying autoimmune mechanisms and chronic neuroinflammation—that cause persistent symptoms.[8] With a high prevalence of neurological and neuropsychiatric symptoms in post-COVID-19, it was suggested that SARS-CoV-2 is highly neurotropic.[9] It is also important to identify potential risk factors for post-COVID-19 and understand patient susceptibility. The literature reveals that females, children older than 10 years, multisystem inflammatory syndrome, severe clinical symptoms in the acute disease, poor premorbid physical or mental health and comorbid allergic diseases are associated with an increased prevalence of post-COVID-19.[5]

Symptomatology

The symptomatology of post-COVID-19 is heterogeneous in both clinical presentation and time course and can affect any organ system. These symptoms may reflect persistent symptoms from the acute COVID-19 infection, such as loss of taste or smell and headache. They may reflect exacerbation of underlying conditions such as mental health and neurodevelopmental conditions. Moreover, there are bio-psycho-social and environmental factors that contribute to the manifestation (Table 1).

Table 1. Symptoms and signs of post-COVID-19 classified by system

Systemic / constitutional	Fatigue (generalised, exercise intolerance or post-exertional malaise), sleep disturbances, fever
Neuropsychiatric	Anxiety, depression/low mood, increased somatic symptoms, school avoidance
Autonomic dysfunction	Dizziness, orthostatic intolerance, headache, nausea, syncope
Neurological	Headache, tremulousness, numbness, difficulty with attention, difficulty with memory, cognitive fatigue “brain fog”
Respiratory	Shortness of breath or dyspnea, chest pain or tightness, cough, exercise intolerance
Cardiac	Tachypnoea/palpitation, dizziness, syncope, chest pain, exercise intolerance
Gastrointestinal	Nausea/vomiting/reflux, abdominal pain, bowel irregularities (constipation/diarrhea), lack of appetite
Musculoskeletal	Weakness, muscle/bone or joint paindisturbances, fever
Otolaryngology	Abnormal smell or taste

Table 2. Summary of neurological post-COVID conditions

Neurological	Neuropsychiatric/neurocognitive
Headache, dizziness	Anxiety
Fatigue	Depression
Sensory problems (numbness)	PTSD
Motor problems (balance, poor handwriting, muscle weakness, coordination)	Regression
Sleep disorder (insomnia, hypersomnia, poor sleep quality)	Cognitive impairment symptoms (brain fog, attention loss, memory impairment)
Speech/language problems	Confusion, delirium, hallucination
Visual/hearing problems	Weak social skills
	Temper outburst/mood swings

In children, post-COVID-19 symptoms cluster into three groups: (1) fatigue, pain and mood swings; (2) ongoing respiratory symptoms; (3) cognitive problems (Table 2). Neurological and neurocognitive domains are commonly affected, potentially causing serious impairment with a substantial impact on the child. Not only is daily functioning affected, but well-being and mental health are also affected by neurological post-COVID conditions.[10]

Fatigue is one of the most common symptoms of neurological post-COVID conditions. The prevalence is variable in the review and meta-analytic studies, in the range of 10% to 50%. Of note, some studies found some of the children experienced persistent fatigue after 6 to 12 months of acute infection, which might have a serious impact on daily activities. Multiple factors may contribute to the symptomatology, such as systemic inflammation, sleep disturbances and inactivity, as well as other factors such as pandemic-related restrictions.

Cognitive impairment symptoms are common, such as "brain fog". It comprises characteristic symptoms such as poor concentration, fuzziness of thought, confusion, slowed thinking and mental fatigue. Other domains, such as executive function, memory, attention and learning, are also disturbed, and studies have shown variable recovery times.

The COVID-19 pandemic has also had a significant detrimental impact on people's mental health, including depression, anxiety and mood instability. These may be related to the direct effect of the infection or immune response, although the psychosocial factors also contributed, for example, pandemic-related restrictions, school suspension and parental stress. Although the problem appeared to have onset after the pandemic, a significant proportion of the population experienced it as a worsening of underlying neurodevelopmental or mood conditions. In a large cross-sectional study of Hong Kong families with children aged 2 to 12 years, the risk of psychosocial problems was higher in children with special educational needs, accompanied by elevated parental stress.[11] Thus, the neuropsychiatric conditions associated with COVID-19 should be well addressed, and targeted interventions should be formulated.

Management

With an enhanced understanding of risk factors and the trajectory of post-COVID-19 conditions, research gaps were identified in the field. In July 2023, the RECOVER Initiative (REsearching COVID to Enhance Recovery), established by the U.S. National Institutes of Health, was activated and launched an invitation for enrollment in clinical trials for Long COVID conditions.[12,13] Overall studies with larger samples, longer follow-ups and the inclusion of control samples would be more appropriate. Due to the multi-organ involvement and potentially significant impact on everyday functioning, the management of post-COVID-19 conditions should be holistic, targeted and multi-disciplinary.

In the Child Assessment Service (CAS), in order to facilitate the assessment of these children, a post-COVID-19 synopsis was developed based on literature and evidence (Appendix 1). The synopsis comprised three sessions, including questions relevant to the physical impact of COVID-19 (covering both neuropsychiatric symptoms and medical symptoms). It is completed by the referrer to aid the arrangement of the first intake and subsequent assessment in CAS.

Conclusion

Although 4 years have passed since the start of the pandemic, much about COVID-19 infection remains to be discovered. Post-COVID-19 conditions represent a significant public health concern, but there are no guidelines to address the diagnosis and management. More research and international collaboration are needed to fill knowledge gaps and develop management guidelines that support optimal patient care and minimise the public health impact of COVID-19 infection.

References

1. World Health Organization. Coronavirus disease (COVID-19) pandemic [Internet]. Geneva: WHO; 2025. Available from: https://www.who.int/emergencies/diseases/novel-coronavirus-2019 (Assessed on 1 Apr 2025).

2. World Health Organization. A clinical case definition for post COVID-19 condition in children and adolescents by expert consensus, 16 February 2023 [Internet]. Geneva: WHO; 2023. Available from: https://www.who.int/publications/i/item/WHO-2019-nCoV-Post-COVID-19-condition-CA-Clinical-case-definition-2023-1 (Assessed on 1 Apr 2025).

3. National Institute for Health and Care Excellence. COVID-19 rapid guideline: managing the long-term effects of COVID-19 [Internet]. London: NICE; 2024. Available from: https://www.nice.org.uk/guidance/ng188 (Assessed on 1 Apr 2025).

4. Lopez-Leon S, Wegman-Ostrosky T, Ayuzo Del Valle NC, Perelman C, Sepulveda R, Rebolledo PA. Long-COVID in children and adolescents: a systematic review and meta-analyses. Sci Rep. 2022 Jun 23;12(1):9950. doi:10.1038/s41598-022-13495-5.

5. Zheng YB, Zeng N, Yuan K, Tian SS, Yang YB, Gao N. Prevalence and risk factor for long COVID in children and adolescents: A meta-analysis and systematic review. J Infect Public Health. 2023 May;16(5):660–672. doi:10.1016/j.jiph.2023.03.005.

6. Calcaterra V, Zanelli S, Foppiani A, Verduci E. Long COVID in Children, Adults, and Vulnerable Populations: A Comprehensive Overview for an Integrated Approach. Diseases. 2024 May 6;12(5):95. doi:10.3390/diseases12050095.

7. Rao S, Gross RS, Mohandas S, Stein CR, Case A, Dreyer B. Postacute Sequelae of SARS-CoV-2 in Children. Pediatrics. 2024 Mar 1;153(3):e2023062570. doi:10.1542/peds.2023-062570.

8. Ha EK, Kim JH, Han MY. Long COVID in children and adolescents: prevalence, clinical manifestations, and management strategies. Clin Exp Pediatr. 2023 Nov;66(11):465–474. doi:10.3345/cep.2023.00472.

9. Condie LO. Neurotropic mechanisms in COVID-19 and their potential influence on neuropsychological outcomes in children. Child Neuropsychol. 2020 Jul;26(5):577–596. doi:10.1080/09297049.2020.1763938.

10. Howe de la Torre S, Parlatini V, Cortese S. Long-term central nervous system (CNS) consequences of COVID-19 in children. Expert Rev Neurother. 2023 Jul-Dec;23(8):703–720. doi:10.1080/14737175.2023.2239500.

11. Tso WWY, Wong RS, Tung KTS, Rao N, Fu KW. Vulnerability and resilience in children during the COVID-19 pandemic. Eur Child Adolesc Psychiatry. 2022 Jan;31(1):161–176. doi:10.1007/s00787-020-01680-8.

12. National Institutes of Health (NIH). RECOVER Clinical Trials [Internet]. Bethesda (MD): NIH; 2024. Available from: https://trials.recovercovid.org (Assessed on 1 Apr 2025).

13. Gross R, Thaweethai T, Rosenzweig EB, Chan J, Chibnik LB, Cicek MS. Researching COVID to enhance recovery (RECOVER) pediatric study protocol: Rationale, objectives and design. medRxiv [Preprint]. 2023 May 12:2023.04.27.23289228. doi:10.1101/2023.04.27.23289228. Update in: PLoS One. 2023 Jun 23;18(6):e0286297. doi:10.1371/journal.pone.0286297.

Name: _____
Sex: F/M Age: _____
ID: _____

Department of Health

Child Assessment Service

Post-COVID 19 synopsis (to be filled by referrer)

Reason for referral: _____ **CAC: _____**
(refer to patient address and center catchment)

Section 1. Questions relevant to the physical impact of COVID-19		
✓	**Questions**	**Please circle or specify:**
	Age when infected COVID-19?	
	How was it diagnosed?	Nucleic acid test/ serum antibody/ RAT/ clinical diagnosis with known exposure
	Clinical manifestation?	Asymptomatic
		Mild sx.: fever, cough, sore throat, malaise, headache, myalgia, nausea, vomiting, diarrhea, anosmia, dysgeusia
		Moderate sx.: croup, bronchiolitis, pneumonia
		Severe sx.: acute respiratory distress, septic shock, cardiac shock, encephalopathy, stroke, encephalitis, multisystem inflammatory syndrome
	Type of healthcare sought?	Home care/ designated clinic/ GP/ private paediatrician/ tele-care
	Hospitalization? How long?	
	History of ICU care?	
	History of ventilator care?	
	Any post-intubation complications?	
	Treatment?	Symptomatic, Ritonavir-boosted nirmatrelvir (Paxlovid)/ Remdesivir, steroid, IVIg, others _____
	Prior health conditions?	Prior medical conditions:
		Prior mental/ behavioural issues: attention, anxiety/mood, developmental delay, learning, developmental delay, others_____
	Vaccination status?	No. of dose: Type:
	Any relevant imaging studies for COVID-19?	
Section 2a. Post COVID-19 conditions (neuropsychiatric symptoms)		
✓	**Symptoms**	**Please circle or specify:**
	Anxiety	
	Difficulty with attention/ concentration	
	Difficulty with memory	
	Cognitive fatigue/ “brain fog”	
	Difficulty with everyday tasks	
	Frequent mood swings	
	Weak social skills	
	Temper outburst/Aggressiveness	
	Hallucination	
	Obsessive-compulsive symptoms	
	Suicidal ideation	
	Headache	
	Psychosomatic symptoms	
	Developmental regression	
	Sensory problems	Numbness, sensitivities to noise and light
	Motor problems	Balance problems, handwriting, coordination problem, muscle weakness
	Speech/ language abnormalities	Comprehension, expressive communication skills, articulation
	Visual acuity/ hearing problems	
	Sleep problems	Tiredness, restless sleep with interruptions Increased nightmares/sleepwalking, daytime sleepiness
Section 2b. Post COVID-19 conditions (Medical symptoms)		
	Systemic/ constitutional	Fatigue, sleep disturbance, fever
	Autonomic dysfunction	Dizziness/ lightheadedness, orthostatic intolerance, headache, nausea, syncope
	Respiratory	Shortness of breath, chest pain or tightness, cough, difficulty with activity/ex. intolerance
	Cardiac	Palpitations or tachycardia, dizziness/lightheadedness, syncope, chest pain, difficulty with activity/ex. intolerance
	Musculoskeletal	Weakness, muscle/bone/joint pain
	Gastrointestinal	Nausea/ vomiting/ reflux, abdominal pain, bowel irregularities, weight loss, lack of appetite
	Otolaryngology	Abnormal smell or taste

Footnote:

World Health Organization (WHO) defines Post COVID-19 Condition (commonly known as long COVID), as the continuation or development of new symptoms 3 months after the initial SARS-CoV-2 infection, with these symptoms lasting for at least 2 months with no other explanation.

Signature: _____
Name/ Post:_____
Date:_____

Recent Publications and Scientific Presentations

Publications

Tong ASW, Wu MMF, Liu SKY. Clinical profile of children with Autism Spectrum Disorder (ASD), Attention Deficit Hyperactivity Disorder (ADHD) and dual diagnosis in Hong Kong. HK J Paediatr (New Series) 2025;30:69–75.

Tsang L, Lam L, Siu E, Lam C, Leung C. Communication needs and support for children and adolescents with complex communication needs requiring hospitalization in Hong Kong: an explorative study. Int J Qual Stud Health Well-being. 2025 Dec;20(1):2446025. doi: 10.1080/17482631.2024.2446025. Epub 2024 Dec 24.

Scientific Presentations

三歲定八十?! 先天與後天因素對兒童發展的影響 on 12 July 2025 at Pathways Foundation by Dr CHAN Ying-ting, Purdy.

Special learning needs education course in children with autism spectrum disorder on 10 April 2025 at HKU SPACE by LAM Ling, Lorinda.

Common development problems: developmental delay, language delay, dyslexia, ADHD and ASD on 28 January 2025 at Institute of Advanced Nursing Studies, Hospital Authority by Dr CHAN Wai-man.

Behavioral management for children with Autism Spectrum Disorder: Updates of intervention approaches on 14 December 2024 at St. Francis University by LAM Ling, Lorinda.

Certification Workshop of Copying Speed Test for Hong Kong Secondary Students (CST-HK) on 22 November 2024 at Hong Kong Occupational Therapy Association by CHUI Mun-yee.

A workshop on the assessment and care of high risk neonates – a multidisciplinary approach on 18 November 2024 at The University of Hong Kong – Shenzhen Hospital by Dr WONG Lai-yin.

Special learning needs education course in children with Autism Spectrum Disorder on 14 November 2024 at HKU SPACE by LAM Ling, Lorinda.

Intellectual assessment and assessment of adaptive functioning for children with physical and multiple disabilities on 6 November 2024 at M. Soc Sc. Programme (Clinical Psychology), Department of Psychology, The University of Hong Kong by CHEN Yuk-ki, Theresa.

Transition care in adolescents with cerebral palsy and recent development on 30 October 2024 at The Hong Kong Society of Child Neurology & Developmental Paediatrics Neruodevelopmental conference: Transition care in adolescents with cerebral palsy by Dr WONG Lai-yin.

Case presentation of adolescents with cerebral palsy on 30 October 2024 at The Hong Kong Society of Child Neurology & Developmental Paediatrics Neruodevelopmental conference: Transition care in adolescents with cerebral palsy by TAM Ka-yan.

Case presentation of adolescents with cerebral palsy on 30 October 2024 at The Hong Kong Society of Child Neurology & Developmental Paediatrics Neruodevelopmental conference: Transition care in adolescents with cerebral palsy by POON Yuen-ching, Candice.

Administration of WPPSI on 25 October 2024 at MSocSc (Clin. Psy./Edu/Psy.) Course Department of Psychology, The University of Hong Kong by TSANG Fung-king.

General approach to clinical assessment of children: assessment of behavioural, social and emotional aspects of children on 2 October 2024 at Department of Psychology, The University of Hong Kong by TSANG Yee-ha, Lucia.

Transition care for children with cerebral palsy on 12 Aug 2024 at RTHK 1 Healthpedia 《精靈一點》by Dr WONG Lai-yin.

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