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INVITED COMMENTARY

More than a feeling: understanding function and health related quality of life after pediatric neurocritical illness

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As more children survive neurocritical illness, stakeholders are fostering a focus on improving long-term survivorship for children and their families. This rational, yet ambitious, undertaking is further complicated by how a successful survivorship is defined and measured [1, 2]. Performance-based assessment of physical, emotional, and cognitive function informs referral to therapeutic services, such as physical therapy or behavioral health, with specific needs changing longitudinally [3]. Alternatively, optimizing an individual's quality of life (QOL) is arguably the ultimate priority for healthcare providers and families, after a desired goal of survival is assured [4, 5]. Generally speaking, QOL comprises an individual's perception of their position in life within their culture and in relation to their goals, expectations, standards, and concerns [5]. Health researchers often focus on the aspects of QOL that relate to how an individual feels about the status of their health, thus termed health related QOL (HRQOL). The relationship between these performance-based/clinician-observed measures and self-reported measures of QOL in children with neurocritical illness is important to explore to improve understanding of the impact of pediatric critical illness on the population and how we can help individuals achieve their recovery goals. The ability to identify children at risk for poor HRQOL outcomes is beneficial for the purposes of shared decision-making, setting future expectations and goals, and anticipating rehabilitation needs. Thus, the clinical implementation of routine longitudinal assessments that include both performance and HRQOL self-report outcomes to support patients and families through neurocritical illness recovery is innovative and research in this area shows it is vital.

In this issue of *Neurocritical Care*, Holding et al. [6] used validated measures to explore the relationship between health function, via the Functional Status Scale (FSS), and HRQOL, assessed via the PedsQL Generic Core Scales (aged 2–18 years) and Infant Scales (aged 1–24 months), in 195 children who survived neurocritical illness. The FSS was scored by physicians (unclear if by chart review or examination) at baseline, hospital discharge, and first visit to their center's innovative Pediatric Critical Care and Neurotrauma Recovery Program clinic (median time to follow-up 53 days). The proxy (parent/guardian) completed the HRQOL measure at the time of the clinic visit (no baseline assessment). The authors hypothesized that decreased functional status from baseline to hospital discharge would predict worse overall and individual domain HRQOL scores at the clinic visit.

They found 43% of proxies reported HRQOL ≥ 1 standard deviation lower than age-matched healthy children. Also, FSS scores were reported as three groups with reference to change from baseline: no score change (58%), 1–2 point increase (26%), and ≥ 3 point increase (16%). Their key finding was that change in FSS ≥ 3 at discharge was associated with worse overall HRQOL and worse physical HRQOL but not other HRQOL domains after adjustment for confounders in multivariable regression models. In addition, female sex was associated not only with lower HRQOL overall but also each domain. Although limited, prior literature on sex differences in

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pediatric HRQOL support this finding, with sex discrepancies increasing as children age [7, 8]. The authors posit that this finding could be due to hormonal differences or societal influences on gender behavior norms, with boys and parents of boys being less likely to report experiencing difficulties. It is also possible that proxies may perceive HRQOL of their sons and daughters differently.

This study's findings are well aligned with emerging literature on pediatric critical care survivorship [9, 10]. In multicenter prospective studies of children with community-acquired septic shock and respiratory failure, 35% and 20%, respectively, had worse HRQOL compared with their baseline status [11]. How should clinicians interpret this work? First, although the constructs are related, we should take care not to directly equate an individual child's functional status with their perceived HRQOL [5, 12, 13]. Second, individual child and family preferences and goals should drive medical decision-making [1, 14]. Third, consider that both function and satisfaction with functioning may change over time during the recovery period with rehabilitation and that children may view the latter differently than their parents/guardians (and ask the child whenever possible). Fourth, we should strive to implement routine clinical longitudinal assessments of function and HRQOL to adapt our plan of care to the child's new level of functioning and to identify and address unmet medical and social needs that contribute to a thriving survivorship for children and their families [15].

Further, some experts have reservations regarding the extent to which the measure used for this study captures HRQOL alone versus functional performance [5, 16, 17]. For example, asking the child how often it is hard for them to run is more aligned with a self-reported measure of physical functioning, whereas asking if they are satisfied with their ability to run is more aligned with HRQOL. This distinction is highlighted by their finding that, of the multiple multivariable regression models completed for each of the HRQOL domains, change in FSS score significantly improved the physical domain model only, and is further supported by their finding that children without a change in FSS score experienced lower HRQOL scores in emotional, social, and school domains.

These findings suggest there may be other factors influencing HRQOL aside from new impairments in health function, such as sleep, family functioning, and the lived environment. Other studies by this research group report > 50% of children experienced sleep disturbances 3 months post ABI, and fatigue severity was associated with worse QOL 20 years post pediatric TBI [18, 19]. LeBlond and colleagues [20] recently reported that among children ≤ 4 years, family functioning was significantly associated with HRQOL among TBI or orthotic injury populations 6 months after injury. Lastly, when exploring the link between functional status and functional performance or HRQOL, the environment in which the child lives may be a mediating factor and has been associated with parents' satisfaction with their child's participation in daily life activities within the home 6 months after pediatric critical illness [21, 22].

To summarize, Holding et al. [6] have provided foundational knowledge on the lived experiences of children as perceived by their parent/guardian and robustly highlighted the need for continued assessment and support post neurocritical illness. As we think about neurocritical illness survivorship as a continuum versus a single time point (i.e., hospital discharge), resources, such as interdisciplinary post-PICU follow-up programs, may be one instrumental approach toward assuring that all families are equipped to maximize their child's HRQOL during recovery and as they continue to develop across their life span [23]. The landscape of pediatric critical care is changing, and we must be willing to think flexibly, work collaboratively, and continuously evaluate our processes of care and advocate for what is best for our patients to achieve our ultimate goal of supporting children to live the best version of their lives.

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